"Journeys toward adjustment: Exploring the role
of emotions and beliefs from pre-diagnosis of inflammatory
arthritis through the first 12 months"

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Abstract

The intention of this thesis is to explore the role of emotions and beliefs from pre-diagnosis of inflammatory arthritis through the first 12 months. Inflammatory arthritis (IA) is an umbrella term for chronic, progressive and systemic auto-immune diseases and for the purpose of this study will include Rheumatoid Arthritis (RA) and Psoriatic Arthritis (PsA). These diseases can progress rapidly, causing synovitis and damaging cartilage and bone around the joints (chapter 1). The impact of these non-curable illnesses is physical and psychological (chapter 2), and may permeate into all aspects of life, (work, families, relationships).

However what is unknown is how people in the early stages of IA manage or cope with their diagnosis or whether pre-existing influences (such as Illness Beliefs, chapter 3) have an impact in the first year. If this is understood with more clarity then the clinical team could use appropriate interventions to improve patient care and ultimately outcome. In order to meet the aims a longitudinal hybrid approach (chapter 4) was used. Fifteen participants were followed for the course of a year with interviews pre and post consultation, then at twenty-six and fifty-two weeks. These data were analysed using inductive and deductive thematic analysis based on the framework of Illness Beliefs (chapter 5 and 6). The presentation of the data also included a narrative approach using both the quantitative and qualitative findings (chapter 7).

The findings from this study show that even at the end of their first year patients with IA come to their own acceptance, yet each travel in a different journey to reach this outcome. The journeys are determined by coping strategies as patients learn to adjust and adapt by renegotiation and battling through based on a pivot of their own perceived normality. Their definitions of adjustment and adaptation differed from those in the literature and showed lack of consensus across this cohort of patients. The journeys cannot be viewed in isolation but are determined also by social support and the need to be believed, with illness beliefs entwined.

From a clinical perspective facilitating communication and tailored education and support at the early stages may reduce distress, and promote flexible coping earlier. Future research needs to develop a greater understanding of these journeys by interviewing a larger cohort of patients and evaluating tailored support programmes.

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List of abbreviations used in this thesis

ACR	American College of Rheumatology
Anti-TNF	Anti-Tumour Necrosis Factor
AS	Ankylosing Spondylitis
BRI	Bristol Royal Infirmary
CASPAR	Classification of Psoriatic Arthritis
CRP	C-Reactive Protein
DAS	Disease Activity Score
DMARDs	Disease Modifying Anti-Rheumatic Drugs
EMS	Early Morning Stiffness
ESR	Erythrocyte Sedimentation Rate
EULAR	European League Against Rheumatism
RF	Rheumatoid Factor
HAQ	Health Assessment Questionnaire
HCP	Health Care Professional
HBM	Health Belief Model
IA	Inflammatory Arthritis
IPA	Interpretative Phenomenological Analysis
ITA	Inductive Thematic Analysis
NBT	North Bristol NHS Trust
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NRAS	National Rheumatoid Arthritis Society
NSAIDs	Non-Steroidal Anti-Inflammatory Drugs
OT	Occupational Therapist
PROMs	Patient Reported Outcome Measures
PsA	Psoriatic Arthritis
RA	Rheumatoid Arthritis
RCT	Randomised Controlled Trial
SCT	Social Cognition Theory
TA	Thematic Analysis
TB	Tuberculosis
UHBT	University Hospitals Bristol NHS Trust
UWE	University of the West of England
WHAT	Weston Healthcare Trust
WHO	World Health Organisation

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Chapter 1: Introduction to inflammatory arthritis

The overall aim of the thesis is to explore the journey through the first year of being given a diagnosis of inflammatory arthritis (IA). The focus will be on the impact of the diagnosis, looking at the role of illness beliefs and whether these underpin adjustment, adaptation or acceptance. Chapter 1 will examine the physiological nature of IA, chapter 2 will look at the psychological impact, including adjustment and adaptation, chapter 3 will explore the theoretical routes that may underpin adjustment and chapter 4 will explain the methodology and methods used within this thesis. The following chapters (chapter 5, 6 and 7) will explore and present the results, chapter 5 from an inductive perspective, chapter 6 from deductive perspective and chapter 7 will use a combination of qualitative findings plus findings from questionnaires to describe four possible journeys during the first year. The final chapter (chapter 8) reviews the findings and the implications for research and practice.

Chapter 1 provides the background to IA; its physiological nature and the potential impact of the physical aspects (symptoms and loss of function, body image and deformity) on a person's general health, and also on their lifestyle (work, partners and families). It will also address how the diseases can be managed (both with pharmacological and non-pharmacological treatments) with assistance from the Rheumatology team.

1.1 Inflammatory arthritis: Background

Inflammatory arthritis is a collective term for a group of autoimmune diseases that can cause joint pain and damage. It is a major healthcare problem that includes both clinical and personal impact with high individual and societal costs (Deighton and Scott, 2010). There are over 210 different types of rheumatological illnesses that can affect people of every age and culture. The most common - rheumatoid arthritis (RA) can affect up to 2% of the general population (Klippel and Dieppe, 1995) and is one of the most prominent inflammatory rheumatic diseases of the Caucasian population affecting approximately 0.5% (WHO, 2003). The other common inflammatory disease is psoriatic arthritis (PsA); the exact prevalence is unknown but appears to be between 0.04 % in the Faroe Islands (Gladman *et al.,* 2005) to 1 % in the United States (Brockbank *et al.,* 2001). Similar to RA, it is a chronic inflammatory arthritis; however it is associated with psoriasis (Taylor, 2002)

although the link between any skin psoriasis and joint involvement is often not made or indeed obvious at the early stages of the disease (Gladman *et al.,* 2005).

RA and PsA are chronic conditions. The course of any chronic illness can essentially take three general pathways depending on the illness characteristics. These can be progressive, constant, or relapsing (episodic), each of which has its own demands on both the patients and their families (Rolland, 1987). A progressive disease is one that is continually progressing in severity, for example Alzheimer's disease. This progressive deterioration demands on-going adaptation, with continual role changes for patients and often increasing strain on family members. A constant course illness is one in which an event occurs but then it stabilises, for example myocardial infarction. Recurrences can occur but the individual or family are generally faced with a semi-permanent but stable health change and its consequences. The third kind of disease course is characterised as relapsing or episodic illnesses, for example asthma or ulcerative colitis. The individual and family experience ongoing uncertainty of fluctuating symptoms and crises, which require constant and ongoing flexibility in adaptation and adjustment.

It is impossible to put any type of IA into one of these defining pathways. Inflammatory arthritis in its aggressive form can progress steadily with debilitating consequences (Deighton and Scott, 2010), especially if the individuals' disease fails to respond to medication thus putting the disease into the "progressive" group. However, it could be argued that some people with RA or PsA may be categorised into the "constant course" where a person has a flare but then their condition either stabilises, or enters into a remission type phase (Cush, 2007). Other patients may find their disease fluctuating, going into frequent but unpredictable periods of high or low levels of disease activity. This places them into the episodic course, thus demonstrating the changing nature of these illnesses with disease patterns fluctuating from week to week and also day to day (Hill and Hale, 2004).

The past decade has seen a major improvement in managing these conditions both from pharmacological and self-management perspectives, which has been captured in the guidelines from the National Institute for Health and Clinical Excellence (NICE, 2013) and other European and North American groups (Combe *et al.,* 2007; Smolen *et al.,* 2010). First, it is important to understand the physiological mechanisms of inflammatory arthritis, specifically RA and PsA, both of which can have similar consequences.

1.2 Physiological aspects of rheumatoid arthritis

RA is a chronic inflammatory disease, which manifests as multiple painful, swollen joints (Emery *et al.*, 2008) associated with stiffness and fatigue. It is unpredictable in nature and characterised by exacerbation (flares) and low disease activity and if uncontrolled, inflammation of the synovial lining the joints (synovitis) can eventually lead to joint destruction and loss of function. The aetiology is unknown but factors such as infections, stress and trauma appear to act as a trigger in people with a genetic predisposition; for example twin studies have indicated that genetic factors may account for up to 60% of disease susceptibility in RA (Deighton *et al.,* 1992). The current thought in this complex disease is that there are both genetic and environmental factors (Ollier, Harrison and Symmonds, 2001); this is reinforced by clinical practice where some patients with RA have a strong family history, whereas others do not.

The most common age of onset of the disease is the fourth and fifth decades (Hill and Ryan, 2000), with an apparent link between gender and the disease with a ratio of 3:1 women: men (Lawrence *et al.,* 1998). This ratio declines with age suggesting a hormonal relationship, supported by evidence that manifestations of RA can subside in about 70% of women during pregnancy but then recur in the early postnatal period (Klippel and Dieppe, 1995). A decreased risk of RA has also been reported in women with previous pregnancies and those taking oral contraceptives. Other risk factors reported are inconclusive (for example diet, caffeine and smoking) and more research is still needed (Oliver and Silman, 2009).

Patients often present with symptoms that are usually symmetrical with synovitis, pain and tenderness of the peripheral joints of hands and feet predominant. The American College of Rheumatology (ACR) criteria for the diagnosis of RA are that the first four of the following criteria must have been present for at least six weeks (Arnett *et al.,* 1988) and that RA is defined by the presence of four or more of seven variables: morning stiffness, arthritis of three or more joint areas, arthritis of the hands, symmetry, rheumatoid nodules, radiological erosions and a positive rheumatoid factor (RF). RF is a human antibody against portions of IgG molecules; it is approximately 50% sensitive in early disease, rising to 70-80% in established disease. High titres are an important prognostic indicator and sero-positive individuals are more likely to have more severe erosive RA (Vittecoq *et al.,* 2003). However, caution is required in interpreting results as false positives can be detected in a number of people (Oliver and Silman, 2009).

Unfortunately the criteria are not sensitive in patients with disease duration of less than 12 months (Huizinga *et al.,* 2002), for example radiological progression and rheumatoid nodules are often features of chronic disease and therefore may not be seen early in the disease. The criteria were developed in a population of patients who were selected by their disease rather than as a diagnostic tool (Arnett *et al.,* 1988).

When the disease is developing the synovial lining of the joints becomes inflamed and congested with t5 lymphocytes, B cells, macrophages and plasma cells. Increase in disease activity causes a rise in inflammatory markers, such as C-reactive protein (CRP), erythrocyte sedimentation rate (ESR) and plasma viscosity (PV). This inflammatory process causes the synovial lining of the joints to gradually thicken and form a pannus that invades the articular cartilage causing erosions of the cartilage and bones, which are visible on ultra-sound in the early stages and later on can be seen on X-ray (Emery, 2011). As the long-term course of RA is variable, studies report different rates at which deterioration occurs in the course of the disease (Brown *et al.*, 2008) with the rate of radiographic changes to joints greatest in the first 3-5 years. It is these physical changes that can lead to pain and disability, which in turn can have an impact on everyday life. Delays in diagnosis and therefore delays in treatment can result in poor outcomes through progressive joint damage and loss of function (Möttönen *et al.,* 2002), meaning prompt referral to a specialist is essential.

1.3 Physiological aspects of psoriatic arthritis

PsA is an inflammatory arthritis (IA) associated with a negative rheumatoid factor, enthesitis (inflammation at the site of tendon or ligament insertion), dactylitis (inflammation of the entire digit), axial (spinal) involvement and often skin involvement. Once described as a mild disease, PsA is now recognised as having the potential for joint damage and disability outcomes similar to RA (Mease and Goffe, 2005). Despite people with PsA exhibiting less joint tenderness, the severity of the inflammation has been underestimated with joint deformity and radiologically-detectable damage demonstrated in at least 40% of people and 11-19% reporting functional disability (Sokoll and Helliwell, 2001).

PsA affects men and women equally, with a peak age of onset between 35 and 45 years of age. The pathogenesis and cause of PsA are multi-factorial, with genetic, environmental and immunologic factors playing major roles in the development of the disease. Evidence of a genetic component was first discovered

in the1970s in a study of more than 100 families (Moll and Wright, 1973); it was found that the risk of PsA was 50 times greater in first degree relatives of psoriatic arthritis patients than in the control group.

PsA tends to affect joints in an asymmetrical manner, typically affecting the distal interphalangeal and proximal joints with dactylitis affecting approximately 30% of patients (Gladman *et al.,* 2005). The severity of skin involvement varies but on average PsA develops approximately 10 years after the first signs of psoriasis, with skin involvement developing first in approximately 70% of patients (Pitzalis, 1998), although there are some patients who never appear to get skin involvement yet present with inflammatory joint problems characteristic of PsA (Gladman *et al.,* 2005). There is no specific blood test for PsA with substantial variation in diagnosing (Gorter *et al.,* 2002). The diagnosis is made primarily on the basis of history, physical examination and radiographic features often using the recently developed CASPAR criteria (Taylor *et al.,* 2006). Patients with PsA are typically sero-negative for RF, with other laboratory abnormalities including raised inflammatory markers especially ESR and CRP. Patients with PsA have unique and distinct radiographic damage features different from RA, with asymmetrical joint involvement and increasing osteolysis (reabsorption of bone) and formation of bony spurs leading to the classic "pencil and cup" deformity as seen on X-ray (Chandran, Schentag and Gladman, 2007).

PsA and RA have signs and symptoms that can be challenging when making the diagnosis, particularly when differentiating between them at a time when skin involvement of PsA may be neither recognisable nor present. As the early symptoms and often the course of RA and PsA can be similar, the impact on patients will be considered under the combined term of inflammatory arthritis (IA).

1.4   The physical impact of inflammatory arthritis for the patients

This section looks at the common physical symptoms that people with IA experience and how these symptoms have an impact on their lives.

1.4.1 Pain

IA is a chronic painful musculoskeletal condition characterised by spontaneous pain (pain at rest) and hyperalgesia (noxious stimuli) causing stronger pain than normal (Schaible, Ebersberger and Banchet, 2006) and may be due to either inflammatory chemicals or inflammation of local nerve fibres and/or related

mechanical factors. Whatever the cause, the aims of the management are the same; to decrease the pain, to improve function and improve quality of life (Pisetsky, 2007). Clinical practice suggests that treatment of inflammation relieves pain; this is seen in the experience of many patients who receive a corticosteroid injection into an inflamed joint, with the subsequent quick-onset relief of pain. It is important though to realise that people with IA may often have pain for a number of co-existing reasons, which are individual to that person (Edwards *et al.,* 2006). Pain is used as a primary indicator of health by both clinicians and patients and whilst the causal link between pain and other symptoms is often unclear, it is still regularly reported. Medical approaches seek to treat and hopefully reduce pain by the administration of medication and/or fusion of joints, but this is not always effective and framing pain in this way can often be problematic and exacerbate rumination and worry (Eccleston and Crombez, 2007). Eccleston and Crombez (2007) suggest that seeking an alternative way of thinking about pain may help in breaking out of the pain cycle and that seeing pain in a different light may be more effective, such as looking at improving the patients' quality of life despite their pain. Those people with pain who believed that it was not necessary to reduce or avoid pain to function in life were more likely to be able to work, experienced less distress and used fewer health care services (McCraken *et al.,* 2004). This is looked at further in the self-management section (section 1.7.3).

Pain often fluctuates and has an impact on other associated symptoms; for example Dickens, McGowan and Dale (2003) found that the levels of pain influence depression. There appears to be a link between depression and pain, but whilst some studies suggest that pain leads to depression (Carr, Gibson and Robinson, 2001; Sharpe, Sensky and Allard, 2001) other studies suggest that depression leads to increases in pain (Huyser *et al.,* 1999; Zautra *et al.,* 2001) and this is looked at in detail when reviewing the psychological aspects in chapter 2, (section 2.2).

1.4.2   Stiffness

Stiffness is a factor that is not well documented in the IA literature, yet despite this it is often used as a clinical indicator of treatment (especially in pharmacological treatments). In one study, while 100% of patients with RA reported early morning stiffness only approximately 50% of PsA patients experienced the same symptom (Garg and Gladman, 2010). In PsA the stiffness may result from inflammatory involvement of entheses, the point at which the tendons or ligaments insert to bone. In contrast, there is more literature concerning RA and stiffness, with

morning stiffness causing an impairment of morning function (Khan *et al.,* 2009). Morning symptoms including stiffness and pain that last for more than an hour in 24-49% of patients (Khan *et al.,* 2009), with severe morning stiffness being a strong predictor of early retirement in patients with less than three years disease duration (Westhoff *et al.,* 2008). It is proposed that there is a temporal relationship between morning stiffness and the cytokine levels of TNF and IL-6 (Straub and Cutolo, 2007).

1.4.3   Loss of function

Disability is an umbrella term that covers impairment, activity limitations and reduced participation. Impairment refers to a problem experienced by an individual in involvement of life situations (WHO, 2012). This impairment or loss of function has a high cost, both financially and personally for people with IA. Synovitis can lead to tethering of the soft tissues with subsequent impairment and erosions, and together these can lead to loss of joint stability leading to functional impairment, activity limitations and reduced participation (Firestein, 2003). For example in a mixed methods study 10 out of 12 patients with early RA were suffering foot pain related to inflammation or impairment or both causing disability, which had a profound effect on their ability to walk (Turner *et al.,* 2006). Albers *et al.* (1999) report that even in the early years of IA 53% of people have a reduced work capacity, 57% have reduced leisure activities, 55% have a reduced level of independence and 23% have a reduced income, compared to age matched controls.

Tight control of IA disease activity (inflammation) has been shown to have significant association with lower functional disability levels after an average of 3.6 years, where tight control was measured using a disease activity score and indicated at <2.6 (Tanaka *et al.,* 2008). Tight control of the disease through medication results in the reduction in erosions and therefore the reduction of disability. Although tight control is a main therapeutic goal for clinical practice the value of the measures used by clinicians must be viewed within the context of the person's individual life style and psychological status.

1.4.4   Fatigue

The occurrence of fatigue is now recognised as an important symptom of IA, interfering with all aspects of life (Carr *et al.,* 2003). Significant fatigue has been reported by up to 70% of people with RA as being as severe and frequent as pain (Wolfe, Hawley and Wilson, 1996). However, patients also reported that they seldom

discuss their fatigue with the HCPs (Hewlett *et al.,* 2005), and a study by Repping-Wuts *et al.* (2007) suggests that although fatigue is common, only 6% of the clinical encounter time is spent discussing fatigue. Qualitative studies on fatigue experienced by people with IA show that fatigue varies in duration and frequency and is different from normal tiredness (Carr *et al.,* 2003; Hewlett *et al.,* 2005; Repping-Wuts *et al.,* 2009). It has been defined as an overwhelming, sustained sense of exhaustion impacting on capacity for mental or physical work (Gladman *et al.,* 2007).

The cause of fatigue is likely to be multifactorial, including physiological, contextual and psychosocial components (Hewlett *et al.,* 2011). Evidence suggests that there are contradictory results regarding correlation of fatigue with other symptoms. In some studies higher levels of fatigue were related to higher levels of pain, disease activity and disability (Riemsma *et al.,* 1998; Pollard *et al.,* 2006). However, in contrast to this other studies show that RA fatigue was not related to disease activity *per se*, but was predicted by disability and general health (Repping-Wuts *et al.,* 2007). Data relating to fatigue in PsA are sparse. In one study the range of PsA fatigue varied from 57% patients reporting moderate fatigue and 32% severe fatigue (Schentag *et al.,* 1999), compared to a later study where 26% patients reported overwhelming fatigue (Chandran *et al.,* 2007). In PsA fatigue is related to pain, psychological distress, gender and level of disability (Husted *et al.,* 2009). However, longitudinal studies are needed in both RA and PsA to identify fatigue predictors, as it may be that fatigue includes elements of mood or coping style, as well as inflammation or disease severity. The important thing is that fatigue has been recognised as a core outcome to be measured in both RA and PsA in clinical trials and practice (Gladman *et al.,* 2007, Kirwan *et al.,* 2007), and from patients' perspective the consequences of fatigue are multi-dimensional (physical, emotional, social and cognitive) (Tack, 1990).

1.5   Impact of IA on everyday life

1.5.1   Work

Work loss is an important outcome of chronic inflammatory diseases (Tillett, De-Vries and McHugh, 2012) with a financial and social impact on the patient and their family (Young *et al.,* 2002) due to loss of income and limited or reduced participation in socialisation (Sokka, 2003); and a direct impact on society, in terms of production loss and costs (Rothfuss *et al.,* 1997; Jacobs, Bissonnette and Guenther, 2011). If the patient cannot continue to work, the loss of income, combined with role alteration, can affect self-esteem (Escorpizo *et al.,* 2007). Most

patients with RA stop work within 10 years of developing the disease, with 40% of patients stopping work within 5 years of diagnosis (Young *et al.,* 2002). There appears to be a lack of studies exploring the issues of work disability relating to PsA in early disease (Tillett, De-Vries and McHugh, 2012). Work loss is especially common in those people with physically demanding jobs who are unable to change to light duties, or those with little control over their work place (Frank and Chamberlain, 2001). As RA most commonly affects individuals in their third or fourth decade of life patients may face many years without being able to work. In the National Rheumatoid Arthritis Society (NRAS) work survey (2003), 54% of participants attributed not being in paid employment to their RA, while 30% of participants only worked part time due to their RA. Whilst this survey is lacking in rigour as the participants were all members of NRAS, which covers a predominately well- educated white population, it had high numbers of respondents and highlights the importance people themselves place on work issues.

In a German study Mau *et al.* (2005) measured employment status comparing over 6000 PsA patients to other rheumatic diseases including those with RA. Although no difference was found in early disease duration compared with the general population, in people less than five years duration they found those with PsA had a reduced employment level of 0.92 standard employment rate, which was equivalent to Ankylosing Spondylitis (AS) but better than RA (0.76 – 0.81), Systemic Lupus Erythematosus (SLE), Granulomatosis and Systemic Sclerosis (SSc). The most influential factors within this PsA population were disease duration and education levels, as reported by others (Allaire, Anderson and Meenan, 1996, Reisine *et al.,* 2001). The study did not consider sick leave nor any reduced income or change of employment roles, all of which may be important factors in personal impact of the disease.

Factors contributing to work issues may be external, including environmental and commuting aspects (Allaire 2004; Burton *et al.,* 2006*)*, organisational barriers and attitudes of society and work colleagues *(*Barlow, Wright and Kroll, 2001), or internal barriers, including pain and fatigue (Wallenius *et al.,* 2009), limited physical functioning (Barlow, Turner and Wright, 1998) or reduced self-esteem (Straughair and Fawcitt, 1992). To help people remain in work there are a number of strategies highlighted in the literature. These include early identification of work problems by using a screening tool (Hammond, 2004), and vocational training or intensive work rehabilitation for people changing jobs (De Buck *et al.,* 2002). Preliminary data within one Scandinavian study indicated that a combination of active drug therapy and multi-disciplinary team care may reduce rates of permanent work disability with early

RA, (20 % reduction in full time sick leave and an increase in people working full time of 14% over two years) (Nordmark *et al.,* 2006). Although this is a relatively short-term study, its novel emphasis was on modifying job conditions and developing the necessary skills needed to resume or continue with their work. An evaluation of an American work rehabilitation programme for people with a range of chronic illnesses in employment also demonstrated positive effects of an intervention giving people the necessary skills and confidence to remain in employment (Allaire, Niu and Lavalley, 2005). However, as these programmes are both rare and costly, the study may have limited applicability.

Changes in people's roles can have an impact on their self-esteem and this is also linked with changes in body image which can also impact on a person's day to day life.

1.5.2 Body image and deformity

"Body image is the mental picture people have of their physical self, and equally importantly, the mental picture they believe others have of them" (Luskin Biordi, Warner and Knapik, 2006). Physical appearance changes seen in IA are often due to progressive damage to the tendons and ligaments, and to damage (erosion) of the bony landmarks to which they are attached. The consequence of this is joint instability resulting in joint deviation, particularly of the fingers, wrists and toes (Beasley, 2012). These visible physical changes can often be embarrassing and devastating to the person who is already trying to adjust to the symptoms and functional loss (Barlow, 2009). Monaghan *et al.* (2007) suggest that women with RA have lower self-esteem compared to women without RA, and this is linked to dissatisfaction with body image. The authors go on to suggest that psychosocial issues (attitudes and social functioning) are also associated with body image, and that physical appearance predicts depression in RA (Monaghan *et al.,* 2007). The perception of disrupted body image has been linked with PsA and can lead to depression, with suicidal ideation in more than 5% of patients (Gupta and Gupta, 1995).

Skin involvement in PsA may have a profound effect on body image. Psoriasis can present at any age and its prevalence varies depending on ethnicity, for example low in Japanese populations and virtually non-existent in aboriginal Australians (Langley, 2012). These IA symptoms and physical manifestations can influence the patients' perception of their physical attractiveness and alter body image leading to loss of self-esteem (Mease, 2009). To overcome this and achieve a sense of control the patients need to develop behaviours and beliefs that

will improve their strategies of coping with the fluctuating nature of their disease. Helping patients' identify what they can realistically achieve as opposed to what they cannot develops positive thinking and a sense of empowerment and is a major role for all health care professionals in the development of self-management skills (McGowan, 2005).

1.6 The effects of the illness on the patients and their partners and families

The spouse or live-in partner in particular seems to bear a great proportion of the stress of their partners' chronic illness (Das Chagas Medeiros, Ferraz and Quaresma, 2000). The reason given is that they are considered the primary provider of social support in a person's life (Reynolds *et al.,* 1992; Rolland, 1994). These particular studies looked at the quality of marriage and social support, and analysed these factors in relation to psychological well-being for the spouses, also addressing the relevance of more severe disease. Couples may approach the challenge of chronic illness by sharing some or all aspects (Mann and Dieppe, 2006) or they may develop separate responses to the challenges including coping strategies that may even conflict (Danoff-Burg, Ayala and Revenson, 2000).

The degree to which the spouse or partner is supportive and the effect of that support, that is whether it is positive (Gallant, 2003) or negative (Manne and Zautra 1990), may be related not only to the understanding of the disease but also to the differences in the perceptions between partners and patients about the patient's health state, their pain and well-being. For example if a partner perceives the illness to be worse than it is they may be over-protective (Thompson and Pitts, 1992). Conversely, if the patient is in pain but no physical signs are evident the partner may feel the illness is not as the patient claims (Cohen and Wills, 1985). Van Lankveld *et al.* (2004) took this concept further and piloted two education programmes, which looked at ways of decreasing passive coping where spousal participation was compulsory in one group. They restricted the education programmes to look only at people who were diagnosed with RA rather than other general chronic conditions so the programme could meet specific needs. The results showed that in both groups there were positive changes in coping, similar positive changes in disease activity, and the main difference was that at follow-up assessments patients in the experimental group reported more improvement in disease-related communication with their spouses. Even though this study does not show any additional benefits of spouse participation in cognitive management programmes, it does suggest that there can be an increase in communication.

However, it could be argued that spouses' willingness to participate in the study reflects an existing underlying interest in increasing their understanding and knowledge.

Other education programmes have also tried to address the issues of partner participation. Riemsma, Taal and Rasker (2003) looked at whether group education for patients with RA and their partners has an influence on outcome compared to patient groups run without partners present. After twelve months self-efficacy (confidence) scores for coping were significantly higher for patients participating in group education without a partner, compared to those in groups run for patients and partners together. They did not focus on the relationships of the partners. It may be that the partners who attended were more dominant in the relationship than the patients or the presence of partners inhibited the patients' potential shared learning experiences.

Increased social support is related to improved mood in chronic illness (Cohen and Wills, 1985), and this has been identified as the case for patients with RA (Goodenow, Reisine and Grady, 1990; Doeglas *et al.,* 2004). However, there appears to be no such research within PsA.

The interpretation of illness within couples is paramount when working with patients and partners to improve self-management of chronic illness. This has been reiterated in previous studies looking at chronic illnesses: for example in cancer patients the differences in pain interpretation between patients and their partners were associated with poor outcome for the patients' mood and quality of life (Miaskowski *et al.,* 1997). Heijmans (1999) found that where spouses minimised the seriousness of Addison's disease, this had a more detrimental effect on the patient's health than where spouses over-inflated the condition. As Lim and Zebrack (2004) argue diverging views on an illness can be a cause of strain and stress on family members. It is therefore important to look at ways to promote a more cohesive approach towards chronic illness, especially when facing unpredictable day-to-day living, as in the case with IA.

Education and discussion are paramount in building the trust between couples. Couple research has found communication processes to be crucial in facilitating healthy couples' functioning (Olson *et al.*, 1989; Epstein, Baucom and Rankin, 1993; Schmaling, and Sher, 2000). Important discussions for couples include understanding the illness and its psychosocial demands over time; what can affect the course; and how to maintain a balanced life (Rolland, 1994). It is suggested that meeting with couples both individually and together is useful as an initial assessment and this gives the clinician a better sense of

the current issues, which should be dealt with as a couple or (when appropriate) separately. What is unexplored within the literature is the support required or needed by the patient at the point of diagnosis and in the early stages of their life with IA.

From the patient perspective adjustment may be made more difficult if patients are unable to continue to meet the expectations of family and friends as to how well they are coping (Bediako and Friend, 2004), and this may contribute to depressive symptoms. Following diagnosis of IA both the patient and their family have a long emotional journey, with adjustments having to be made on all sides (Mann and Dieppe, 2006). Riemsma, Taal and Rasker's (2003) study is not the only education program for arthritis patients in which family members can participate (for example Kaye and Hammond, 1978; Keefe et al., 1996). Radojevic, Nicassio and Weisman (1993) looked at all aspects of education with family members and randomly assigned patients to one of four groups: behavioural therapy with family support, behavioural therapy without family support, information sessions, or no intervention. The only positive outcome was that the group of patients who had received behavioural therapy with family support achieved significantly greater reductions in number of swollen joints.

This thesis will qualitatively explore partner and family support that is required or given throughout the first year of the patients' journeys and evaluate the effect that this may appear to have, if any, on the adaptation or adjustment of the patient. Whilst the partner and family are important components within the support system it is not known whether the needs of patients at the time prior to or after the diagnosis are met or how they are affected.

1.7 To control rather than cure

1.7.1   Pharmacological treatment of IA

The role of medication is two-fold, to reduce symptoms and to prevent damage to the joints (Pincus et al., 2002; Brown, 2003). The major pharmacological interventions include analgesics, non-steroidal anti-inflammatory drugs for symptom control, steroids to prevent erosions in the first few years (Da Silva et al., 2006) and disease-modifying drugs (DMARDs) and biologic therapy to alter the course of the IA. The DMARDs Sulphasalazine and Methotrexate have more favourable efficacy and toxicity profiles compared with other DMARDs, but within 2-4 years over 50% of patients change to a second DMARD as the first is no longer effective (Ranganath, Khanna and Paulus, 2006).

Over the last decade pharmacological treatment has been revolutionised by the introduction of anti-TNF therapy. This came after the discovery that the pro-inflammatory cytokine tumour necrosis factor α (TNF-α) played a central part in the pathogenesis of the disease and that blocking this would lead to major improvements in symptoms and signs (Feldmann, 2002). Studies have shown that these TNF-α antagonist medications are remarkably effective in patients who have not responded to the more conventional disease modifiers, including Methotrexate (Emery, 2011).

Furthermore, studies have shown that these novel drugs can inhibit structural damage by blocking the TNF-α (Lipsky *et al.,* 2000) and have shown an improvement in radiographic scores (Klareskog *et al.,* 2004). This means for newly diagnosed patients there is a potential reduction in erosive damage and therefore a better functional outcome. In terms of toxicity anti-TNF agents have produced side effects in line with their mode of action, the most common being increased risk of infections and the reactivation of active TB (Furst *et al.,* 2004). Appropriate screening and education can reduce the risk of both. There are now further options for patients who have failed to respond to anti TNF therapy; one is an anti-B cell therapy (Rituximab) which depletes B cells and is currently being promoted as a therapy for patients who have failed to respond to the previous drugs (Edwards *et al.,* 2004). Other new drugs are currently being launched and awaiting decision from National Institute of Clinical Excellence (NICE) for approval.

Overall disease modifying drugs are effective for symptoms and signs of IA but biological therapies offer greater suppression of structural damage. However, there are a group of patients who find that these drugs are not suitable for them, or for whom they do not contain the disease completely (Feldmann, 2002). Furthermore, in addition to pharmacological approaches, all patients should be offered non-pharmacological interventions to reduce symptoms and improve self-management in order to improve outcome (Deighton *et al.*, 2009). Whilst medication can help to control symptoms it does not always return patients to a completely symptom-free state (Smolen *et al.,* 2007) therefore patients need to use non- pharmacological treatments and self-management strategies.

1.7.2   Non-pharmacological treatments for IA

NICE provides recommendations or national guidance for the appropriate treatment and care of people with specific conditions. Although there are no guidelines for PsA there are recommendations for RA, one of which is access to a multi-disciplinary team with a named member of the team responsible for co-

ordinating their care (NICE, 2013). A previous survey of members by NRAS identified that only 63% had access to a rheumatology specialist nurse, 57% to a physiotherapist, 48% to an occupational therapist and 39% to a podiatrist (NRAS, 2003). Given that the survey was completed by a proactive group of patients this is likely to be an over-optimistic estimate of the deficit in services provided around the country, although findings were produced prior to the national guidelines. Hill and Ryan (2000) recognised that health care professionals (HCPs) can play a vital role in educating and empowering patients to take control of their lives and their illness. HCPs need to address both physical and psychological aspects of the disease to assist in the adoption of self- management strategies. This has been reinforced by the musculoskeletal services framework (Department of Health, 2006a), which specifically mentions the necessity of nurse specialists to support, educate and enhance the self-management of patients with arthritis.

1.7.3   Self-management

Self-management was first reported in rehabilitation in childhood asthma where Creer, Renne and Christian (1976) felt that the term indicated that the patient was an active participant. This relates to the work of Bandura (1986) which indicated that self-management strategies are strongly linked with coping mechanisms. Self-management strategies have been developed using problem-solving skills and proactive coping theories (Schreurs *et al.,* 2003), and short-term planning (Bodenheimer *et al.,* 2002). This development is a shift away from the paternalistic models of health care where the patients were deemed as passive recipients (Taylor and Bury, 2007). This gradual shift of health care responsibility to the individual in the day to day living with an illness encompasses United Kingdom (UK) initiatives such as expert patient programmes (Barlow *et al.,* 2002) with a goal to empower patients to become actively involved in their care. Self-management has the potential to benefit psychological well-being (Lorig and Holman, 2003) and has been described as the outcome of collaboration between doctors, patients and other involved health care workers and agencies (Department of Health, 2006b). There appears to be no absolute definition of self-management (Barlow *et al.,* 2002) however in a pilot study for patients with arthritis self-management was referred to as an inter-disciplinary group education based on the principles of adult learning, individualised treatment and case management theory (Alderson *et al.,* 1999). Not only is this outdated it also excludes any individualised approaches to self-management.

In their review of self-management approaches Barlow *et al.* (2002, p 178) defined self-management as:

"…. The individual's ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent with living with a chronic condition."

Thus self-management encompasses all activities that individuals carry out to protect their health and manage or ameliorate the effects of their illness within the context of their own lives (Whittemore and Dixon, 2008), coping with the psychological problems generated by chronic illness. It is a dynamic, active process of learning, practicing and exploring the skills necessary to enhance quality of life in conjunction with traditional medical care of chronic illnesses (Lorig and Holman, 2003) achieved by promoting active involvement of the patients and their families.

Therefore, the person with IA is a fundamental part of the rheumatology team and, being responsible for the day to day care of their illness, must be fully informed about their disease and treatment options to make decisions about their long-term care. Bayliss, Ellis and Steiner (2007) state that self-management of IA leads to optimal health outcomes, with the individual assuming preventive or therapeutic health care activities (often in collaboration with health care professionals). Kralik *et al.* (2004) found that while healthcare professions identified self-management as structured education, patients identified it as a process initiated to bring about order in their lives. This reinforces the fluctuating nature of IA described by Paterson (2001) who describes the shifting perspective with wellness and illness moving between foreground and background, which are in part due to the symptoms and in part due to psychological factors. A patient needs to learn about the combination of treatment, rest and medication which is constantly changing in order to combat the nature of the disease. Patient education can help patients make informed decisions about adjusting their treatment regimen and in attaining the necessary self-management skills and confidence to deal with their disease (Lorig and Holman, 2003).

The goals of self-management are threefold: To enable patients to medically manage their illness (e.g. taking medication, adhering to diet); to cope with the effects of the illness or impairment and carry out activities; and to manage the emotional impact (Lorig and Holman, 2003). Traditional didactic patient education offers information and technical skills (Iversen, Hammond and Betteridge, 2010). In

contrast, self-management interventions are problem-focused and emphasise patient-generated goals to facilitate behaviour change (Lorig and Holman, 2003). Problem–solving, positive reappraisal and distraction have been highlighted for the past 20 years in exploratory studies (Smith and Wallston, 1992) and reaffirmed by UK education programmes (Barlow, Turner and Wright, 1998). Both studies show that people who have passive coping skills and those who blame themselves showed evidence of poorer adjustment to their illness.

Riemsma, Taal and Rasker (2003) identified an improvement in self-efficacy (patients' perception of self-confidence) and fatigue in patients with RA attending a cognitive self-management programme compared to patients attending routine follow-up. This programme focused on changing knowledge and behaviours and showed a positive benefit on both physical and psychosocial health status. Hammond, Bryan, and Hardy, (2008) used both cognitive and behavioural strategies based on standard self-management programmes and cognitive behavioural techniques with a substantial skills element (e.g. practicing joint protection in the group sessions). The RCT showed significant improvement in pain, self-efficacy, and perceived control in the intervention arm. However, in these two studies, mean disease duration was twelve and seven years respectively and it may be different for people around the time of diagnosis. Both studies showed sustained benefit at twelve months. In terms of patient characteristics there is little evidence to suggest which patients benefit the most, although Hammond, Bryan, and Hardy (2008) suggest that for self-management programmes to be effective there needs to be a theoretical base. Group behavioural programmes may be more effective than individual education and make a better use of resources and time (Hammond and Freeman, 2004). This may link in with Bandura's social cognition theory (section 3.5) which promotes positive reinforcement from those around you. However only 50% of patients would even consider attending a group education programme (Hammond and Badcock, 2002); therefore readiness for change should be evaluated before an intervention is offered (section 3.3).

Barriers, including readiness to change, can have a detrimental effect on self-management causing a negative effect on disease outcome, mortality and quality of life (Bayliss, Ellis and Steiner 2007). How people self-manage their chronic illness may depend not only on self-efficacy beliefs but also beliefs and experiences they have (Bandura, 1986). Patients will already have a pre-set of ideas about their condition before they are seen by the medical team, and these "lay beliefs" may be rooted in common sense, family traditions or hearsay

(Donovan, 1991). They have been shown to lie behind much of people's behaviour concerning their health and illness and this is explored in section 3.7.

Barriers may include poor or unhelpful social support, difficulties with time management, low self-efficacy, physical symptoms such as fatigue making it impossible to attend groups, conflicting health beliefs and psychological issues such as depression causing isolation (Jerant, Friederichs-Fitzwater and Moore, 2005). These aspects may be amenable to intervention if they are identified by appropriate assessments or if the self-management is tailored towards individuals' needs at the appropriate time. It is hard to differentiate the benefits of each programme or aspect of self-management without understanding and evaluating the concepts around coping strategies, how these concepts are integral in self-managing a long term condition (see section 3.2) and how members of the team can enhance promotion of education and skills.

1.7.4   Role of the rheumatology nurse specialist

Nurse-led clinics often provide an holistic approach to patient care taking into account physical, psychological, social and spiritual needs, with nurses functioning either independently or within a multi-disciplinary team (Smolen and Aletaha, 2011). In a sample of 40 patients with RA attending RA review clinics, patients perceived the nurse specialist consultation as different from the medical consultation, and were using the nurse as the medium for addressing psychological concerns (Ryan *et al.*, 2003). This reinforces the work by Hill *et al.* (1994) who demonstrated an increase in knowledge and a decrease in physical and psychological symptoms in RA patients randomised to a nurse specialist, compared to those seeing a medical consultant. The role of nurse specialist has expanded in other areas including recognition of the need for access to advice (Thwaites, Ryan and Hassell, 2008). As a result of this need many nurse specialists have set up telephone advice lines and this service is now seen as an integral way of supporting patients.

A recent multicentre study reviewed the care of 181 patients with confirmed RA who were randomised to either care led by a rheumatology nurse specialist or a consultant rheumatologist (Ndosi *et al.,* 2013). The findings indicate that there was little difference in ordering of bloods, or referrals to other team members but those attending the nurse clinics received more patient education and psychosocial support, and had fewer rates of either unplanned admissions or visits to A & E departments. Although the study has some limitations, for example information on interventions was collected in a quantitative approach; it does provide robust evidence to support the patient satisfaction with and effectiveness of nurse-led clinics within the UK.

1.7.5   Role of the rheumatology physiotherapist

Most people with RA have poorer levels of aerobic fitness than those without and in a prospective study of older women, slow gait, weak grip and limited exercise, (all common in IA), were predictors of decline in function (Sarkisian *et al.,* 2000). Despite all the evidence supporting exercise and physiotherapy very little is understood about the factors that influence patients' adherence to the exercises that are given to them. One study found that perceived benefits of exercise, and greater exercise self-efficacy significantly predicted exercise among patients with RA (Eurenius and Strenström, 2005).

Three types of physiotherapy have been considered to be appropriate in the early stages of IA. Firstly a need for traditional exercise and education around the specific joints affected by the arthritis, secondly a self-management programme including the use of hot and cold therapies, and thirdly a more general training aimed at increasing general mobility and muscle strength. Two systematic reviews concluded that aerobic and strengthening exercises lead to significant improvements in both physical and psychological status in IA and also importantly do not exacerbate disease activity (Strenström and Minor, 2003; Van den Ende *et al.,* 2003), although long-term evaluation was not done. Intensive hydrotherapy for patients can improve grip and activity levels for up to two years, with long-term therapy having the benefit of reducing the rate of hospital admissions (Strenström, 1994). Hydrotherapy is the term given to exercise in warm water, also known as aquatic exercise; it is a popular therapy for many people with musculoskeletal conditions as the buoyancy of the water eases joint movements. In the United Kingdom hydrotherapy is led by a qualified physiotherapist and is recognised as a physical therapy treatment, unlike the European approach in which balneotherapy, the medical application of natural thermal mineral waters, is usually associated with passive bathing.

A meta-analysis of randomised controlled trials could find no evidence that hydrotherapy showed greater pain relief than land-based exercises (Hall *et al.,* 2008). However, there were fundamental discrepancies between the various hydrotherapy interventions, for example the temperature of the water, and analysis included musculoskeletal and neuropathic diseases rather than just IA. From an anecdotal perspective hydrotherapy remains a popular choice of exercise with RA patients and the benefits may be multi-factorial rather than just based on pain as examined in the review.

1.7.6   Role of the rheumatology occupational therapist

Occupational therapy (OT) aims to facilitate task performance and reduce the consequences of arthritis for activities of daily living (ADL) (Steultjens *et al.*, 2004) through therapeutic and educational interventions (Hammond, Young and Kidao, 2004). OT emphasises maintaining hand function with wide range of treatments including ADL training, joint protection, upper limb exercises, splinting and individualised or group self-management programmes.

There appears to be no reported evidence of the effectiveness of OT within PsA. However, Hammond, Young and Kidao (2004) carried out a randomised control trial (RCT) with patients with early RA (that is less than two and a half years since diagnosis). A total of 326 patients were randomised to OT plus rheumatology care (intervention) or rheumatology care only (control). The intervention group received 8 hours of OT, including four one-hour individualised treatments and one two-hour group education programme. Outcome measures included functional assessment, hand status (grip and function), psychological status (self-efficacy, anxiety and depression, control) and also self-reported adherence to strategies taught. Patients were assessed at six-month intervals up to 24 months. More assistive devices were given to the OT group than the control group and these were used more frequently, and more splints were provided to the OT group. However, in both groups over a third (44%, 43%) did not wear the splints provided. Although the study showed that the intervention did not influence significantly the health status of people with early RA, it did improve self-management techniques. A previous systematic review suggested that OT support and intervention are better provided later in the disease (Steultjens *et al.,* 2002) and this was reinforced by the qualitative arm of the study in which patients deemed OT supportive, reassuring and informative but felt that it would be more effective at a later stage (Hammond, Young and Kidao, 2004). However the self-management techniques may be preventative but longer-term studies are needed to confirm this.

When diagnosed with IA patients require time, not only to adjust to the disease, but also to its manifestations and the alterations that they may have to make to their everyday life. It is thought that people may remain in denial about their condition for anything up to five years (Hill and Ryan, 2000). All of these factors can have a bearing on the impact the disease may have on the person and this issue is examined throughout the thesis.

1.8   Summary

The disability, distress and life changes due to IA make it likely that most aspects of the person's life will be touched (Walker, Holloway and Sofaer, 1999). With modern medication regimens, multi-disciplinary team support and good self-management, although it cannot be cured, IA can often be well managed and controlled albeit with lifestyle changes. This chapter has shown the huge physical and social implications and changes that patients have to contend with when faced with an unpredictable chronic illness. However, most of the literature is on long disease duration, and little is known regarding the time around diagnosis.

The symptoms, consequences and self-management strategies described in this chapter will have major implications for the patient's lives. These implications will have psychological impact and require considerable adaptation and adjustment by the patients and their families, in an attempt to regain control and meaning in their lives. The effect of being diagnosed with inflammatory arthritis on psychological status and the concepts of adaptation and adjustment are examined in chapter 2.

Chapter 2: Psychological impact, adjustment and adaptation

The previous chapter focused on the physical impact of inflammatory arthritis, its consequences, the pharmacological control of IA and the support that the clinical team can give to a patient. The aim of this thesis is to understand the journey in the first 12 months of a patient receiving a diagnosis. To understand this trajectory this chapter first addresses the psychological implications of receiving a diagnosis.

In the absence of effective cures for chronic conditions, such as IA, the unpredictability of this condition has both a physical and psychological effect on a person. This combination can lead to frustration and emotional consequences including depression and anxiety. As the physical changes occur people need to come to terms with the diagnosis of having a chronic disease as well as accommodating these changes. People with a diagnosis of IA can experience pain virtually every day and on many days it can be intense, can interfere in everyday life activities and may also be emotionally challenging. The literature overall shows a wealth of information focusing on the psychological aspects of having IA which re-emphasises the importance that this can have on adjustment and adaptation. The psychological and physical impact may influence the person's adaptation and adjustment in their individual journeys. Secondly this chapter will therefore review the current understanding of adaptation and adjustment to a long-term condition and the theoretical approaches suggested by the literature.

2.1 Justification of the literature review

The themes to be addressed in chapters 2 and 3 were likely to be overlapping therefore the 2 searches were conducted simultaneously. This review was undertaken in a systematic manner, but it was not a systematic review as a general narrative approach best suited the reporting of the findings (Green, Johnson and Adams, 2006). The longitudinal aspect of the study meant that the literature was revisited several times in an iterative approach. Due to this and the nature of a narrative review, numbers of articles identified were not recorded although in hindsight this would have been an appropriate action to have taken.

A comprehensive review was undertaken using the following databases: AMED, BNI and CINHAL to resource a comprehensive review of nursing and allied health care journals, both international and UK based; Medline to include abstracts

and journals from the international biomedical literature; Cochrane Library as a collection of six databases that contain different types of high-quality, independent evidence to inform healthcare decision-making and a seventh database that provides information about Cochrane groups; and PsycINFO covering psychology literature. Exclusion criteria included those not retrievable, or not available in English. The search was conducted from the earliest date available for each database to the last date of the search (November, 2013).

The search terms included: rheumatoid arthritis, combined using Boolean terms of 'or' and 'and' as appropriate with diagnosis, newly diagnosed, emotional response, anxiety, depression, helplessness, quality of life, adaptation, adjustment, coping, self-efficacy personality, support and illness beliefs. The term rheumatoid arthritis was replaced with psoriatic arthritis and the searches repeated, then again with the term inflammatory arthritis. Truncation was used as necessary, for example cop* for terms relating to cope. When searching for terms relating to illness beliefs, Boolean terms and/or were used to included perception and cognitions based on the rationale that in the literature the terms of illness beliefs/ illness perceptions/ illness cognitions are used interchangeably. Findings were supplemented by searches on key authors in the field, advice from experts during research team meetings, including patient partners, academic nurses and psychologists.

As expected the narrative review led to an insurmountable number of articles. This was narrowed down by reviewing the title and abstracts of those identified and their relevance to the topic and aims of the study. A pragmatic approach based on the reading of research and clinical expertise was taken to reduce the number of theoretical models with regards to adaptation, adjustment coping and IA. These were chosen based on their relevance to fluctuating long term conditions from a research and clinical perspective, and in discussion with the supervisory team.

2.2   Psychological impact of receiving a diagnosis

Studies of people with IA suggest that most patients do not initially attribute their symptoms to a long-term illness but relate them to stress, or normalise symptoms in terms of increasing age and expected changes (Sakalys, 1997) and therefore do not seek medical help. The decision to seek medical help within chronic illness is not just influenced by disease severity but by perceived impact of the illness (Zola, 1973). Having made the decision to seek help for their symptoms, people then experience the bewilderment of receiving a diagnosis or explanation (Taylor and Bury, 2007). Some people may be mentally prepared, for example IA

has a familial component so some people, on reaching the consultation, may have an awareness of IA, and therefore their reaction will be based on previous knowledge or experience (Kangas, 2002). The primary reaction for others may be shock – they may be stunned or bewildered that someone, often young, can be given a diagnosis of arthritis (Dingwall, 2001).

Illness, whether short or long term, has an impact on individuals (Dingwall, 2001) both physically and psychologically. Illness makes us re-evaluate our sense of self-efficacy (Rainer, 2002) with a need for the problem to be "fixed". In the short term it evokes physical, psychological and social changes resulting in a reduction of everyday normal activities and also interaction with others (Dobbie and Mellor, 2008). The immediate emotional reactions may comprise fear, shock and anxiety (Shontz, 1982). Shock may be short-lived or may continue for weeks and is most likely to be more pronounced when the diagnosis comes without any pre-warning. This reaction may lead to behaviour that appears detached or automatic (Shontz, 1975). This period is often followed by emotional reactions such as denial, anxiety and continuing fear (Taylor and Aspinall, 1996). Some people find that their normal coping mechanisms fail to work (Moos and Schaefer, 1984) and they must begin to come to terms with the illness.

Immediately after receiving a diagnosis patients are often in a state of emotional distress, displayed as anxiety. Although anxiety within chronic illness may be an expression of a pre-existing tendency towards anxiety it is thought that illness situations may also increase anxiety (de Ridder *et al.*, 2008). These situations include waiting for the diagnosis or uncertainty about the disease course. There is very little in the literature that focuses on the immediate emotional distress post-diagnosis of IA. Evers *et al.* (1997) in a cohort of 100 patients with RA, (disease duration of less than one year), measured psychological distress using anxiety and depression scores, the impact of rheumatic diseases and a general lifestyle and health questionnaire at 12 weeks and 12 months post diagnosis. They found a high prevalence of anxiety and depression post diagnosis (20% of patients) with higher levels in women and those with smaller social networks, and despite improvement in clinical status this psychological distress remained unchanged throughout the first year. This paper is over 20 years old and IA disease outcome has improved (Jurgens, Welsing and Jacobs, 2012) as has patient support, education and treatment (Geenan *et al.,* 2012). However, it does recognise the importance of anxiety at the point of diagnosis and psychologists and physicians have speculated on reasons why some people who face the stress of a chronic illness adjust to finding a new more positive self in the face of chronic illness (Asbring, 2001),

whereas others demonstrate significant emotional and personal decline. A more recent study reviews the changes in psychological distress that have occurred (Overman *et al.,* 2014). In a cohort study 1060 patients with confirmed RA were assessed for psychological distress (using scales taken from the Impact of Rheumatic Diseases questionnaire), functional activity (using the Hospital assessment questionnaire (HAQ)) and symptom severity (ESR and Thompson joint count) at baseline and again 4 or 5 years later as part of a larger cohort study over a time period from 1990 – 2011. Although the study shows that distress has reduced in patients with RA over the last two decades and the authors suggest that this may be linked with improved control of disease and therefore reduced symptoms, there was no definitive relationship. It may be that the level of understanding and the increased education and self-management strategies may also contribute.

Whilst long-term impact is not dissimilar to the short-term effects it may present a greater threat to a person's feeling of normality. Chronic illness may result in a variety of changing outcomes that could have negative effects on the psychological adjustment of the individual, and as a result usually requires ongoing adaptation of the individual and their families. Ultimately a chronic illness requires a reformation of self (Rainer, 2002) to allow the illness to become part of life, not to take over life. The person is challenged to adjust and may be even accept their illness. Both short term and long term impact relate to a person's quality of life (section 2.4) and their perception of normality (section 2.7.5).

Short-term illness is part of life but chronic illness has a long-term impact often causing disruption of lives (Bury, 1982). Confirmation of a diagnosis of a long term condition can change the lives of the patients requiring adaptation and adjustment to the diagnosis. These life events often have a psychological effect on people causing anxiety, depression and even feelings of helplessness, which will now be considered.

2.3   Emotional response

2.3.1   Depression and Anxiety

Studies in IA have shown a link between depression and disease process (Hawley and Wolfe, 1988, Adams and Pearce, 2001, Dickens, McGowan, and Dale, 2003). A recent review study in 2001 showed that depressive symptoms range between 8 and 46% of individuals with RA (Adams and Pearce, 2001). In a two-year randomised, double-blind trial to assess efficacy of etanercept compared with etanercept and methotrexate a secondary outcome was to review patient reported

outcomes (PRO) including depression and anxiety (Kekow *et al.,* 2011). In this study 389 patients with disease duration ranging from three months to two years with active disease were recruited. Those with baseline symptoms of depression who achieved clinical remission were less likely to remain depressed compared with those who did not achieve remission. Conversely patients with no depression at baseline were three times more likely to continue without depression if they achieved remission compared with those who did not. However, the finding of a correlation between disease activity variables and depression does not prove that depression is a direct consequence of disease activity. This relation may be mediated by psychological factors or another factor may be driving the relationship. However, the relationship between depression and symptoms is not necessarily unidirectional; depression influences other outcomes in rheumatic disease such as cognitive–behavioural variables and functional abilities and it may impact on disease activity. Patients with depression are less likely to adhere to treatment regimens (Dimatteo, Lepper and Croghan, 2000) and fewer patients show positive effects of drug treatment (Hider *et al.,* 2009).

In a longitudinal study of 238 patients with RA it was found that 20– 30% of patients with RA experienced increased levels of anxiety at different assessment points (0, 1, 5 and 10 years) in a ten-year period (Ødegärd *et al.,* 2007) as measured by the AIMS (Meenan, Gertman and Mason, 1980). In RA female gender, a younger age and a lower income have been identified as predictors of anxiety in some studies (Kekow *et al.,* 2011). Some studies observed that anxiety may be elevated in patients with an early diagnosis, but anxiety levels have not been found to differ according to disease duration (VanDyke *et al.,* 2004).

Hewlett *et al.* (2002) showed that clinical anxiety was almost three times as prevalent as depression (21.7% cases of anxiety compared with 7.8% of reported depression in a cohort of 553 IA patients). This is an important issue for health care professionals as a longitudinal study by Wittchen *et al.* (2000) found that the risk of developing depression is increased in patients who have anxiety.

2.3.2   Helplessness

Reduced energy or motivation, often symptoms of depression, can clearly interfere with self-management, and the inability to self-manage can also lead to feelings of helplessness and hopelessness (de Ridder *et al.,* 2008). Feelings of helplessness prevail when people identify a lack of control, which may be real or perceived (Al-Dabagh and Feldman, 2014). Research in people with RA has shown that perceived helplessness reliably predicts increases in depressive symptoms

(Smith and Wallston, 1992; Gossec *et al.,* 2014). The sense of helplessness has been shown to mediate between disease severity and depressive symptoms in fibromyalgia (FM) (Palomino *et al.,* 2007), RA (Nicassio *et al.,* 1985) and chronic pain (McCracken, Vowles and Eccleston, 2004). Palomino *et al.* (2007) used both self-report and observer-report measures in patients with FM and found that helplessness appeared to be a critical factor in explaining depression. In a study by Nicassio *et al.* (1985) the self-reports of 200 RA patients showed that their feelings of helplessness were associated with a reduction in their abilities to carry out activities of daily living, although the reason for this association was unknown. It may be that feelings of helplessness led them to perceive greater disability, or it may be that greater disability made them feel helpless. Perceived control over symptoms (as opposed to control over the perceived disease course) seems to predict positive and better adjustment.

Moreover, perceptions of helplessness affect physical function independent of disease severity in established RA (Lorish *et al.,* 1991) and may even affect the inflammatory process (Parker *et al.,* 1993) and quality of life (Cadena *et al.,* 2003). Four hundred and forty-three patients with recent-onset IA were followed from baseline for two years and the outcome at this time showed that there was a close link between helplessness and disease outcome, thus high helplessness scores at baseline were associated with higher HAQ scores at two years (Camacho *et al.,* 2013). However, it was not clear whether the impact of helplessness on HAQ scores was driven by the level of disability experienced or the level of perceived disability.

2.4   Quality of life

People confronted with a chronic illness are faced with the need to accommodate their illness and this may have an impact on their quality of life. Quality of life is multidimensional incorporating three main domains – physical, psychological, and social functioning (Siegrist and Junge, 1989), but beyond this core set there may be additional issues for some individuals such as spirituality, intimacy, sexuality and body image (Sprangers and Schwartz, 1999). Quality of life not only means different things to different people but can also mean different things to the same person at different stages of their life with IA. Internal standards, a person's values and their conceptualisation, can all contribute to their perception of their quality of life at given time points (Dingwall, 2001). Changes in an individual's health status may prompt behavioural, cognitive and affective processes necessary for accommodating any illness. These processes have the potential to change an

individual's standards, values or conceptualisation of their quality of life. Perceiving a suboptimal quality of life may lead to a person re-evaluating and changing their values (Rosen *et al.,* 2012).

Finlay and Coles (2006) suggest that people with psoriasis have a reduction in quality of life that is worse than patients with other chronic diseases such as diabetes and that patients feel stigmatised by their condition (Richards *et al.,* 2001). Although stigma may be due to poor body image it may also be related to the negative perceptions of others or low self-esteem (Camp *et al.,* 2002) and this impacts on quality of life and how a person adjusts to their long term condition (Katz, 1998). A Canadian study compared patients with RA and PsA, looking at their health related quality of life using the SF36, which measures QoL across four subscales (mental health, vitality, emotional and social roles), and four physical subscales (function, pain, general health and physical role) (Salaffi *et al.,* 2009). Patients with PsA reported higher levels of vitality (energy), than patients with RA, however reported more role limitations due to emotional problems and higher levels of pain. Although the results were surprising, they may be due to the more severe disease activity in patients with PsA, who also had on average a longer disease duration. Quality of life issues may be different or related to different domains in newly diagnosed patients.

A recent abstract presentation reviewed the QoL in patients with RA in a longitudinal study lasting five years (Matcham *et al.,* 2013). Again using the SF36, results showed that all QoL domains were significantly poorer than the general population. Greater improvement in mental health over the first year was related to function and being in employment. Although these improvements appear to be sustained, QoL levels still remained low compared to the general population, suggesting if the adaptation and adjustment process or outcome could be fully understood then there may be an opportunity for clinicians to improve QoL by supporting individuals appropriately. This reduced QoL may equate to a perceived disruption in a person's biography.

2.5   Biographical disruption and the concept of a journey

Bury (1982) and Charmaz (1983) suggested that chronic illness can be perceived as a biographical disruption, which encompasses a loss of self or threatened identity. Bury (1982) in a review of RA patients proposed the concept of biographical disruption as a way of defining an individual's altered life course when dealing with an impact of chronic illness. Chronic illness was identified by Giddens

(1979) as not only a critical situation but also as a "disruptive" experience within an individual's life. Bury (1982) suggests that there are three aspects to disruption when chronic illness occurs. The first is a disruption of taken-for-granted assumptions and behaviours, the second is a disruption of the explanatory system normally used by people where they rethink their biography and self-concept and thirdly, there is the response to disruption involving the use of resources in facing an altering situation (for example social and financial resources).

In this classic framework, illness is characterised by dependency, regression and through encounters with the medical professionals, hopefully onto recovery (Bury, 1991), although in the context of chronic illness "recovery" means control rather than resolution of illness. These disruptions necessitate a fundamental re-thinking of the individual's biography with a marked shift from the anticipated normal trajectory of life (e.g. physical hobbies or anticipated career options). This long-term time scale makes the illness a "journey" that is a marked change from the normal paths of a person's life, leading to differing outcomes and consequences than those originally anticipated. The journey itself is an attempt to rationalise aspects between the changed body, self and society using the past experience to have meaning in the present (Martin-McDonald and Rogers-Clark, 2005). It has been closely linked to illness narratives where this reconstruction takes place to account for the disruption of routine daily life (Williams, 1984). However, illness narratives may be continually changing as new symptoms appear, more in-depth understanding occurs, and as the journey progresses, new treatments tried (especially in IA).

This fundamental consequence of chronic illness has also been clarified as loss of self (Charmaz, 1983), with the illness disrupting not only the person's physical self but also their sense of identity and self-worth. The biographical disruption requires a redefinition of the self and the recognising of disability and therefore it may not be possible to restore a person's past identity and this may have an impact on the journey outcome, processes and adaptation and adjustment.

The next section addresses the difficulty in defining and understanding these and also whether they are processes or outcomes. The subsequent section then reviews theoretical models that underpin the understanding of living with a chronic illness.

2.6   Definitions of adaptation and adjustment

There appears to be no consensus in the literature regarding the definitions of adjustment and adaptation, and in some papers the terms are used inter-changeably (Felton and Revenson, 1984; Diamond, 2007). Even in papers that focus on models of change with regard to chronic illness there is a failure to define conclusively these two terms (Taylor, 1983; Paterson, 2001). Dubos (1961) (quoted by Walker, Jackson and Littlejohn, 2004) acknowledged that health is a complex mirage: "From a distance, health and adjustment to illness appear to be a clear concept, but as researchers and clinicians approach and attempt to define it, the clarity disappears." It may be that the terms *adaptation* and *adjustment* are specific to the disease, to the individual, are context–specific (e.g. in home life), or any combination of these. In the studies reported in the following literature, the terms are used exactly as the authors used them, in order to help unpick the similarities or differences between the concepts, but the casual use of the terms clearly demonstrates the lack of clarity.

Adjustment has been conceptualised as *"a response to a change in the environment that allows an organism to adapt to that change"* (Sharpe and Curran, 2006). This suggests that adjustment occurs over time, and it also implies that adaptation is part of or an outcome of adjustment. This links with the origins of adaptation from Darwinian theory which suggests that those most able to adapt to the physical world are most likely to survive, which in turn links with the Latin derivative of *adaptare,* which is to modify, adjust or adapt to new "environment". In health terms, the threat of a new illness could constitute a new environment. For example, within the context of chronic illness (cancer) Watson *et al.* (1991) defined adjustment as being *"the patients' cognitive and behavioural response to their diagnosis".* However, this conceptualisation fails to incorporate an individual's social context. This basic definition was expanded to include social and spiritual dimensions by Brennan (2001), in his social cognitive transition model of adjustment. This model proposes that patients with cancer make psychological changes over time, both positive and negative. It is these changes that Brennan refers to as adjustment. He disputes that rather than describing adjustment as an endpoint or outcome it is a process. It is a method of change as the individual, and those in their social world, manage, learn from and adapt to the multitude of changes which have been precipitated by the illness and its treatment. This contradicts the concept that adjustment is the end result or outcome.

Thus several authors appear to define adjustment as process and adaptation as the endpoint or outcome. In contrast, Sarafino (2006) makes the opposite proposal, of adaptation as a process and adjustment as the endpoint: *"the process of making changes in order to adjust to life's circumstances".* Within the health psychology literature, adjustment as an endpoint has been linked with higher quality of life, well-being and global self-esteem (Sharpe and Curran, 2006). However, this fails to take into account the notion that quality of life or distress can occur independently of illness or can be the result of other individual differences. In other sciences more formal definitions have been ascertained to enable transferable frameworks to be established (Smit *et al.,*1999). In geographical sciences they include the notion that adaptation may be planned or spontaneous and in response to or in anticipation of change of conditions (Watson, Zinyowera, and Moss, 1996). This is important within the context of IA as self-management outcomes focus on long-term changes and individual control.

Affleck *et al.* (1991) in their review of appraisal of control in people with RA, discuss psychosocial adjustment, but also talk about perceptions of control having a significant impact on psychological adaptation. Neither term was defined; they do however suggest that variables such as patients' mood may affect adaptation. Reid (1984) contends that optimal adaptation to a chronic disease depends on the patients' ability to come to terms with what he/she can or cannot control. Affleck *et al.* (1991) reported that those patients with RA who described greater personal control over medical care and treatment expressed more positive mood, and this was correlated with more positive adjustment to their illness (but did not define adjustment).

Adjustment has been defined by others as *"some aspect of psychological adjustment"* (Sharpe and Curran, 2006). This is not encompassing enough within chronic illness, in that it fails to include aspects around social isolation or physical symptoms. Stanton, Revenson and Tennen, (2007) identified five elements of successful adjustment to a chronic illness: the successful performance of adaptive tasks (e.g. adjustment to disability); the absence of psychological disorders; the presence of low negative affect and high positive affect; adequate functional status (work status); and satisfaction and well-being in life. These concepts suggest that adjustment encompasses multiple components that cross interpersonal, cognitive, emotional, physical and behavioural domains, all of which may be interrelated. Kaptein, Scharloo and Weinman (2001) summarised their definition by suggesting, *"Adaptive tasks are activities that lead to a state of adjustment".* This again suggests that adaptation is the process whereas adjustment is the outcome.

Tanyi and Weiner (2008) in their study with 16 women with end stage renal disease describe adjustment as beginning on the day of receiving their diagnosis, (i.e. a process), and although they infer that adjustment is both physical and psychological they do not give a clear definition. However, the idea and the recognition that adjustment begins with diagnosis may have important connotations for people with IA, and will be explored in this thesis.

The lack of an agreed definition for adaptation and adjustment within IA suggests that HCPs and patients may have different understandings of the treatment and self-management processes and outcomes and therefore different definitive end points. For example a patient may feel that they have adapted to their disease when the medication controls their disease enough for them to return to work, whereas an HCP may feel that adaptation occurs when a patient has re-evaluated their work-life balance to accommodate the illness. Alternatively, an HCP might use the term adaptation to refer to practical adaptations such as a jar-opener, or a ramp at the front door, whilst reserving the term adjustment for the way in which patients re-conceptualize a life that includes chronic illness. In the absence of a consensus and for the purpose of this thesis adaptation and adjustment will be defined as:

Adaptation is the practical or <u>behavioural</u> changes the person has to make in order to make their life successful in terms of activities of daily living.

Adjustment is the <u>psychological</u> change the person has to make in order to maintain a quality of life that they perceive as satisfying.

What is unclear and will be explored in this thesis is whether these are processes or outcomes or whether the definitions are inconsequential to people with IA. The definitions will be explored by asking patients to define adaptation and adjustment during their interviews, and examining the qualitative data carefully. From the patient perspective it may be that the exact definitions are unimportant. Having provided a working definition of adaptation and adjustment, the possible processes that are taking place are now explored from a theoretical basis (chapter 2.7 and 3). These will be revisited in the discussion to link the theory to the findings from this study (chapter 8). These findings will establish whether any theoretical relationship between the frameworks and practice exists so that we can support the patient appropriately.

Adaptation and adjustment may affect outcome, but perceived potential and actual outcome may affect adaptation and adjustment. Coping strategies used will

also depend on and feed into adaptation and outcome and these are discussed in chapter 3.

2.7 Theoretical frameworks of behavioural adaptation and psychological adjustment

Folkman and Greer (1997) suggest that models provide a framework for understanding how individuals function with a long term condition, and how people may generate and maintain psychological well-being despite living with a chronic, potentially serious condition. Theoretical frameworks that have proposed how people achieve psychological adjustment to chronic disease that are the most relevant to IA are discussed in this section.

Taylor and Aspinwall (1996) propose that in order for people to begin to adjust, cognitive "adaptation" needs to begin. They emphasise three themes; a search for meaning, an attempt to gain mastery or control over the illness and an effort to restore self-esteem. This approach is important in IA as it acknowledges that adjustment to illness constantly changes over time. Therefore, when IA changes with flares, remissions and daily fluctuations in pain and stiffness, together with changes in pain medication or activity, the demands on psychological adjustment will alter.

When a person faces living with a chronic illness the search for meaning is often within the context of the impact of the disease. There is little research on the meaning that IA patients construct about their illness (Walker, Jackson and Littlejohn, 2004). The majority of literature focuses on patients with cancer where meaning refers to a person's understanding of the implications that a condition has on self, priorities and goals (Fife, 1995). It may be difficult for patients with a diagnosis of IA to create meaning due to the fluctuating nature of the illness; however, they may be able to find elements of control.

The potential models relating to psychological adjustment and behavioural adaptation are now reviewed in the following sections, the concept of gaining mastery (section 2.7.1), pendular reconstruction model (section 2.7.2), shifting perspectives model (section 2.7.3), response shift model (section 2.7.4), normality models (section 2.7.5) and transformation model (section 2.7.6). These models will then be revisited with reference to the findings in this study.

2.7.1   Gaining mastery

Based on research interviews with women with RA, Shaul (2005) suggests that there are three stages in the process of psychological adjustment: becoming aware of the condition; learning to live with it; and "mastery". Each stage included "sub phases" that at times overlapped depending on the person. The early stage began when the women acknowledged that the twinges of pain would necessitate medical intervention and sought help, often when symptoms began to interfere with daily life. Following a diagnosis, the next stage focused on learning to live with RA, and commonly they re-set their life goals. Mastery was about achieving a satisfying quality of life, managing their roles and allowing them to live with their arthritis. Interestingly it did not mean that the women could control their disease or a flare, but that they were able to manage the impact of the disease. The process Shaul discusses is based on people taking control, redefining their life (including what constitutes normality to them), with gaining a sense of empowerment. Although the study is 19 years old, and all participants were women (men may have a different journey), it emphasised the transitional process of RA and shows that psychological adjustment is complex and ever changing. Shaul (1995) described mastery as similar to normalisation, in which individuals integrate the illness and illness related coping strategies into their daily life (section 3.2).

This mastery meant that people were no longer recognising their illness as temporary, but as a permanent long term condition. However, the interviews were retrospective therefore subject to possible recall bias. Also with no disease duration reported and yet patients reporting mastery, it could be assumed that the patients had already developed coping strategies that enabled them to *"master"* their illness. It may be different for newly diagnosed patients; therefore a prospective study is vital in helping to understand how newly diagnosed patients respond to their illness.

2.7.2   Pendular reconstruction model

Yoshida conceptualised the sense of self and identity in people with acute spinal injury as a pendulum where identity swings back and forth between the non-disabled and the disabled aspects of self (Yoshida 1993). This framework built on earlier ideas from Blumer (1986), who identified the centrality of self as a medium through which people interpret situations and take subsequent actions. Subsequently, frameworks were developed to illustrate the reconstruction of self either as "process" or "outcome". Both Bury (1982), through his biographical disruption (section 2.4), and Williams (1984) through narrative reconstruction,

examined how individuals "order", or make sense of, their long term illness, in order to reconstruct a sense of self. However, while biographical disruption suggests that the process is linear, Yoshida (1993) proposed that it is a dynamic process, moving back and forth between a pre- and post-trauma sense of self. The model was based on a study with interviews with adults with an acute spinal injury, rather than people with a more gradual onset of disability, therefore we do not know if a similar process occurs in IA.

Although there is no static end goal in Yoshida's pendulum, the concept does suggest that there is a sense that individuals should move psychologically through different identities, one being with "disabled identity as aspect of total self", which would imply behavioural adaptation and psychological adjustment to the condition.

This idea of a "dynamic" changing concept may be useful for any condition with uncertainty, especially when treatment regimens are being changed or started. Within the context of IA there may be movement back and forth, not only on a day-to-day basis but also long term, with the pendular movement occurring both physically and psychologically. Thus, although as yet untested in IA, this model could potentially be descriptive and useful in IA, where the symptoms are fluctuating, unpredictable and potentially accumulative. It could be postulated that the pendulum swings between perceptions of past, current and future selves, and therefore could be conceptualised as a multi-dimensional pendulum.

2.7.3   Shifting perspectives model

Paterson's model of shifting perspectives arose from a synthesis of qualitative findings and has not yet been tested in a fresh data set (Paterson, 2001). This model proposes that living with a long-term condition is an ongoing and continually shifting process between an illness in the foreground or wellness in the foreground perspective. Here, a perspective is defined as a representation of beliefs, perceptions, expectations, attitudes and experience about what it means to be a person with a chronic illness within a particular context relevant to the individual.

A wellness in the foreground perspective includes an attempt to reconcile self-identity with the identity that is shaped by the illness, the construction of the illness by others and by life events (Fife, 1995). In contrast an illness in the foreground perspective is the perspective of threats to control. These can include signs of disease progression, lack of skill to manage the disease, disease-related stigma and interactions with others that emphasise dependence (Paterson, 2001).

Similar to Yoshida's pendular reconstruction model (1993), Paterson argues that illness is an ongoing and continually shifting process, in which wellness-in-the-foreground or sickness-in-the foreground have specific functions in that individual's own world (Paterson, 2001). People with a chronic health condition live in two different worlds with two different identities (Donnelly, 1993) consequently the shifting perspective model contains elements of both illness and wellness. The major paradox in the concept of shifting perspectives is that when wellness is in the foreground and the illness is distant, managing the disease may be at the forefront of the patient's life; namely, a person feels that the illness is distant because they are paying attention to it, in order to contain its impact. The person needs to recognise the disease as part of their life whilst at the same time minimising the significance of the illness and its limitations. This model might successfully account or the variations in the experience of a fluctuating condition such as IA, although it has not yet been explored in this condition.

However, ignoring the changing state of the disease in order to sustain wellness in the foreground may actually contribute to disease progression. As Shaul (1995) shows, people then may not heed the need for support or therapeutic interventions such as medications to control inflammation in the long term; therefore although they may feel well, their disease may be progressing. The shifting perspectives framework indicates there are no right or wrong perspectives, but aims to reflect people's changing needs and situations.

2.7.4   Response shift model

After receiving a diagnosis of a chronic illness, people redefine their own personal standards of what constitutes health, and change their values and priorities accordingly away from what was previously deemed as normal for them through reflection and self-evaluation; this is known as a response shift (Howard and Dailey, 1979). A response shift is a psychological change in one's perception of the quality of life following a change in health status (Sprangers and Schwartz, 1999). This response shift may be due to a change in their internal standards, or an internal re-definition or re-conceptualisation of their illness (Sprangers and Schwartz, 1999). Its foundation lies in the fields of education (Howard and Dailey, 1979) and organisation change (Golembiewski, Billingsley and Yeager, 1976), and it was re-developed to look at health-related quality of life, where a third component (changes in values) was added to the model (Sprangers and Schwartz, 1999). One crucial assumption of the model is that people want to feel as good as possible about themselves either in

the past or present, thus the response shift is directed towards maintaining some element of homeostasis.

This phenomenon was recognized initially in patients with terminal diseases who, despite a worsening of the physical condition, did not necessarily report deterioration in quality of life (Addlington-Hall and Kalra, 2001). In a qualitative study by Beaton *et al.* (2001) of patients recovering from work related upper body musculoskeletal pain, "feeling better" was contextualised within the experience of each individual and was not necessarily related to the change in disease status measured by symptoms, impairment or function. This has implications for patients, HCPs, and researchers when the outcome measurements in any chronic illness are paramount in treatment aims: a person may perceive they are better (response shift) but a clinical trial using specific questionnaires may not capture this improvement. In a small qualitative study that interviewed five women with RA, it was found that core values changed over time (Sinclair and Blackburn, 2008). This "reprioritisation" shows the importance of personal values within a fluctuating illness such as IA and may influence intervention techniques by HCPs.

2.7.5   Normality models

The concept of change in a patient's perspective of what constitutes a "normal life" has been proposed as an explanation of change to long-term illness. It is suggested that a dynamic model captures the interaction of changing concepts of a normal life together with normalisation of symptoms (Dingwall, 2001). There are many varying definitions of normality within the concept of illness, with boundaries of normality being fluid and influenced by time and circumstance (Tishelman and Sachs, 1998). For people with motor neurone disease it was suggested that there is a move from the biographical disruption at the point of diagnosis as described by Bury (1982) (see section 2.4), to re-establishing a sense of normality (Locock, Ziebland, and Dumelow, 2009). However, Brown and Addington-Hall (2008) suggest that this sense of normality is a new "dynamic normality" and the sense of old normality is abandoned. Their description suggested repeated cycles of incorporating each new phase of the illness into a new "normal" daily life. This process of normalisation (Sanderson *et al.,* 2011) is a behavioural attempt used to maintain a normal life. Whilst Thorne and Patterson (1998) suggest that some individuals choose not to normalise because of concerns that this would prevent them from creating realistic identities, the work by Knafl and Deatrick (1986) identified four key elements in normalisation. These include: acknowledging the impairment; defining

life as basically normal; minimising the consequence of the illness; and engaging in behaviour that demonstrates normality. Knafl and Deatrick (1986) recognise and account for a person's need to come to terms with their illness within their daily life in their largely behavioural model. In contrast to this, Kelleher (1998) postulates normalisation as a largely cognitive process that involves bracketing off the impact of the illness to minimise its effect.

Although IA remains an unpredictable disease the efficacy of anti-tumour necrosis factor (anti-TNF) therapies (Deighton, 2009) have allowed some patients to return to "normal life": a concept that may not have been considered at the time of Bury's research (1982). Sanderson *et al.* (2011) found that despite these advances some people with RA (disease duration of 3-40 years) found they were required to consciously reconceptualise their "normal" life incorporating fluctuating symptoms and a changed self. Sanderson's "shifting normalities" may be an important concept for those newly diagnosed with IA in coming to terms with a fluctuating illness. This study indicated that even with the "non-normal" life there were different concepts; disruption, struggling for normality and fluctuating normality, these concepts will be re-visited in chapter 8.

The challenge that IA brings for patients is the fluctuating nature of the disease and its unpredictability despite the advancement of interventions and treatment. Normality has been identified in studies of people with arthritis as both an important outcome and an important aspect of living with the disease (Dildys, 1996; Carr *et al;* 2003; Fair, 2003). However, it was the study by Sanderson *et al.* (2011) that suggested the interaction of concepts of a normal life, normalisation of symptoms and of the illness appear to be dynamic in nature. They proposed a concept of shifting normalities, which indicates that biographical concepts need to be seen within the context of the symptoms, adjustment processes and self. Whilst this concept arose from interviews with people with RA, it has not yet been examined prospectively in newly diagnosed patients.

Chronic illness has an effect on each individual person's ability to function at what society perceives as normal (de Ridder *et al.,* 2008). An individual's struggle for normality is related to trying to understand the change in their life situation and seeking to answer the question of why they have an illness (Öhman, Söderberg, and Lundman, 2003). There have been accounts of patients whose normal and disrupted biographies "co-exist" (Sanders, Donovan and Dieppe, 2002). For example, patients with osteoarthritis described their condition as part of ageing, i.e. "normal", but also as causing significant disruption to their lives due to pain and reduction in physical function (Sanders, Donovan and Dieppe, 2002).

2.7.6 Transformation model

Researchers have described transformation in a variety of chronic illnesses, including HIV (Baumgartner, 2001), arthritis (Dubouloz *et al.,* 2004), diabetes (Paterson *et al.,* 1999), coronary artery disease (Dubouloz *et al.,* 2010) and spinal injury (Carpenter, 1994). Transformation has largely been defined according to its perceived outcomes rather than its purposes or its component parts. Mezirow's description of transformation in adults, focuses on the process of knowledge, beliefs and values as related to their actions (Mezirow, 1990), i.e. the cognitive and emotional processes that drive actions that result in transformation. Meizirow's transformation model shows a process characterised by an initial reaction phase that leads to two distinct and sequential phases (embracing the challenge and integration of new ways of being). People living with chronic illnesses begin the transformation process in the initial phase as a catalytic experience (onset and diagnosis) that is a turning point. In the embracing stage people make a decision to acknowledge the challenge that the chronic illness presents to them. This involves a critical evaluation of the challenges to their personal situation and the role of friends or family. This critical reflection leads towards change as the person starts to understand and make adjustments. The last phase is the integration of new ways of being. Thus the person identifies and experiences the outcome of the previous phases, but with understanding and acceptance of both their social and personal contexts, which may include interaction with HCPs and healthcare systems. The transformation model has three aspects: the progression from one phase to other; the duration of each phase; and the iterative process influenced by their social world (significant others, healthcare system) and social and personal contexts (i.e. readiness to progress). It has been noted by the original researchers that the initial phase can last up to five years. Thus it should be acknowledged that the process is complex and iterative, and people with chronic illnesses can return to former phases.

Dubouloz *et al.* (2004) examined this model in the context of rehabilitation with people diagnosed with early RA. They found critical reflection based on new knowledge of the illness encouraged a new direction within people's coping mechanism, one of enhanced self-respect. This enabled people to develop self-care strategies transforming dependence and incompetence to interdependence and self-responsiveness. Although Dubouloz *et al.* (2004) did not examine how transformation occurs; the model, along with the shifting perspectives model, does suggest that the encouragement of active self-awareness and self-reflection during the adjustment process is an additional, important aspect for clinicians to recognise.

In the context of this thesis, transformation refers to people being transformed by the experience of living with the chronic illness so that they are able to move beyond focusing on the burden and suffering associated with the illness. Embedded in this is the implication that transformation represents the "adaptive ideal' of living with a chronic illness (Patterson *et al.,* 1999).

2.8 Summary

Alongside descriptions of the disruption of chronic illness, there is a growing body of research literature that documents the path people take to psychologically adjust and behaviourally adapt to their illness. Understanding these concepts may help HCPs support the patient in this journey. In part, these concepts or theoretical models have been brought about to explain the diversity of the disruption of having a chronic illness. Early focus on loss and the burden of sickness has now shifted towards health contextualised within illness and more positive themes where the focus is on reshaping the self (Yoshida, 1993), empowering potential (Fleury, 1991) and optimising health within chronic illness (McWilliam *et al.,* 1996).

The models have not been explored in early IA therefore it is difficult to ascertain which, if any, will be pertinent to the journeys of people newly diagnosed with IA. If it was known how early IA patients started to conceptualize their illness and move toward psychological adjustment, it could potentially inform the support offered by HCPs, and also provide insight into the behavioural responses and choices that patients make. Therefore these theoretical models will be explored during prospective interviews with people newly diagnosed with IA and will be reflected on further in the discussion (Chapter 8).

Although the existing literature is based on recall (retrospective interviews) it does suggest that the process of adaptation and adjustment, despite the lack of clarity, is influenced by a number of pre-conceptions. The pre-conceived ideas that individuals have about different conditions (illness beliefs) may be present before their diagnosis and influence their coping strategies utilized on their journey to adjustment. Illness beliefs and coping strategies will be reviewed in the next chapter.

Chapter 3: Potential theoretical routes to achieving adjustment

Having discussed the potential impact of inflammatory arthritis (chapters 1 and 2) and the need to adjust and the impact that this brings to one's life (chapter 2), this chapter will explore the potential coping strategies that a person may adopt and some theoretical aspects that may contribute to the success of these skills and choices. It will look at a person's readiness to change and how this is influenced by their self-efficacy and social cognition theory, and then will review illness beliefs and their impact on IA, effect of support networks on psychological adjustment and personality and chronic illness.

3.1   Ability to cope

Individuals vary significantly in how they adjust to their arthritis and this is not always explained by the level of disease activity alone but by their ability to cope. Coping was originally conceptualised as a defence mechanism with its origins in psychoanalytic theory as discussed by Steed (1998). However, this approach was criticised by Folkman and Moskowitz (2000) who argued that it underestimated the complexity of the nature of both the coping efforts and the changes necessary. Coping is now a recognised variable in understanding adjustment to long-term illness including RA (Ramjeet Smith and Adams, 2008) and refers to the cognitive, emotional and behavioural strategies people employ in their lives in an attempt to manage the consequences of their disease (Lazarus and Folkman, 1984). Coping has been classified in terms of the focus of the strategies, for example: emotion-focused and problem-focused coping, or in terms of the expected outcome, for example active or passive coping (Snow-Turek, Norris and Tan, 1996).

The term coping is often used interchangeably in the non-psychology literature with "self-management", but patients have been shown to be able to distinguish between the terms (Nicklin *et al.,* 2010). In their qualitative study patients identified terms and developed the wording for measures of RA fatigue from their own perspective and during analysis it was seen that patients differentiated between "managing" their practical issues with RA fatigue and "coping" with their emotions and it is these definitions that are used in this thesis. This chapter reviews the possible strategies that patients may use towards achieving psychological adjustment (as discussed and defined in chapter 2.6) and how this relates to their self-management of a long-term condition.

3.2   Coping strategies

Moos and Schaefer (1984) suggest that three processes constitute the coping process: cognitive appraisal (i.e. an evaluation of the stressors and available resources), to inform use of coping skills and adaptive tasks (behaviour and cognitive change). This "crisis theory" suggests that the cognitive appraisal of a particular problem is influenced by three factors: physical and social environmental factors, illness related factors and background and personal factors (fig 3.1).
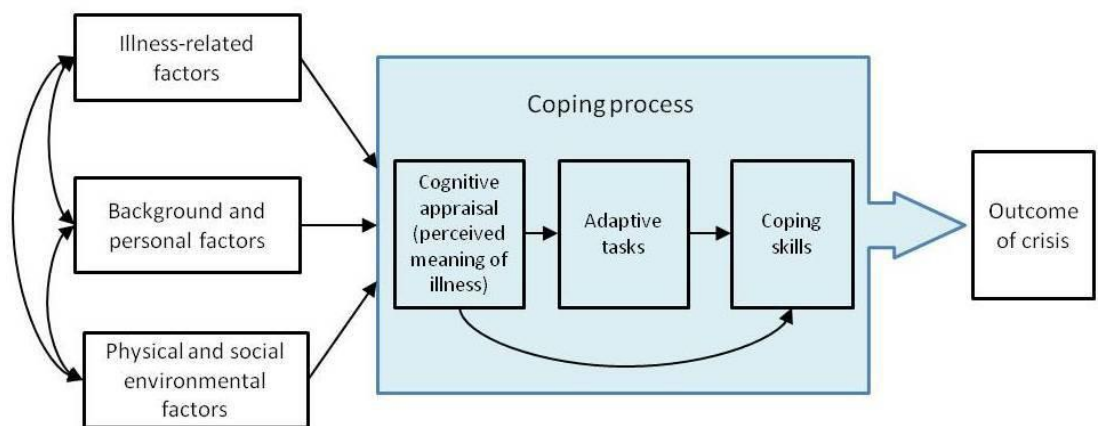
Figure 3.1 Diagram of crisis theory (adapted from Moos and Schaefer 1984)
(Used with permission of the author)

3.2.1   Influences on the coping process

➢   Physical and social environmental factors

The physical environment includes the person's home situation and their access to care and availability of services. In a review of social factors using self-report questionnaires of patients with arthritis, environmental aspects of safety, aesthetics and social cohesion were predictive of positive health outcomes such as exercise and positive mental well-being (Pollock, Christian and Sands, 1990). Social support is also influential and discussed in section 3.8.

➢   Illness-related factors

These are the perceived threats that a person may associate with their health problems. The greater the perceived threat the more difficult it

is to adjust to the illness (Cohen and Lazarus, 1979). Perceived threats are related to illness beliefs, an aspect reviewed in section 3.6. Thus a patient who perceives their arthritis as disabling may struggle more to cope than someone who deems their arthritis as non-life threatening compared with a diagnosis of cancer.

➢ Background and personal factors

People who cope successfully with chronic illness tend to have resilient personalities (Pollock, Christian and Sands, 1990); this allows them to perceive the positives in most challenging situations. Spiritual beliefs and religion may impact on cognitive and emotional processes (Wachholtz, Pearce and Koenig, 2007), which may then influence biological mechanisms, thereby directly impacting on pain (Rippentrop et al., 2005). For example, positive spirituality may reduce the impact of pain by reducing stress, acting as a form of distraction, and often by providing social interaction (George et al., 2000). However, research has also shown that negative spirituality based cognitions (for example the belief that God has abandoned the person) are related to increased symptoms such as pain sensitivity (Rippentrop et al., 2005).

These three factors combine to influence cognitive appraisal (figure 3.1), and thus the coping process. However, the model does not indicate which of these factors influence people moving from appraisal into adaptive tasks (behaviour and cognitive change) and on towards utilizing coping skills. Coping has traditionally been classified according to the focus of the strategies: emotion-focused and problem-focused (Folkman and Lazarus, 1980) and more latterly, active coping and passive/avoidance coping (Brown and Nicassio, 1987). It is possible that people cope in different ways when dealing with the wait for a diagnosis, versus dealing with the diagnosis, and differently again when the treatment has begun and they are adapting to the long-term effect of the illness. Therefore, these coping models act as a building block or basis through which it is possible to examine the development of the patients' coping strategies.

To promote psychological adjustment, patients should remain as active as reasonably possible, acknowledge and express their emotions in a way that allows them to take control of their lives, engage in self-management and try to focus on potential positive outcomes of their illness (Arends et al., 2013). Patients who can use these strategies have the best chance of successfully adjusting to the challenges posed by chronic illness (de Ridder et al., 2008). Adaptation and adjustment to having IA, including its implications and learning to live with them has

been found to influence coping mechanisms towards gaining control (Shapiro *et al.,* 2010) whilst being realistic about physical outcome.

3.2.2   Problem-focused coping

Problem-solving has been shown to be used in a cohort of nearly 200 patients with RA or OA, who used information seeking, pain control and cognitive restructuring (Dixon *et al.*, 2007) to maintain a sense of control. Techniques such as relaxation and active efforts to reduce pain in IA have been shown to contribute to reductions in next day pain as well as enhance positive mood (Keefe *et al.*, 1997). Melanson and Downe-Wambolt (2003) in a population of 77 older patients with RA found that they mainly used problem-focused coping strategies to manage their illness, which is consistent with other studies looking at the older population (Mahat, 1997; Katz, 1998). However, all studies reported that the perceived illness related stressors for this population were linked to physical limitations and a perceived lack of control. In contrast, it may be that newly diagnosed patients or people waiting for a diagnosis don't have the same level of physical disability and therefore focus on a different way of coping, but no studies could be found that have explored this.

3.2.3   Emotion-focused coping

There are two main categories of emotion-focused coping: avoidance and inhibition of emotions, and expression and acknowledgement of emotions (de Ridder *et al.,* 2008). In North American and Western European cultures the regular use of avoidant non-expressive styles of emotion regulation has been shown to be disadvantageous for psychological adjustment in cardiovascular disease and cancer (Grossarth-Maticek, Eysenck and Vetter, 1988). In contrast, a population-based cohort study within Asian cultures found that in people with cardiovascular conditions, non-expression of emotion was psychologically advantageous (Hirokawa *et al.,* 2004). This suggests that the benefits of emotional non-expression may be culture-specific.

An emotion-focused intervention for patients with IA (Zangi *et al.,* 2009) consisted of a programme lasting four months involving 10 x four and a half hour sessions. Each session related to a different aspect of living with a chronic illness (for example recognising one's own emotions and what is meant by being healthy and being ill). There was an overall focus of using mindfulness interventions to strengthen

positive emotion-focused coping strategies. The intervention reduced pain and fatigue in participants for up to one year, although as this was not a randomised control trial improvements may have been made due to better disease management or the symptoms improving naturally or even emotional disclosure.

Another randomised controlled study in inflammatory rheumatic diseases (Zangi *et al.,* 2011) compared mindfulness delivered in 10 group sessions over 15 weeks to a control group who received a CD of mindfulness home exercises. The results showed significant reduction in emotional distress, pain and symptoms and improvement in self-efficacy in the active group, with sustained effects at one year, while emotional expression improved in both groups. Out of the 814 participants approached, only 73 were randomised. This suggests a selection bias towards already motivated individuals. The results demonstrate the benefits of mindfulness in rheumatic diseases with patients who have mean disease duration of 16.2 years although there appears a dearth of studies in newly diagnosed patients.

One strategy that appears to help people adjust is seeking emotional support from others. In a study of women who had just undergone surgery for breast cancer (Levy *et al.,* 1990) those who actively sought and received social support had higher natural killer cells present in their blood, indicating a positive physiological response. The quality of that social support was not addressed, yet quality of social support has been shown to be important to people with RA (Minnock, Fitzgerald and Bresnihan*,* 2003); social support is explored in section 3.8.

3.2.4   Passive/avoidance-focused coping

In a postal survey of 287 patients with RA, passive coping (that is reliance on others, restricting social activities) was associated with greater pain, disability and depression than those patients who used active coping (Brown, Nicassio and Wallston, 1989). A later study by Covic, Adamson and Hough (2000) also suggested that passive coping was linked with physical disability. It has been suggested that "passive coping" is actually a contradiction in itself and that passive coping is actually a non-coping strategy, and is deemed as maladaptive and detrimental to the health of RA patients (Covic, Adamson and Hough, 2000). There is some agreement that exclusive use of passive coping responses is associated with poorer adjustment and negative affect, whereas active coping is consistently associated with better adjustment and positive affect in IA (Folkman and Moskowitz, 2000, Newman, Steed and Mulligan, 2004) and in HIV (Young, 1992). However, those studies did not address fluctuating conditions and in IA it may be that passive coping such as resting and doing nothing will help to reduce symptoms of a flare and thus should be viewed

as an active coping response or that pain had made it impossible for active management and therefore a causal relationship cannot necessarily be assumed.

Although these categories seem to clarify the situation from a theoretical perspective for research, in clinical situations it is likely that people fluctuate between problem-focused and emotion-focused based coping, and passive/avoidance focused coping. Although it is intrinsically appealing to categorise coping into discrete strategies often the categories are over simplified and conceptually difficult to separate. It may be that people at different stages or even with the same problem may need to adopt more than one strategy, or alter their strategies, and this can be defined as flexible coping.

3.2.5   Flexible coping

Flexible coping is a useful way to combine different coping strategies both within the same situation and across situations. In general, individuals who are able to change their strategies in response to the situation demonstrate "flexible" coping (Cheng, 2003). This more varied coping approach may allow for better matching between the coping strategy and the needs of a particular situation and may suit the fluctuating and unpredictable nature of IA. Based on cognitive flexibility it allows the person to maintain control by assessing the effectiveness of each problem and solution (Kato, 2012) and changing appropriately. Thus in IA if passively resting does not relieve a swollen joint then actively seeking help (problem solving) to solve the same problem is needed, possibly with emotional support from the family.

The following table (table 3.1) gives examples of the different coping strategies discussed in this chapter and show how the combinations of these can be encompassed into flexible coping.

Table 3.1: Examples of coping within IA

Coping strategy	Definition	Explanation	Theoretical Examples	Reference
Problem-focused	Patient targets the causes of stress in practical ways	Seeking out information to address a particular problem	Use of ice or heat to relieve pain	Lazarus and Folkman (1984)
Emotion-focused	Patient tries to reduce the negative emotional responses to the stressor	Distraction Isolation (withdrawing from company to protect oneself) Discussing feelings openly	Telephoning a friend as a shoulder to cry on	Lazarus and Folkman (1984)
Passive/avoidance-focused	Feelings of helplessness to deal with the illness; relying on others to resolve the stressful event or situation	Reliance on others to do everything to resolve the situation	Allowing HCPs or family to decide on treatments.	Brown and Nicassio (1987)
Flexible coping	The ability to discontinue an ineffective coping strategy and produce and implement an alternative coping strategy	Trying different approaches for the same problem; or different approaches for different problems	Managing fatigue by pacing and planning a day's activity, and also by seeking help from others, and by phoning a friend to talk it through	Kato (2012)

3.2.6 Summary of coping strategies

Coping mechanisms are a dynamic way of managing a situation that an individual has perceived as stressful, which suggests that no single coping mechanism is inherently better than another. It is not a standalone phenomenon but something that involves the person, the environment and the inter-relationship between the two (Lazarus and Folkman, 1984). There is little evidence in the literature about how people with IA experience, cope with or adjust to chronic illness in the initial period around diagnosis or whether they combine their coping strategies in a flexible coping strategy. Coping will be explored through data collection and analysis and will be re-considered in the discussion (chapter 8).

A key aim of health care is for patients with IA to adjust to and self-manage their condition. The adoption of different coping strategies and participation in self-management may be influenced by several aspects including the individual's readiness to change.

3.3 Readiness to change

The effectiveness of self-management depends on clinician, treatment and patient characteristics (Holman and Lorig, 2004). One patient characteristic is a readiness to change, which refers to behaviour change as a process instead of a discrete event, with people moving from no intention or motivation to change, to the internalisation of new behaviour (Dijkstra *et al.,* 2001). Readiness to change is a central concept in the Transtheoretical Model of change, which was developed to explain the process of change in psychotherapy. Several stages of readiness to change have been defined (Prochaska and Velicer, 1997), from the pre-contemplation stage where people have not yet thought about changing behaviour through to thinking about change (contemplation), preparing to change, action and then maintenance of the new behaviours. Readiness to change is expected to predict successful behaviour change (Jensen *et al.,* 2003) and has been assessed in different behaviours such as smoking (Prochaska and DiClemente, 1986) and excessive drinking (Rollnick *et al.,* 1992). In fibromyalgia readiness to change was also linked to social support and personality (Dijkstra *et al.*, 2001) which, due to its fluctuating nature may also be important in IA as determined in fluctuating normalities (section 2.7.5).

3.4   Self-efficacy

Self-efficacy is the confidence that a person has to undertake a particular behaviour in order to achieve a desired outcome and is thus linked with self-management (Bodenheimer *et al.,* 2002). Self-efficacy is a vital component for goal setting and success with making changes and as a consequence will improve self-esteem and reduce negative impact (Hibbard *et al.,* 2007). A parallel randomised controlled trial of CBT versus conventional care in patients with RA and fatigue showed that self-efficacy was improved in the intervention group suggesting that self- efficacy is amenable to change (Hewlett *et al.,* 2011). This was supported by a qualitative study where patients attending a cognitive-behavioural program for RA found that by utilising the sessions their self-efficacy improved enhancing their self-management skills (Dures *et al.*, 2012), thus reinforcing the importance of self-efficacy.

Bandura (1993) argued that self-efficacy beliefs are important mediators in how and whether people feel in control of their lives. These differ from person to person, based on past interpretations and present day interaction with their environments and other people (Stretcher *et al.,* 1986) and are a fundamental principle of Bandura's social cognition theory.

3.5   Social cognition theory (SCT)

Bandura and Locke (2003) suggest that behaviour is influenced by goals and expectations and indirectly linked to three beliefs: belief in oneself (self-efficacy); beliefs about the consequences of a behaviour (outcome expectations); and beliefs about social norms. According to Bandura (1986) there are several ways of influencing self-efficacy including setting and achieving minor goals, vicarious or observational learning, and verbal persuasion. These relate to learning from peers within groups (SCT).

Steed *et al.* (2005) designed a study based on SCT, a self-management programme for people with diabetes that incorporated techniques to promote self-efficacy such as problem-solving and goal setting. The intervention group were compared to a non-intervention group who only received follow up assessments. Participants were assessed at baseline, six weeks and three months. At the follow up assessments the intervention group had significantly higher scores on diet, exercise and blood monitoring compared with the control group, with significantly increased self-efficacy, supporting Bandura's theory that increasing self-efficacy can

improve self-management. It is important to note however that only 50% of people approached participated in the trial, which may relate to readiness to change. This concept of self-efficacy is known to influence the relationship between coping and outcome (Lowe *et al.,* 2008) and is often used as both a process and an outcome measure in self-management within IA (Lorig *et al.,*1989) (section 1.7.3).

3.6   Illness beliefs

Leventhal *et al.* (1998) developed a common sense model (CSM) based on patients' beliefs, this included five domains of identity, time line, consequences, cause, and control. The main purpose of any belief is to provide some in-depth understanding about issues that relate to our own ideas (Damasio, 2000). From a psychological perspective beliefs are crucial to our personality as many of our attitudes, our behaviours and our ability to cope can be attributed to implicit or explicitly held beliefs (Lazarus and Folkman, 1984). Beliefs are powerful because as social constructs they provide the "mental scaffolding" for appraising, explaining and integrating new situations (Halligan and Aylward, 2006), in other words making sense of what is happening. How people self-manage their chronic illness may depend not only on self-efficacy beliefs but also on other beliefs and also experiences they have. Patients will already have pre-set ideas about their condition before they are seen by the medical team, and these "lay beliefs" may be rooted in common sense, family traditions or hearsay (Donovan, 1991). They have been shown to lie behind much of people's behaviour concerning health and illness. Therefore this section will explore these beliefs and their relevance within IA.

A number of terms to describe beliefs about illness are used in the literature, including illness cognitions, beliefs, representations and illness schemata (Kaptein *et al.*, 2003). Despite their different titles they all reflect the same premise and throughout this thesis the term "illness beliefs" will be used.

3.6.1   Identity beliefs

Identity beliefs are closely linked with beliefs about associated symptoms, for example if we are asked to define a common illness such as a cold we will often focus on the physical aspects of the disease. It may be argued that people like to have a label for their symptoms, and in a study of patients with early lupus where outward physical signs were not yet evident, the diagnostic label enabled them to legitimatise their symptoms (Hale, Treharne and Kitas*,* 2007). Similarly, Kralik *et al.* (2004) found that the medical team underestimated the impact of receiving a

diagnosis of RA, yet for the women concerned, although their beliefs about having a long term illness were negative, the label was helpful as it allowed the condition to be perceived by others as real.

3.6.2   Causal beliefs

A natural response to the onset of illness is often "Why me?" or "Why did I get this?" Attempts to identify the cause can be driven by people trying to make sense of the experience, and in turn may provide a sense of predictability or control (Taylor and Bury, 2007). Causal illness beliefs are often based on information gathered from previous experiences, as well as conversations or opinions from friends, family, medical professions and media (Hale, Treharne and Kitas, 2007). For most illnesses, almost all people already have some beliefs about the cause. However, as Taylor, Lichtman and Wood (1984) found in their study of people with breast cancer, these beliefs often differ from medical fact. For other people the cause is irrelevant. In a study of 1999 patients with RA nearly 60% attributed their disease to psychological factors (Hyphantis *et al.,* 2013).

Causal beliefs may predict subsequent health outcomes. Affleck *et al.* (1987) found that patients who attributed their heart attack to stress had greater disease progression 8 years later in comparison to patients who did not have those attributions. Those patients who blamed the initial heart attack on fate or luck were more likely to have another heart attack compared to those who felt their heart attack was due to exercise or diet. According to Williams (1984) patients' beliefs of the cause of their arthritis need to be understood by clinicians if we are to assist the person to engage with their illness, but this has been contradicted by Ailinger and Schweitzer (1993) who suggested that the perceived cause is unimportant. However, what is similar in the two studies are the reasons people gave for their RA, which included stress, other illness, trauma and infection.

Stress is a common causal belief that people hold for illness, and is one of the most commonly reported perceived causes among individuals with breast cancer (Taylor, Lichtman and Wood, 1984), heart disease (French *et al.,* 2001), diabetes (Hampson, 1997), multiple sclerosis and RA (Moss-Morris *et al.,* 2002). A more recent qualitative study by Bergsten *et al,* (2009) looked specifically at patients' beliefs of the cause of their RA. Their findings suggested that patients differentiated between two descriptive categories, "consequences beyond personal control" and "overloaded circumstances" i.e. they had felt a degree of responsibility for contracting their disease. They also found that unlike the study by Ailinger and Scheitzer (1993) patients found it important to talk about the cause

of the arthritis, which reinforces earlier work by Donovan (1991) and Williams (1984). Bergsten *et al.* (2009) assumed that cause is important as their participants with RA were willing to talk about it, but they had actually prompted patients by asking a very specific question about cause, and the impact of the different causal beliefs were not explored. Donovan and Blake (2000) showed in a study of IA that each person places their disease within the context of their own life; therefore taking cause into account may have issues for health care professionals in education and self-management programmes.

3.6.3   Timeline beliefs

This component constitutes the perceived time frame for both the development and/or duration of the illness; these beliefs tend to be re-evaluated as time progresses. People tend to define the timeline in three different ways; acute, chronic and cyclical (Leventhal, Nerenz, and Purse, 1984). Prior to diagnosis of IA, people may only ever have experienced an acute illness such as colds or a sprain, where the illness is relatively short and in most cases can be easy to recover from. Beliefs of the timeline may impact on a person's coping strategy. For example, if a person receives a depomedrone (steroid) injection at their first consultation and their symptoms subside, they may believe their illness is acute and temporary and thus not understand the need for long-term medication. Rutter and Rutter (2002) examined illness beliefs in 209 patients with irritable bowel syndrome (IBS) and found that irrespective of the time from diagnosis, those who perceived their illness to be long term were more accepting of their symptoms and used positive coping strategies.

3.6.4   Consequence beliefs

Beliefs about illness consequences are multi-factorial, including physical, social and economic, and they may also be bi-directional (Rutter and Rutter, 2002). That is to say the symptoms may affect beliefs about consequence (e.g. 'my pain is bad therefore the consequences will be bad'); equally beliefs about consequences may affect perception of symptoms (e.g. 'RA doesn't cause any long term damage so this symptom isn't too bad'). The perception that a disease is rare is often associated with greater beliefs of seriousness and increased emotional distress, than if illness is seen as being common (Heijmans and de Ridder, 1998). It may also be that consequence beliefs may become more realistic over time (Hale, Treharne and Kitas, 2007), which may be due to increases in experience and knowledge.

Beliefs about the future consequence of the illness are likely to affect adherence to treatment. For example, diabetes is potentially serious (Hampson *et al.*, 2001) because poorly controlled diabetes may lead to renal failure and retinopathy, but Gonder-Frederick and Cox (1991) showed that patients who did not experience many symptoms despite their diabetes being unstable, found the long term consequences of diabetes too abstract for them to comprehend, and thus perceived no reason to adjust their lifestyle. Little is known about the consequence beliefs of people with IA at the time of diagnosis.

3.6.5   Control beliefs

The control component of the CSM model originally indicated the extent to which the patients believed their condition could be cured or controlled (Weinman *et al.,* 1996). This was later divided into beliefs about treatment control and personal control (Moss-Morris *et al.*, 2002). Patients who perceive their medications are important (belief about treatment control) may have better well-being than those who do not, through increased adherence, or greater feelings of control. Treharne, Lyons and Kitas, (2004) found that patients with RA, who showed more concerns regarding their medication and greater perception of serious consequences (side effects), reported increased anxiety and depression and reduced life satisfaction. Similarly high levels of personal control have been found to promote lower levels of distress in chronic illness (Sirois, Davis and Morgan, 2006) and predict changing behaviour (Cooper *et al.,* 2010). As people with chronic illness learn more about their illness they will re-evaluate their control and the impact of their illness with new beliefs based on these re-evaluations.

Beliefs about control do not develop in isolation but are related to the patient's understanding of their illness as well as their appraisal of the effect of the treatment relative to their expectations as influenced by their illness beliefs. Patients' adherence behaviour is likely to be the result of a dynamic interaction between beliefs about treatment and illness and beliefs of outcome rather than the product of a single decision.

Knowing a patient's beliefs about their condition is clinically seen to be relevant for managing their condition and capacity to cope, treatment adherence (Horne, 2006) and behaviour (Petrie and Weinman, 1997). The question is how two people with the same illness can have widely different beliefs of their condition and in turn these beliefs can lead the patients with the same illness down very different trajectories. A number of studies have shown that when patients generally hold negative illness beliefs about their illness (e.g. more severe consequences, large

amount of symptoms associated with their condition), their beliefs are associated with increased disability and slow recovery independent of the initial disease severity in psoriasis (Scharloo *et al.,* 1998, Scharloo *et al.,* 2000) and in osteoarthritis (Botha-Scheepers *et al.,* 2006). There appears to be a dearth of research in patients with newly diagnosed IA.

Weinman and Petrie (1997) proposed that illness beliefs may not only explain the variety of coping mechanisms utilized for the same illness but are also directly related to such outcomes as adherence, emotional distress and illness related disability. For the patients the greatest impact lies in their perception of the effect that the disease has on their ability to continue with "normal" everyday life (Hale *et al.,* 2006). It is therefore important for researchers and clinicians to understand the influences behind the patients' thoughts and actions.

If illness beliefs are fundamental in care then understanding these should be considered a starting point for future interventions to facilitate change (Petrie *et al.,* 2002). The ultimate goal for HCPs is to determine whether understanding illness beliefs and how they are placed within CSM can instruct and predict certain outcomes and enable them to facilitate patient self-management in the long term. Stafford (2007) suggests, "It's all just common sense, but dressed up just to confuse people". However, patients may not be aware of their own illness beliefs and how they impact and influence coping. Also, despite the evidence highlighting the importance of illness beliefs there is no literature to suggest that HCPs examine these at the consultation when a person is first diagnosed with IA, nor are there good data on what those illness beliefs are at that time.

3.7   Impact of Illness beliefs

Leventhal, Diefenbach and Leventhal (1992) describe how a person comes to understand their illness within a self-regulating process. The individual adopts coping strategies and appraises progress, which in turn enables them to revise the coping strategy as needed (this acknowledges the role of both cognitive and emotional processes). This influential framework of Leventhal and his colleagues was derived from patients, who had a range of conditions, based on interviews to determine the fear component of their perceived illness. They purport that these beliefs need to be integrated within a dynamic system that includes outcome expectations and monitoring of the change between current status and desired endpoints i.e. the CSM (Leventhal *et al.,* 1997). They also proposed that these illness beliefs would determine coping.

The key construct within the CSM is that lay beliefs about illness are based within existing schemata that people hold, that is, what they perceive is normal, allowing them to make sense of their symptoms and in turn cope with the process of change (Scharloo and Kaptein, 2013). Therefore, the CSM suggests that changes in illness beliefs may lead to behaviour change in self-management. Petrie *et al.* (2000) developed a brief psychological hospital based intervention designed to change inaccurate and negative illness beliefs in patients after their first myocardial infarction (MI). The aim was to modify patients' maladaptive beliefs concerning their MI, as well as to educate them, encouraging patients to develop their own personalised plan of care. Evaluation post hospitalisation and at three months showed that the intervention produced significant changes in patients' beliefs about their illness, their perceived consequences of their illness were improved and level of control increased. They subsequently returned to work significantly quicker than the non-intervention group.

Weinman *et al.* (1996) suggest that illness beliefs may not only be a way of explaining the variety of coping responses to the same illness but may also be more directly related to medication or treatment adherence and to emotional distress. From a clinical perspective, understanding a patients' beliefs about their illness will help practitioners support patients' self-management of their disease, and may even minimise non-adherence. De Ridder *et al.* (2008) showed that such beliefs influence adaptation to long-term conditions and the adoption of both effective coping strategies and self-management skills. For example, at the onset of IA a belief that a swollen knee may be due to excessive running (cause) may make the person rest. However, when the problem persists beyond expectation (timeline) and cannot be eased (control), then they may seek medical help. Inaccurate beliefs may influence adherence to therapy, for example a person who believes that the IA is not a serious condition (consequence) may be less likely to take major drug therapy.

3.7.1   Illness beliefs around the diagnosis of IA

Whilst the literature contains qualitative studies of being diagnosed with RA, peoples' illness beliefs and adjustment, there are no studies within PsA and these RA qualitative accounts all have significant limitations (Shaul, 1995, Dildy, 1996). Shaul (1995) explored only women's experiences but Lütze and Archenholtze (2007) suggests that experiences for men may be significantly different, particularly in their perspective on their role changes in chronic illness. Gender differences have been shown in the way that people cope with the RA (Brown and Williams, 1995). A more recent study reviewed the gender differences in stress and coping in a sample of

2816 people (1566 women and 1250 men) aged between 18 and 65 years old, with different socio-demographic characteristics. Matud (2004) found that after adjusting for socio-demographic variables the women scored significantly higher than the men in chronic stress and minor daily stressors, and the women rated their life events as more negative and less controllable than the men. Women scored significantly higher than the men on the emotional and avoidance coping styles and lower on rational and detachment coping, with men more emotionally inhibited than women. Although the sample size is large, this study used self-report and it may be that men are more reluctant to disclose their coping strategies than women, rather than there being an actual difference.

Two of these qualitative studies are retrospective (Shaul, 1995; Dildys, 1996) and patients' recollections may be coloured by experience, adjustment and recall. All three studies are over 15 years old (Shaul, 1995; Dildys, 1996), and in that time the role of women within both society and the home has changed and therefore the issues, perceptions and expectations raised in the Shaul study (1995) may also have changed. In addition, pharmacological intervention for IA has been revolutionized by new and more effective drugs, rapid instigation of therapies and the introduction of biologic therapies in the past 8-10 years (Feldmann, 2002). It is becoming rare to see patients with severe disabilities but patients' illness beliefs are influenced by their social world (Leventhal, Brissette and Leventhal, 2003), and it may be that patients still assume that IA inevitably means disability and possibly a wheelchair in the future. The illness beliefs and subsequent coping strategies identified in these old studies may therefore no longer be applicable to the experiences of current IA patients. The studies all interviewed patients at a single time point, rather than prospectively following the journey over time. None of them specifically explored the five illness beliefs or how these were woven into the individuals' life styles and coping strategies. Only Shaul (1995) explored changes in adaptation, perceived control, and mastery over time but did not explore what had influenced these changes, and the study was retrospective. Understanding these issues and influences would enable professionals to better support that patient journey. It also may be that a long-term relationship between the interviewer and the participant would illicit more details than those demonstrated in studies that used self-report. The aim of this doctorate is therefore to follow patients through the first year at the time of these changes, in a novel approach to try and ascertain not only what happens during that first year, but also to gain an understanding of whether a therapeutic intervention around illness beliefs might be developed to facilitate this journey.

Illness beliefs set the stage for coping, adaptation and adjustment; however they are not in isolation but are embedded within the social context. Social networks have been shown to be important in adjustment and adaptation within chronic illness (Affleck *et al.,* 1988) and within IA (Dobbie and Mellor, 2008).

3.8   Effect of support networks on psychological adjustment

Social support is a set of interactive and dynamic processes in which actions or behaviours are directed at an individual to positively affect his or her social, psychological or physical well-being (Boutin-Foster, 2005). Patients with RA who had a greater number of close friends and relationships reported fewer activity losses and made more activity modifications than those with fewer close relationships (Katz, 1998). Being able to turn to others for support may mitigate the effects of pain and functional impairment and alleviate the psychological distress associated with them. Patients with arthritis who receive support from their family and friends exhibit greater self-esteem (Fitzpatrick *et al.,* 1988), psychological adjustment (Affleck *et al.,* 1999) and report less depression (Revenson *et al.*, 1991).

The unpredictable nature of IA presents individuals with a number of difficulties and challenges. These lead to changes in lifestyle affecting not only the person (Felton and Revenson, 1984), but also other close family members (Coyne and DeLongis, 1986). Supportive close relationships have been shown to be important for health while the absence of family or social support predicts mortality and morbidity in obesity, smoking and hypertension (House *et al.,* 2003). Marital quality has been shown to predict both initial health and changes in health over three years in the general population (Wickrama *et al.,* 1997).

Social support reduces psychological distress such as anxiety or depression (Sarason *et al.,* 1997) and promotes positive psychological adjustment to IA. Doeglas *et al.* (2004) found that patients with RA who had high levels of emotional social support experienced much higher levels of emotional well-being and were less depressed than those without. Smaller social network size leads to reduced levels of social activity for people with RA (Evers *et al.*, 2003).

Treharne *et al.* (2005) found in a study of 154 patients with RA that more social support was related to less anxiety and depression, greater life satisfaction and less fatigue. RA patients with early disease who had lower perceived social support were found to display worse pain, more depression and more anxiety than those with higher perceived support (Evers *et al.,* 2003). Social support is also related to less fatigue (Huyser *et al., 1999*) and greater psychological well-being in

RA (Revenson *et al.,* 1991). However, what may be important is the timing and type of support. Treharne *et al.* (2005) found that those RA patients with intermediate and established disease who received high levels of social support had less fatigue but conversely those in early stages showed more fatigue. The type of social support was not discussed in this study and it may be that people with early RA received more emotional and less practical support and vice versa for those with later disease, who may have had physical disability. Social support does not necessarily have to come from family or friends. Participants in a Swedish study reinforced the importance of meeting others with arthritis and sharing experiences (Primdahl, Wagner and Horslev-Peterson, 2011) even at the early stages of developing arthritis. For participants the opportunity of talking about their illness within a group who understood the implications of their disease also led to improved coping ability.

However, social support can be a double-edged sword, especially if the support is not asked for, when it may increase stress levels (Bolger, Zuckerman and Kessler, 2000). Social support may be perceived as problematic or non-supportive (Revenson *et al.,* 1991) when it is either not desired, not needed or does not match the recipient's needs (Riemsma *et al.,* 2000). Patients with RA who received negative support from partners in the form of criticism demonstrated poorer outcome (Waltz, Kriegel and Bosch, 1998) and detrimental changes in depression and anxiety at times of heightened stress (Zautra *et al.,* 1998). If the support is not asked for, this can increase stress levels (Bolger, Zuckerman and Kessler, 2000). Riemsma's paper on problematic social support in RA reinforced the previous findings of Revenson *et al.,* (1991) and found that in 197 RA patients, those receiving more problematic support had more depression (Riemsma *et al.,* 2000). The participants in this study had a mean of over 5 years of disease duration, and newly diagnosed patients may require different levels or types of social support and this is not yet known.

3.9 Personality and chronic illness

Personality traits may influence how people manage their illness especially with the fluctuating nature of IA. These traits may include their outlook on life generally including temporal orientation, optimism and self-esteem.

3.9.1 Temporal orientation and self-management

Research into psychosocial factors, that might explain both variations in self-management and illness beliefs, has often overlooked temporal orientation. The

temporal framework determines the extent to which individuals focus on potential, immediate outcomes from an illness versus distant outcomes, when deciding how to act (Orbell, Perugini, and Rakow, 2004). This is important in the process of coming to terms with a long term illness because Orbell, Perugini, and Rakow (2004) showed that individuals who are more future-orientated tend to act in ways that encourage positive future outcomes and reduce negative outcomes. They tend to minimise their attention to the negative effects of current behaviour if there is a likelihood of future benefits. In contrast, individuals who are more present-orientated direct their behaviours more towards the achievement of immediate positive outcomes. They tend to live day-to-day, without concern for the way their current behaviour might affect them in the future. Temporal orientation is a relatively stable characteristic and is associated with a variety of other personality traits such as positivity, and goal-directed thoughts and actions (McGrath and Tshan, 2004, Simons *et al.,* 2004, Hall and Fong, 2010). Individuals who are more future-orientated tend to be more conscientious, motivated and persistent in working to their long-term goals while in contrast; individuals who are more present-orientated are more likely to be sensation seekers (McGrath and Tshan, 2004, Simons *et al.,* 2004,).

Alberts and Dunton (2008) looked at how temporal orientation influences proactive behaviours in situations that are deemed threatening, for instance when a patient has been given a diagnosis of a chronic illness. They found that when a threat to quality of life was relatively low it was expected that individuals would behave in a manner consistent to their dominant temporal orientation. No studies could be found looking at temporal orientation in early IA. Temporal orientation could be considered a form of optimism, so the next section looks at how optimism is linked to adjustment.

3.9.2   Optimism versus pessimism

The evidence put forward and reinforced by Alloy, Abramson and Chiara (2000) is that those who make optimistic attributions (i.e. those who are hopeful) fare better psychologically than those who make pessimistic attributions. Optimistic beliefs play a significant role in adaptation to chronic disease showing positive effects on both mental and physical health (Taylor and Aspinall, 1996). This concept has been developed in the literature to encompass three basic beliefs (Fournier, Ridder and Bensing, 2002). Positive outcome expectancies are beliefs that one will generally experience good future outcomes; positive efficacy expectancy is confidence in one's ability across demanding situations and has been

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shown to be stable across several chronic illnesses including diabetes (Kavanagh, Gooley and Wilson, 1993) and RA (Taal *et al.,* 1993); and optimistic bias is a perception that one is less likely to experience negative events than others (Armo and Taylor, 1998).

Positive outcome expectations about the future or positive efficacy beliefs about one's coping skills are believed to be stable personality traits, whereas optimistic biases are assumed to be states that are sensitive to the perception of personal threat, which may be due to the loss of control related to experience of negative events (Kralik, 2002). When women with RA were followed over 12 months, it was shown that it was the capacity to consciously think beyond the present circumstances with optimism and hope that changed their outlook and allowed them to move beyond the confines of the illness (Kralik, 2002). It was the optimism and hope that were important, rather than the degree of physical debilitation they experienced.

Holding on to positive outcome expectancies has been shown to be associated with reduced depression for patients with RA (Treharne *et al.,* 2007) and better well-being in patients with other illnesses (Seligman and Csikszentmihalyi, 2000). Patients in the early stages of IA use more optimistic-like denial specific to the disease, than patients with longer disease duration (Treharne *et al.,* 2004). The reason for this optimism is unknown and will be explored within the thesis.

3.9.3   Self-esteem

Self-esteem is concerned with internalised judgements; it is a motivational mechanism where we seek positive feedback from others to feel good about ourselves. Self-esteem may influence the association between adjustment and coping (Somerfield and McCrae, 2000). Positive self-esteem has been shown to be related to both physical and psychological health in patients with RA (Lightsey *et al.*, 2006). A longitudinal study by Powell, Dolan, and Wessely, (1990) assessed patients with chronic fatigue and found that low self-esteem acts as a factor in the risk of long-term depression.

Nagyova *et al.* (2005) hypothesised that higher levels of self-esteem may positively influence the relationship between pain and psychological well-being. European patients with confirmed RA (n=31) or asthma (n=97) were followed over a four-year period, interviewed yearly and assessed for pain, adjustment to disease, self-esteem and general health. The overall findings indicate that high levels of pain were directly associated with low self-esteem and worse adjustment to the illness. In contrast, individuals with high self-esteem perceived themselves as well adjusted.

These annual reviews cannot provide evidence for causal relationships; an intervention study with assessments at more regular intervals is needed. However, despite its limitations the study does suggest that self-esteem may be an important personality trait related to adjustment in RA, although no work has been conducted in early disease.

3.10 Summary

This chapter has explored factors that may contribute to the way a person develops and changes to accommodate their IA. It has shown that external factors such as social support and internal factors such as coping strategies, readiness to change, self-efficacy and illness beliefs may be important. However, little is known about this in IA, and even less about the time of diagnosis, even though these factors are potentially significant in helping patients on their journey. Furthermore, the few studies that have been conducted in IA are either retrospective, cross-sectional, restricted to women, or were conducted many years before current, more successful treatments were initiated. Further gaps in knowledge include whether or how these illness beliefs influence adjustment in the disease trajectory of patients even before they are officially diagnosed, whether they are gender specific, whether they are influenced by beliefs about disease severity, or objective disease state. Importantly, nothing is known about what actions by the health care team might influence patients' illness beliefs and hence self- management. All these gaps in knowledge need to be addressed if we are to understand the best way to support patients in the initial year after diagnosis.

The aims of this thesis are therefore:

1) To explore participants' beliefs and emotions prior to having a confirmed diagnosis of IA.
2) To explore and understand the experience of having a diagnosis of IA.
3) To investigate how beliefs and emotions change over the first year, and which factors influence adaptation and adjustment to IA.
4) To understand the role of illness beliefs in newly diagnosed patients and whether these beliefs influence adaptation and adjustment to IA.
5) To assess and examine quantitatively changes in illness perceptions and adaptation and adjustment during the first year of living with IA.

These will be addressed through a longitudinal, prospective study that is described in the following chapter.

Chapter 4: Methodology and methods

The choice of methodology is driven by the research question, but also includes consideration of the literature, what is realistic and most importantly the intended primary outcome. Having reviewed the background literature in the preceding chapters and demonstrated the gaps in knowledge in early IA, this chapter will focus on the theoretical perspectives of research and the methodological approaches used in this thesis. This chapter will also examine the role of the patient research partners and the role of the researcher herself, acknowledging the impact that both have on the research study.

4.1   Theoretical standpoint

Deciding on an appropriate method and engaging with its philosophical underpinnings is an essential component of rigour in the research process (Appleton and King, 2002), yet this justification often remains unreported. Before the researcher addresses the chosen standpoint it is important to define the core terminology used in the philosophical debate behind research. The study of being, or "ontology", questions the nature of reality (Patton and Sullivan, 1980). This includes debates about whether there is an objective "real" world that can be observed and measured; or whether reality is a product of how people construct or interpret their own situation. Epistemology is the theory of knowledge; including how knowledge can be obtained, and the relationship between the knower and what can be known (Guba and Lincoln, 1994). Epistemology and ontology are intertwined, for example if the researcher accepts the ontological position of an objective reality then they must assume a position of objective detachment, free from bias. If the opposite is true, it is neither necessary nor indeed desirable to be detached from the research process, and the researcher acknowledges her own influence on the process of knowledge construction. However, researchers often hold a complex view of reality in which some aspects of human experience are deemed more objective and observable (e.g. some symptoms), and others are deemed more subjective and context-dependent (e.g. emotional responses to illness).

Whilst these viewpoints may appear diametrically opposed, a philosophical basis for inquiry known as "pragmatism" has been suggested as a framework (Doyle, Brady and Byrne, 2009) to accommodate this flexible understanding of what can be known and how that knowledge can be generated. Pragmatism has the potential to encompass both quantitative (objective) and qualitative (subjective)

approaches to research, and their respective underlying assumptions. Pragmatists focus on the idea that all human inquiry involves imagination and interpretation, and is shaped by both intention and values; but it must also be grounded in empirical data, thus no research is entirely value free but can still be rigorous (Bowling, 2009). For pragmatists the aim of the research is not to seek a truth that is independent from human experience but to achieve a better and richer understanding of the world. This can be through scientific analysis, social negotiation, interpretation, or any combination of these approaches. Thus pragmatism best fits with the aims of this thesis.

4.2   Qualitative, quantitative and mixed methods paradigms

Qualitative and quantitative research methods are used to answer different types of research questions, and if used appropriately produce valid and valuable pieces of research (Johnson and Onwuegbuzie, 2004). Traditionally used as a method of inquiry within the social sciences, qualitative research often consists of a set of interpretive methods that look at the world within an individual's context (Ritchie and Lewis, 2003). The focus is on why and how people make decisions and their thoughts, behaviours and feelings rather than what, when and where, thus enabling the researcher to bring meaning and sense from the participant's perspective (Denzin and Lincoln, 2000). Methodological approaches include grounded theory, action research, and phenomenology with data collected thorough interviews, participant observation, field notes, reflective journals and non-participant observation; qualitative research is naturalistic and non-experimental (Bowling, 2009).

Limited in their generalisability and with the potential of having a degree of bias (Ritchie and Lewis, 2003), qualitative methods are complex and time consuming. In the qualitative research paradigm, the researcher is part of the process of co-constructing the data (Snape and Spencer, 2003) and often the sole creator of the findings. Therefore it is crucial for the researcher to maintain transparency throughout the research process with reflexivity and self-awareness (e.g. through reflexive diaries), with clear explanations of the steps of their analysis, which are often criticised as being omitted (Attride-Stirling, 2001).

Quantitative research, in contrast, has its base in a positivist framework, a concept developed by Auguste Comte in the early 19th century, with emphasis on the use of scientific methods to empirically test hypotheses, seeking to reach statistically significant findings (Creswell and Clarke, 2007). Quantitative data collection relies on representative sampling and structured and standardised data

collection instruments that fit constructs such as symptoms into predetermined response categories (Bowling, 2009), generating numbers for analysis. The results are concerned with objectivity and thus compare, generalise and test statistical significance with the aim being to establish, confirm or validate mathematical relationships between variables (Leedy and Ormrod, 2005, Punch, 2005). An example might be a randomized controlled trial to test an intervention, and evaluating it with validated self-report measures or objective measures such as blood tests. However, its weakness lies in the inability to explain why people did what they did; quantitative methods do not explain thoughts, reasons or factors that may influence the outcome (Sandelowski, 2000).

Over recent years it has been suggested that mixed methods should be the third methodology (Tashakkor and Creswell, 2003), because if both have a role to play in determining the answers to the research questions, then a combination is needed to enrich our understanding. Mixed methods encompass both qualitative and quantitative approaches and methods where the investigator collects and analyses data, and integrates the findings in a single study (Tashakkori and Creswell, 2007). Mason (2006) suggests three reasons for using mixed methods: by encouraging creativity it is possible to find new ways to approach research questions; it enhances the researchers' capacity for linking macro and micro real life experiences within complex situations; and it extends the logical explanation, adding depth within the research. There is no absolute rule about the order of the data collection (Creswell and Clark, 2007); it depends on the research question. For example qualitative data might be used first to inform the content of a questionnaire for quantitative data collection; at other times, quantitative findings could be followed by qualitative interviews to increase understanding of what took place (e.g. in an intervention) (Denscombe, 2008). Methods can also be used concurrently.

One characteristic of mixed methods is that the approach should specify how the qualitative and quantitative aims relate to each other (Denscombe, 2008). The broad aims of this study are to understand the patient journey over the first year of diagnosis of IA, and any influences on this journey measured both qualitatively and quantitatively. Although primarily qualitatively driven, this study uses both approaches concurrently to enhance the depth of the research findings with the participants of the qualitative study (aims 1-4) providing further context through their quantitative questionnaire data. In addition, a companion quantitative study will address change in outcomes over time (aim 5). Qualitative methodology will explore the patients' experiences looking for themes across four time points in the first year, and then across the year as a whole. However, there may be important contextual factors such as social support or levels of anxiety or depression that may not be 75

identified during the interviews and will therefore be captured through validated questionnaires administered concurrently at the interviews in order to contextualise the data from the qualitative findings. The use of quantitative methods within the qualitative study is necessary in order to gain a complete understanding of what happens to each patient throughout the first year of diagnosis. An example of this may be when Illness perceptions data are reviewed: the quantitative data can show how much change occurs across the four time points whereas the qualitative data can capture the diverse nature of the changes, reasons as to why they occur and what affects them. Therefore four qualitative interviews will be carried out (pre-consultation, 2 weeks after the initial consultation, at 26 and 52 weeks); at each time point patients will also be asked to complete a package of validated questionnaires. In addition a quantitative study in a larger group of patients will complement these finding by enabling statistical testing of change, thus allowing the data to be generalisable and complementing the insight and depth of patient experiences captured in the qualitative study.

4.3   Qualitative methodology

4.3.1   Capturing the qualitative data within this thesis

The aims of this research are to gain an insight into the first year of IA - people's perceptions, experiences and beliefs about their illness and their motivation to adapt or adjust or their reasons for lack of change over time. It examines the data collectively as a longitudinal story. The method of data collection needs to allow patients to reflect back as well as to think prospectively about their joint problems and their overall experiences, and thus requires them to tell and retell their story, exploring attitudes, beliefs, behaviour or other phenomena.

Interviews rather than focus groups were chosen for two main reasons. Interviewing allows structure but flexibility simultaneously (Elliot, 2005). The interviewer is able to explore issues and expand on specific points to gain clarity. From a pragmatic perspective it was important to capture people's experiences and beliefs before they saw a rheumatologist, who would inevitably have an influence on these. However, the time frame between recruitment from the GP referral letter and the first consultation was likely to be short, making it impossible to bring a focus group of 6-8 people together as there were likely to be too few patients available at the same time. Secondly, as it is human nature to conform to the majority (Asch, 1958) it was decided that one to one interviews would ensure that patients' individual

experiences were investigated sensitively, rather than potentially obtaining a consensus of the strongest voices.

Individual interviews are the best method of collecting data to provide a thorough, undiluted account, which focuses on the person at that time (Ritchie and Lewis, 2003). Interviews are concerned with answering questions about the experience and the meaning that people place on their experiences within their social contexts (Ritchie and Lewis, 2003) and how they make sense of these experiences. It has been argued that interviewing is overused in qualitative research (Silverman, 2011) and this can give the researcher a false sense of authenticity (Silverman, 2009). However, for this thesis they provide the best method of gaining the data needed to answer the research questions, providing an insight into the person's life from their individual perspective with an opportunity to explore this in the context of their beliefs and also with the opportunity to clarify any possible misunderstanding or seek greater depth in certain areas.

Face to face interviews were carried out prior to the patient's initial consultation with the rheumatologist; 2-4 weeks post consultation, at 26 weeks and finally at 52 weeks. In longitudinal research the benefits are the ability to explore changes in beliefs over time and form a relationship with the participants. The time points were chosen from a pragmatic perspective, ideally it would have added more depth if the interviews were more frequent but this would create participant burden and possibly a lower uptake. The frequency of the interviews allowed cross- sectional analysis at individual time points and longitudinally over time to describe any patterns of change and to look for any possible relationships.

4.3.2   Designing the interview schedule

A topic guide (appendix 1) was developed, based on the literature available relating to being newly-diagnosed and illness beliefs, and in discussion with the supervisory team, including the patient partners in order to formulate neutral, non-directive open questions (Moule and Hek, 2011). The questions covered impact of the joint problems on the person and their social networks, as well as their perceptions of the cause, their possible diagnosis, consequences and treatment, and their illness beliefs. The interview schedule was developed for each time point as a prompt to facilitate discussion between the researcher and the participants, allowing new ideas to be pursued and developed during the course of the conversation. At the 52-week interview participants were asked to reflect back and review their journey to see if their perceptions of their IA at the start were realistic.

As the literature review shows that health care professionals use the terms adjustment and adaptation interchangeably, with little reference to their perceived meaning, this will be explored as these concepts may be different at different times during a patients' journey and for different personalities (see sections 2.5 and 2.6). As this thesis is looking at the journey and the road to behavioural adaptation and psychological adjustment it was deemed important to understand the patients' perceptions of these terms. In all interviews participants were asked to define adaptation and adjustment with examples, and it was reiterated that there were no correct answers to this question.

4.3.3   Taping the consultation

Where possible, and with written consent from the consultant as well as the patient, the initial medical consultation was digitally recorded. These recordings were not transcribed but were listened to in order to verify what the patient was told, providing context and allowing comparison with the patient's beliefs and understanding.

4.4   Quantitative methodological approach

4.4.1   Capturing the quantitative data in this thesis

The same questionnaires will be used with patients in the qualitative study, and in the companion quantitative study. Careful consideration of the choice of questionnaires was taken with advice sought from the patient partners. As this thesis is collecting novel data, and the effect of external aspects on the journey are unknown, it was important to capture as many aspects that may influence their first year as possible without overloading the participants. Patient reported outcome measures (PROMs) are scales or questionnaires developed to purposefully evaluate specific outcomes (Juniper, 2009).

To be deemed useful a PROM must show evidence that it is not only measuring what is intended but also that it is reliable (Bell, 1993, Streiner and Norman, 2008). Face validity ensures that the methods appear sensible and credible and the language used is acceptable to the target audience and straightforward to interpret. Content validity is examined by reviewing the content of the scale to ensure that all relevant items are included and misleading items are avoided. Criterion validity is present if the scale has been tested successfully against a gold-standard scale, consistently reflecting the true status of the patients. Construct validity ensures the scale converges with or diverges from other variables

as expected according to their biological or psychological construct (for example anxiety should correlate with depression). The scale must also be reliable, i.e. multi-item scales must demonstrate internal consistency between the items, as shown by moderate or strong inter-item correlations (Harman, 1976; Bowling, 2005). PROMs also need to be stable, thus not show change in patients whose condition remains unchanged, but be able to demonstrate sensitivity to change thus reflecting change in patients perception of their clinical condition (Bowling, 2005). A PROM should also be feasible to complete, with clear instructions and acceptable questions; scoring should also be straightforward.

4.4.2 Quantitative data collection

The literature search investigated a range of potential variables that may influence an individual's journey, these included mood and coping, functional disability and its importance, support from others and presenting symptoms; having explored these aspects a package of validated questionnaires was formulated. A review of the literature showed that there was no single PROM specifically to measure adaptation or adjustment within IA, therefore it is hoped that these validated questionnaires will collectively provide vital information on the journey that each patient takes and the importance of these aspects in their adjustment. The questionnaires will also provide novel information on how illness beliefs change over time and how people place this in the context of their social, emotional and physical situations together with their disease progression.

A questionnaire package at all four-time points assessed key clinical, mood and cognitive variables (Table 4.1 and appendices 2 - 13).

The first section focused on mood and cognitive variables (section 2.3). Depression and anxiety were measured using the Hospital Anxiety and Depression scale (HADs) (Zigmond and Snaith, 1983). Although it may be criticised as not being sensitive to cultural differences (Matcham *et al.,* 2013), the HADs was designed to be used with patients who are receiving medical care, thus it has the advantage that it does not contain any questions that refer to somatic symptoms; it is also quick and easy to both complete and score. Cronbach alpha scores range from 0.78-0.93 for the anxiety scale and 0.82-0.90 for depression, indicating internal consistency. Tests of specificity and sensitivity vary, however they are shown to favourably compare with other valid tools (Beck's Depression Inventory and Patient Health Questionnaire (PHQ)) (Hermann, 1997, Smarr and Keefer, 2011). HAD scores have been found to be sensitive to pharmacologic and psychotherapeutic interventions (Bjelland *et al.,* 2002),

within the general population, patients with cancer and medical conditions (Goldberg, 2010).

The Arthritis Helplessness Index (AHI) assesses patients' perceptions of helplessness (Nicassio *et al.,* 1985), both perceived helplessness and feelings of control as defined by the learned helplessness theory (Seligman, 1972) whereby participants expect their efforts to be ineffective and therefore become more passive in their management. All psychometric work was carried out on individuals with confirmed RA and more recently used with patients with OA, fibromyalgia, SLE and scleroderma (Brady, 2003). Estimated to take less than three minutes to complete and slightly longer to score, it has been criticised as no formal norms have been published and cut off scores between the ranges were empirically derived to categorise 20% of the sample as low helplessness and 20% as high helplessness (ref). Cronbach's alpha was borderline as acceptable for a unidimensional scale (0.69) (DeVillis and Callahan, 1993), however having been validated in RA and deemed quick to use it was considered appropriate for this study.

Impact of a disease may have an effect of on person's quality of life as they adjust and adapt to a different normality (section 2.4). RA Quality Of Life (RAQoL) is a disease specific tool to assess impact of RA on activities, social interaction, emotional wellbeing and relationships (De Jong *et al.,* 1997). Developed as a PROM for patients with RA, with easy to comprehend instructions and a short recall time period of one week, it is a quick self-report tool. Again internal consistency is high (Cronbach alpha is 0.92), and it has been shown to correlate with symptoms and disease activity. Although longer in length than other potential quality of life questionnaires (e.g. Short Form 36) it was chosen for its good responsiveness and validity and also importantly it contains a "physical contact" dimension unique to RAQoL, which may be important to newly diagnosed patients where the physical component to the disease may be at the forefront.

The next section of the questionnaire pack focused on cognitive variables. The Medical Coping Modes Questionnaire, (MCMQ) measures three different coping modes, confrontation, avoidance, and acceptance (Feifel *et al.,* 1986). With no specific measures for the outcomes of adaptation or adjustment, questionnaires with a focus on coping strategies may help identify the processes that newly diagnosed patients use on their journey within this study (section 3.2). Therefore MCMQ was used to assess coping modes. Developed with the participation of general medical patients using a 19-item questionnaire, it purports to measure the extent to which patients use three cognitive-behavioural coping strategies. It is brief to complete compared with other coping questionnaires and has the advantage that the

questions are designed to capture responses to a physical illness. Although not disease-specific it has been validated in life-threatening illness (cancer, heart disease) and long term conditions (RA, OA and dermatological conditions) (Feifel *et al.,* 1986).

The Stages of Change profile (SOC), (Keefe *et al.,* 2000), developed in arthritis, measures the patient's perception of the need to change behaviours (self-management). The SOC profiles comprise five reliable scales that are consistent with the stages of the transtheoretical model of change (Prochaska and DiClemente, 1983). Developed using cluster analysis in patients with RA and OA, it identifies five distinct subgroups of arthritis patients: pre-contemplation (not considering taking action), contemplation (considering), preparation for action, action, and maintenance of new behaviours. Understanding the patient's stage of change alongside their coping strategies may have important clinical implications in adaptation and adjustment. For example, it is possible that any subgroups of patient characteristics on their 12 month journey from diagnosis that are identified in this study may predict participation in and responsiveness to training in pain-coping skills, exercise interventions, or other formal self-management training programmes. Also, one may be able enhance the outcomes of self-management interventions for arthritis by tailoring treatment to the patient's particular stage of readiness to change.

Function was assessed using the Health Assessment Questionnaire (HAQ), (Fries *et al.,* 1982) and its impact by the Personal Impact HAQ (PI HAQ), (Hewlett *et al.,* 2002). The HAQ is a self-report questionnaire with an emphasis on general function measuring ADL over the past week. Although 30 years old, it remains the gold standard for measuring functional status for arthritis (Maska, Anderson and Michaud, 2011), and is frequently used in other conditions including HIV (Sousa *et al.,* 2008) and general population studies (Hubert, Bloch and Fries, 1993). It takes less than 10 minutes to complete and has a short recall period of one week, increasing reliability (Maska, Anderson and Michaud, 2011). Although less responsive to change among people with lower levels of disability (Wolfe, Michaud and Pincus, 2004), it has been shown to correlate well with both clinical and laboratory measures of disease activity (Bruce and Fries, 2003).

Changes in physical function may have great significance for some patients who are newly diagnosed and in turn may affect their adaptation or adjustment (Hewlett, Smith and Kirwan, 2001). Conversely, for other patients function around diagnosis may not have a high degree of meaning if symptoms such as pain are more prevalent than disability. Therefore the PI HAQ was used alongside the HAQ to potentially add context to the meaning of measuring function. Using positive

phraseology with the term "importance", the questionnaire was constructed over a four-phase study with cohorts of patients with RA and is sensitive to change (Hewlett *et al.,* 2004).

The Significant Other Questionnaire was used to measure social support (Power, Champion and Aris*,* 1988). It was chosen as it measures different social support that may be provided by a range of significant role relationships within an individual's social network, the perceived quality of this support, and whether it matches the individual's expectations for that particular relationship. Perceived unhelpful social support is known to be detrimental (section 1.6), thus this questionnaire will look at perceived needed support after diagnosis which may have an impact on the input needed by the team to support the patient.

Pain and fatigue were measured using visual analogue scales (VAS) (Scott and Huskisson, 1979). The VAS is a unidimensional measure that can be used as self-report or with assistance and has been widely used within the adult population for people with arthritis. The pain VAS and fatigue VAS are simple methods of assessment and have been found to take less than a minute to complete. They are reliable, with good test–retest reliability, although this is reduced in people with cognitive impairment (Jensen, Karoly and Braver, 1986). In patients with chronic inflammatory conditions the pain VAS has been shown to be sensitive to changes (Hawker *et al.,* 2011).

This comprehensive pack of questionnaires provides clinical and psychological data and are shown in appendices 2-13. Interaction with health care professionals or changes in medication (for example increase in steroid dose) may have an impact on a person's coping strategy and disease outcome. Therefore, health care utilisation and medication use were also collected at each time point using a very simple questionnaire (appendix 12). These data will determine the amount of care and support a person has received (e.g. nurse clinics), in order to review any relevance to their illness beliefs.

4.4.3   Measuring illness beliefs

If, as suggested, illness beliefs should be acknowledged in consultations and accepted as a basis on which to move forward with patients as regards to their treatment (Hill *et al., 2007*), then the initial process is to identify the patient's individual illness beliefs. Several methods have been used to try to capture the illness representations in a questionnaire form. Prochaska *et al.* (1988) used a questionnaire to assess illness beliefs in primary care while Lacroix (1991) used one in respiratory patients. However, neither took into account the fluctuating nature of

disease. These PROMs were not theoretically based and have not been evaluated in more than one patient group. Lau *et al,* (1989) were critical in their analysis and concluded the findings did not adequately capture the illness representation theory.

The illness perception questionnaire (IPQ) (Weinman *et al.,* 1996) measures illness beliefs using items generated by patients and by researchers based on Leventhal's description of illness representation components (Leventhal and Nerenz, 1985). In the general version each of the items refers to "illness" but states this term can be replaced with a specific illness (e.g. arthritis). The questionnaire was developed and then tested in 848 patients (MI, RA, diabetes, chronic pain, renal failure, asthma and chronic fatigue syndrome) and has been shown to be reliable and sensitive to change (Weinman *et al.,* 1996). Since then the IPQ has been used in studies of adjustment in patients with a variety of conditions, including RA (Murphy *et al.*, 1999, Scharloo *et al.,* 1999), heart disease (Cooper *et al.,* 1999), cancer (Buick, 1997), chronic obstructive pulmonary disease (Scharloo *et al.,* 1998) and Addison's disease (Heijmans, 1999). The IPQ has subscales for identity, cause, time-line, consequences and cure/control.

A revised version or IPQ-R (Moss-Morris *et al.,* 2002) was developed after a review of the original IPQ showed poor internal consistency of several subscales. Re-analysis of the data for the cure/control subscale revealed that the items loaded onto two separate subscales, which were then labelled personal control and treatment control. At the same time, the timeline subscale was expanded to include acute/chronic timescales and stable/fluctuating timescales. Another component of the original IPQ was that it had only assessed the cognitive components of the patients' representations, which can limit the description of the patients' illness responses. The emotional responses generated by the illness may have an impact, which was in the original Leventhal's self-regulatory model, but was omitted from the IPQ. The IPQ-R therefore includes an emotional response subscale.

A further addition was the exploration of whether it was possible to assess patients' overall illness representations by asking about their overall understanding of the illness, i.e. a meta-cognition regarding the coherence of the illness to them as an entity. This illness coherence may prove to be a useful dimension to researchers interested in the importance of how the illness makes sense as a whole to the patient and may play an important part in longer-term adjustment and response to symptoms.

The resulting IPQ-R, which is used in this research study (appendix 13), comprise nine subscales: cause, coherence, consequences, personal control, treatment control, emotional response, identity, timeline acute/chronic and timeline

stable/fluctuating. Each subscale comprises 4 to 6 items, and patients rate their agreement with the responses strongly disagree (1), disagree (2), neither agree nor disagree (3), agree (4), strongly agree (5), then each subscale is summed individually. All the subscales demonstrated good internal reliability with the Cronbach alpha's ranging from 0.79–0.89 (Moss-Morris *et al.,* 2002). Data from renal dialysis inpatients was used to investigate the test-retest reliability with good stability (correlations from 0.46-0.88); personal control was the only dimension to show a correlation of <0.5. In addition there is a tick list of symptoms and patients tick items they believe to be associated with their condition (Moss-Morris *et al.,* 2002).

Table 4.1: Content, source and rationale of measures included in the questionnaire package

Section	Scales included	Source	Constructs and rationale
Mood and coping	Hospital Anxiety and Depression scale	Zigmond and Snaith, 1983	Measures levels of anxiety and depression both known to be important in a chronic illness
	Arthritis Helplessness Index	Nicassio *et al.,* 1985	Reviews both the perceived control and feelings of helplessness
	RA Quality of Life	De Jong *et al.,* 1997	Disease specific quality of life questionnaire
	Medical Coping Modes Questionnaire	Feifel *et al.,* 1987	Reviews confrontation, avoidance and acceptance
	Stages of Change	Keefe *et al.,* 2000	Assesses the person's readiness for making changes
Functional impact and its importance	Health Assessment Questionnaire (HAQ)	Fries *et al.,* 1982	Validated questionnaire that measures disability
	Personal Impact HAQ	Hewlett, Smith and Kirwan, 2002	To assess the personal impact of disability
Support from others	Significant Other Questionnaire	Power, Champion and Aris, 1988	To assess the support a person would like to receive and whether this is actually happening
	Medical utilisation		To record the input from the medical teams including community and hospital resources
Symptoms	VAS for fatigue and pain		Important factors in disease management and indicators of disease control
Illness Beliefs	Revised Illness Perception Questionnaire	Moss-Morris *et al.,* 2002	Assesses a person's illness beliefs, including emotions and fluctuating illness

4.5   Summary of chosen methods

To summarise, the data will be collected by a series of interviews and questionnaires at four time points in the primary qualitative study, and solely questionnaires at the same time points for the companion quantitative study. These will be: before the first consultation, 2-4 weeks post consultation, at 26 and 52 weeks. Whenever possible the initial medical consultation for the participants in the qualitative study will be taped in order to determine what was said and to establish the patients' understanding of their diagnosis and treatment.

The next section will examine the process of recruitment and the practical aspects of the methods. It will then rationalise the chosen analysis techniques explaining their practical use within this thesis.

4.6   Aims

1) To explore participants' beliefs and emotions prior to having a confirmed diagnosis of IA.
2) To explore and understand the experience of having a diagnosis of IA.
3) To investigate how beliefs and emotions change over the first year, and which factors influence adaptation and adjustment to IA.
4) To understand the role of illness beliefs in newly diagnosed patients and whether these beliefs influence adaptation and adjustment to IA.
5) To assess and examine quantitatively changes in illness perceptions and adaptation and adjustment during the first year of living with IA

4.6.1   Entry criteria

The entry criteria for both the qualitative and quantitative studies were the same. The first point of data collection for both studies was to be before the patients first saw a rheumatologist (and hence got their diagnosis or commenced treatment). Therefore, any patient referred to the participating rheumatology centres with possible IA was identified from the referral letter using the key criteria of pain, joint swelling and multiple joint involvement (Deighton *et al.,* 2009, Kavanaugh and Ritchlin, 2006). Patients had to be over 18 and able to give informed consent and be able to participate in an interview in English.

4.6.2   Sampling and sample size

For the qualitative study, rather than aspiring to generalisability or representativeness, the research aims to reflect the diversity of a given population (Barbour, 2007). Its focus is to explore the general patterns that define people and phenomena in a specific context, while at the same time preserving a sense of the unique perspectives and aspects that individuals have of their experiences.

There are three broad approaches to sampling in research: convenience, purposeful and theoretical sampling (Bowling, 2009). Convenience entails selecting the most conveniently available group of participants, and is the most frequently used. However, it could be argued that this is the least satisfactory and most lacking in credibility due to researchers having the opportunity to hand pick the participants and therefore be selective towards the desired outcome (Coyne, 2008). In purposeful sampling the researcher actively selects participants who have experience relevant to the research question. Theoretical sampling means the researcher samples incidents or people on the basis of their contribution to the development of theoretical constructs. In this study sampling was purposeful as participants were selected on a basis that they can grant an insight to a particular perspective on the phenomena thus meeting the aims of the study (Bowling, 2009) and therefore all available patients were approached.

In qualitative research therefore the question often arises about what is an adequate sample size. Guidelines for sample sizes in the literature are sparse (Guest, Bunce and Johnson, 2006a). "Sampling" within this framework is not about quantity but quality, insight and depth (Marshall, 1996). The aim in this research is not to count how many people have had a particular experience or to make quantitative comparisons between different populations of people but to explore depth and meaning. In a study to examine the point at which data saturation is reached, Guest Bunce and Johnson (2006b) recommended twelve interviews were minimum. Therefore for this study the researcher aimed to recruit at least fifteen patients to allow for any participant drop out due to its longitudinal design.

For the quantitative study, it was uncertain at the design stage, what variable would emerge from the qualitative data as the main outcome, therefore a sample size calculation was challenging. In discussion with a healthcare statistician, path analysis was considered **(**Loehlin, 1998**).** This would be a novel approach to explore changes over time in the emerging outcome (e.g. illness perceptions). The statistician suggested that as there was a yet unknown outcome still to emerge from the qualitative data, and the statistical approach was relatively novel, then a sample size

of 75 patients would be safest in order to be likely to provide an adequate sample size to demonstrate change. These would comprise data from 15 patients in the qualitative study, and 60 in the quantitative study.

4.6.3   Recruitment

Three hospital sites were involved in recruitment to ensure that a wide range of clinical care was captured in the data. For example, access to additional appointments with clinical nurse specialists or other health care professionals may have an impact on beliefs and adjustment. The three sites chosen had very different clinical protocols. At site A patients are offered access to a nurse specialist within the first 6 months and have access to a rheumatology psychologist; at site B all patients are invited to go on either a simple, moderate or highly complex drug regime (depending on clinical presentation) and see the specialist nurse three times in the first month, and additionally can be referred to a nurse-led 'coping' clinic at any time; at site C patients only have follow-up with the nurse specialist once their IA is controlled (i.e. after approximately 8-12 months). Wiltshire and Swindon Ethics Committee granted ethics approval (09/H0104/66) and Research and Development approval (ME/2010/3413 CSP 30119,) was gained across three NHS hospital sites.

4.6.4   Identifying the patients

The same approach was used for both studies, with the 15 patients for the qualitative study being recruited first. At each site a member of the clinical team, usually a designated consultant reviewed the GP referral letters of all patients. When patients who met the entry criteria were sent their letter for their first consultation appointment, the consultant also sent them a covering letter regarding the qualitative study, together with a reply slip (appendix 15) and an information sheet (appendix 16). A first class stamped addressed envelope was enclosed with a reply slip. If patients responded and agreed to be contacted they received a telephone call from the researcher inviting them to take part and an interview date prior to their first consultation was arranged (figure 4.1). Once the appropriate number of participants had been recruited for the qualitative study then participants would be approached for the second (quantitative) study in the same manner but including the quantitative study information sheet (appendix 17).

4.6.5   Qualitative study procedures

Patients gave written consent for two interviews (pre and post consultation) and their permission to tape their initial medical consultation requested. If their diagnosis was confirmed as IA, (either stated directly by the consultant or treatment commenced on a provisional diagnosis), then they were asked if they would mind being interviewed at a further two time points, 6 and 12 months.

All participants were given the opportunity to choose where they would prefer to be interviewed. Different environments can impact both on the interviewer and the person being interviewed. The participants were unlikely to already be in the hospital system and therefore be unfamiliar with the settings and the topic discussed might be emotive for some people. Therefore, it was decided that as some people might be more comfortable to be interviewed at home, then they were invited to choose between home and hospital. From a pragmatic perspective sometimes the turnaround between the patient agreeing to participate, and their initial appointment with the consultant was minimal, and with clinical rooms at a premium it gave the researcher more flexibility. 58 out of 60 interviews were conducted at the patients home by patient choice.

Participants gave informed consent and were shown the digital recorder; this was then placed between the researcher and the participant. An explanation of the interview process was given, reiterating that there were no right or wrong answers to the questions; the researcher was purely interested in their views and beliefs. Patient interviews generally lasted between 45 minutes and an hour. At the end of each interview participants were given the questionnaire pack. They were asked to complete the questionnaires within 48 hours of the interview and return the questionnaires in the stamped addressed envelope provided.

A reflective diary was made after each visit. These included a description of the social environment and first impressions of the social setting. Notes were factual and contained as little interpretation as possible as their purpose was to add context to the data (see section 4.10.2).

4.6.6   Quantitative study procedures

Recruitment for the quantitative study was to follow on after the qualitative study and use identical procedures. Recruitment for the qualitative study started in April 2010, with an estimated 6-month period given for recruiting 15 patients. This time scale was based on a calculation of the number of patients with newly diagnosed with IA that are routinely seen at hospital site A. However, due to delay in R & D

approval in the other two sites, a lower than anticipated number of patients screened and a lower participant uptake than hoped for the qualitative study, it quickly became clear that recruiting 75 patients for the quantitative study in the available time-frame would be unachievable. Therefore the quantitative study, which addressed aim 5, was withdrawn before any patients were approached to join it. The Local Research Ethics Committee was informed. The implications of this are discussed in chapter 8. The study design is therefore clarified as a qualitative study alone (figure 4.1) addressing aims 1-4, with quantitative data collected only from those interviewees.

Figure 4.1 Final recruitment and study design

Figure 4.1 Final recruitment and study design

GP referral letter

Screened by consultant

Patient contacted by letter with their outpatient appointment

Information sheet sent with consent form and reply envelope

Pre consultation interview Questionnaires completed

2 weeks prior to their first rheumatology appointment

Consultant appointment

Taped consultation

Follow-up interviews Follow-up questionnaires

2, 26 and 52 weeks post consultation

4.7   Patient research partners (PRPs)

The value of patient research partners in research was recognised over 10 years ago and reiterated in the Department of Health's guidelines to support consumer involvement (DOH, 2006). Since then it has become more widely recognised that the patients' personal experience of a disease will provide a different aspect to that of the researchers on the study team (Hewlett *et al.,* 2006). This is fundamental in complementing the researchers' experiences (Trivedi and Wykes, 2002) by bringing a different perspective to the study and therefore improving study design, recruitment and data interpretation. Experiential and professional knowledge can complement and influence each other, with patient research partners and professionals becoming empowered in the process of learning from each other (Schipper *et al.,* 2010). The involvement of patients within the research process has become widely accepted as the norm to validate studies (White and Verhoef, 2005) and give expert advice based on their real life experiences. The term "patient research partners" (PRP) is used in this thesis to reflect both the person's status as a patient with RA and their contribution as a partner in the research process (Hewlett *et al.*, 2006). Two PRPs became members of the research team and were involved in decisions throughout the project. Their experiential knowledge rather than scientific knowledge (Abma, Nierse and Widdershoven, 2009) was valuable and their input continual.

4.7.1   Designing the interview schedule

The patient partners were instrumental in formulating the interview guide. During discussion they reflected back their interpretation of the draft interview questions, they questioned the phrases used and suggested more patient-friendly expressions to use. These techniques helped to clarify the interview prompts, evaluating usefulness, any ambiguity and any major gaps in the questions (Hewlett *et al.,* 2006).

4.7.2   Pilot interview

A pilot interview was carried out with the most experienced patient partner (BD). Her feedback included comments on both the researcher's interview technique and the interview itself. The pilot interview left both the researcher and the patient with negative feelings; therefore the questions were reordered to enable a more optimistic ending to the interview. Changes were also made to the way the

interviewer introduced herself ensuring that the participants were informed of only her research background to avoid clinical questions. Also the study explanation was amended to ensure that participants understood the need for audio-taping in order to make it clearer to participants who may be unfamiliar with research.

4.7.3 The importance of patient partners during the analysis

During thematic analysis, interpretation is a large part of labeling and summarising the data (Thorne, 2000). It is possible that the clinical rheumatology knowledge of the (nurse) researcher may influence the way that the data are extracted, labeled or grouped into themes, therefore the patient partners together analysed one transcript to explore and code the themes. They were guided through the process by a post–doctoral researcher experienced in qualitative research and who had read the transcript but had no insight into the study. The aim of this exercise was to ensure that the labels given to the themes from the researcher and her supervisory team were informed by a patient's interpretation, which is vital to accurately capture the patient experiences. The literature suggests that it is often inappropriate for a person without the illness to speak for those who experience the condition (Davis, 2005). Their findings were then compared to those of the researcher to ensure interpretation was consistent.

4.8   Analysing the qualitative data – Hybrid analysis

Thematic analysis (TA) is recognised as one of the range of methods for identifying, analysing and reporting patterns (or themes) in qualitative data (Gomm, 2004). Described as a "tool" or process to use across different methods (Ryan and Russell, 2000), yet argued as a specific approach in its own right, the aim is to analyse in-depth rich and often complex data, producing interpretive constructs, explanations or hypotheses (Braun and Clarke, 2006). TA can be an essentialist or realist method, reporting experiences, meanings and the reality of participants; or it can be a constructionist method, examining the way in which events, realities, meanings and experiences are the effects of a range of discourses operating within society (Ritchie and Lewis, 2003). The aims of this study were to capture the journey in relation to illness beliefs and other factors. Analysis was conducted across all patients at each time point and also by the individual journeys to give rich insight into the experiences. TA can be done in two ways depending on the research question.

In inductive thematic analysis (ITA) a "bottom up" approach is used and the themes arise from analysis of the patient data, for example reviewing a person's own perception of an experience. Inductive analysis is a process of coding without trying to fit data into a pre-existing coding frame or the researcher's theoretical stance (Ritchie and Lewis, 2003). This contrasts with deductive (or theoretical) thematic analysis, which is driven by a pre-existing theoretical framework (Fereday and Muir-Cochrane, 2008). In deductive thematic analysis (DTA), a "top down" approach is used to see if the data can be fitted to known themes from theory, for example establishing whether the data fit the illness beliefs themes (Braun and Clarke, 2006). This tends to provide a less rich, more specific data set, as it seeks evidence to support or refute a known theory. No study has prospectively explored the patient journey from pre-diagnosis for one year after diagnosis of IA. To explore the research questions of this thesis the themes needed to be patient driven, as this research is novel. However, a second aim was to look at the effects of illness beliefs throughout the journey. Therefore both inductive analysis (driven by patient data) and deductive analysis (driven by theory) were used on the same interviews to give a hybrid approach to understanding and answering the research questions.

4.8.1   Inductive thematic analysis (ITA) – The process

During transcription pseudonyms were inserted in place of patients names. The transcripts were entered into NVivo 8 software (QRS, 2008), a data management tool that facilitates the researchers' qualitative data analysis by managing and grouping the themes that researchers create, and allowing rapid searching and re-coding. There is no consensus in the literature about how inductive thematic analysis is conducted (e.g. Boyatzis, 1998; Tuckett, 2005). Braun and Clarke's (2006) method has been used in this thesis as it provides a rational and detailed approach.

Phase 1: Familiarisation with the data: The first stage of the ITA coding process involves the researcher immersing herself in the data to become familiar with the depth and breadth of the content. In order to do this, the researcher checked the transcripts with the audio recordings and then re-read the transcripts four or five times to search for meanings and patterns. The transcription process itself is a way to familiarise oneself with the data and therefore the researcher transcribed two of the interviews herself.

Phase 2: Generating initial codes: This phase involves the production of initial codes from the data. A code is a label that identifies a feature of the data that appears interesting to the researcher; it refers to the most basic element of the raw data that can be assessed in a meaningful way (Boyatzis, 1998). At this initial point as many codes as possible were noted, and quotes from each interview were placed into as many codes as was deemed appropriate by the researcher (Bryman, 2001).

Phase 3: Searching for themes: This phase involves revisiting and resorting codes into potential themes by combining the initial codes into main themes, with subthemes.

Phase 4: Defining and naming themes: In this last phase the themes are defined by identifying the meaning of each theme and determining what each captures then finalizing the name of the theme to demonstrate this.

Although this has been presented as a linear procedure the research analysis was an iterative and reflexive process. To ensure rigour in qualitative research it is recommended that the data be audible (Guba and Lincoln, 1994). In the context of this work this means that another researcher could arrive at the same or comparable conclusions from the data as the researcher (Sandelowski, 2000). Therefore a sample of the early transcripts were independently analysed by three experienced qualitative researchers at different time points across the data collection, and two patient partners analysed one transcript (section 4.7.3). Comparable conclusions with the researcher were reached.

4.8.2 Deductive analysis (DTA) – The process

Deductive analysis was used to examine patients' illness beliefs, using a theory driven, top-down approach. A coding framework was created, based on literature around illness beliefs within chronic illness (Weinman *et al.,* 1996) and in discussion with Professor Weinman. All the illness beliefs including the expansion of the control aspects, the timeline and emotional representations (Moss-Morris, 2002) were included. To ensure clarity and rigour each illness belief was defined by the researcher in a framework; these definitions were then discussed within the supervisory team to ensure clarity and consensus of opinion. Changes were made to the initial framework to make certain there could be no ambiguity, for example it was important to differentiate illness consequences beliefs about future outcome,

from patients' current illness status. The definitions, together with example quotations from the transcripts are shown in Table 4.2.

Table 4.2: Deductive analysis framework (Based on the paper by Moss-Morris, 2002)

Illness Perception	Definition	Example of Illness Perception
Causal Beliefs	Person's beliefs of the cause of their illness, this could include distal causes and trigger factors. There may be more than one causal belief per person.	"I thought I'd overworked because I was doing some work ... was in a holiday home and I was doing some work there and err... I thought I'd just strained some muscles first of all"
Coherence	Person's overarching belief about how all the parts of their illness fit together (or not) to form a coherent picture.	"I did not really – it did not add up, but I just thought, "well there's no reason for it, I cannot explain it""
Consequence	Person's beliefs about personal future impact of their condition.	"Em, I'd like to think the future's rosy, but being a realist I do not think it is. I think, unless when I see the Consultant next Wednesday he can pin point it and er..say well you've got a virus that's causing this problem and it will get better, I can see a slippery road downhill but hopefully it's a long one, rather than getting worse quickly"
Control - personal	Person's beliefs about what they can do to help regulate their condition. This can be high (e.g. "there is a lot I can do") or low (e.g. "there is nothing I can do about it").	"Um I'm – I'm determined to – I'm not going to – obviously I'm not going to be able to beat it, but I'm going to fight it. And I've never sort of been one to – to shy away from – from a fight. So I'm going to have to learn to live with it. And I'm quite – in some respects I think I'm quite looking forward to the next few months to see how my life changes. And I'm not going to let it define me anymore, I'm going to – I think I'm going to embrace it slightly and see"
Control - treatment	Person's beliefs about the effectiveness of their medical treatment (both negative and positive).	"And I do not want definitive, I do not necessarily want definitive answers. I do not want a cure, you know, an unrealistic cure. I do not want – I just want somebody to say, "OK this is what we think it is. This is what we think is going to work, and we'll deal with it"
Emotional response	Person's belief in how they respond emotionally to their symptoms or illness.	"I suppose you get used to it but it's still frustrating"
Identity	Person's belief about the process of matching symptoms to an illness label.	"Just this one knee that swells up on the side there. I thought, em...thinking about it and talking to people I thought probably rheumatoid arthritis"
Timeline – acute or chronic	Person's belief about whether the illness is short or long term.	"But the first thing it said in the – the rheumatoid arthritis handbook that they gave me was, "This is a lifelong condition.""
Timeline – stable or fluctuating	Person's belief about the variability of the symptoms.	"I know that there's going to be some days where I'm just absolutely, you know, wrecked and not going to be able to do anything, but there's going to be other days where I'm going to feel OK and I need to make the most of those days"

4.8.3   Hybrid analysis

A hybrid analysis was used, which combines inductive and deductive approaches. Fereday and Muir-Cochrane (2006) use this approach, but they formulated their deductive framework from their inductive analysis. For hybrid analysis to be relevant to the specific research questions of this thesis, the framework for deductive analysis was pre-determined and based on illness beliefs. There is no stated correct order of analysis, thus both ways were tried on a sample of three transcripts (deductive followed by inductive, and vice versa). This showed that the inductive approach followed by deductive, captured the wide range of themes more thoroughly and with less repetition. It was therefore decided to analyse inductively to capture all themes based on the patient data, followed by deductive analysis based on illness beliefs, after a time lapse of approximately four weeks. This was a pragmatic approach to allow the researcher to examine the transcripts with a fresh approach. This hybrid approach complements the research questions by allowing the principles of the understanding the patient's perspective to be integral to the deductive approach while allowing for the inductive themes to emerge. It also allows exploration of the theories proposed by psychologists that change is principally based around a person's illness beliefs. Although presented in this thesis as a linear approach the analysis was an iterative and reflective process allowing interpretation of various aspects of the research topic (Boyatzis, 1998).

4.8.4   Use of quantitative data from the qualitative study

The quantitative data from the qualitative study were not intended to provide statistically significant findings in this small sample. The purpose was to add depth to the qualitative data by searching for clusters across the time points and longitudinally looking at individual journeys, reinforcing their meaning for example by illustrating the individual's journey in terms of disability or emotional status. The data were entered onto an excel spreadsheet and simple descriptive statistics (mean, SD) are presented for the group but the datasets are primarily used individually to demonstrate each patient's context. The quantitative data were used to help the initial grouping of patients to explore potential different journey trajectories (methods section 4.9, results chapter 7).

4.8.5 Analysis of individuals versus the cohort

Figure 4.2 demonstrates the analysis process pictorially. Patients were recruited and interviewed at four time points. At each time point they completed a questionnaire package. Each interview (Int) (Int 1 – pre-consultation, Int 2 – post-consultation, Int 3 – 26 weeks, and Int 4 – weeks 52) was transcribed verbatim. Individual analysis was carried out on each interview at each time point, both inductively (ITA) (section 4.8.1) and deductively (DTA) (section 4.8.2). The interviews were revisited as a group and data from the questionnaires collated to form the journey narratives (group analysis) (section 4.9).

Figure 4.2 Map of Analysis
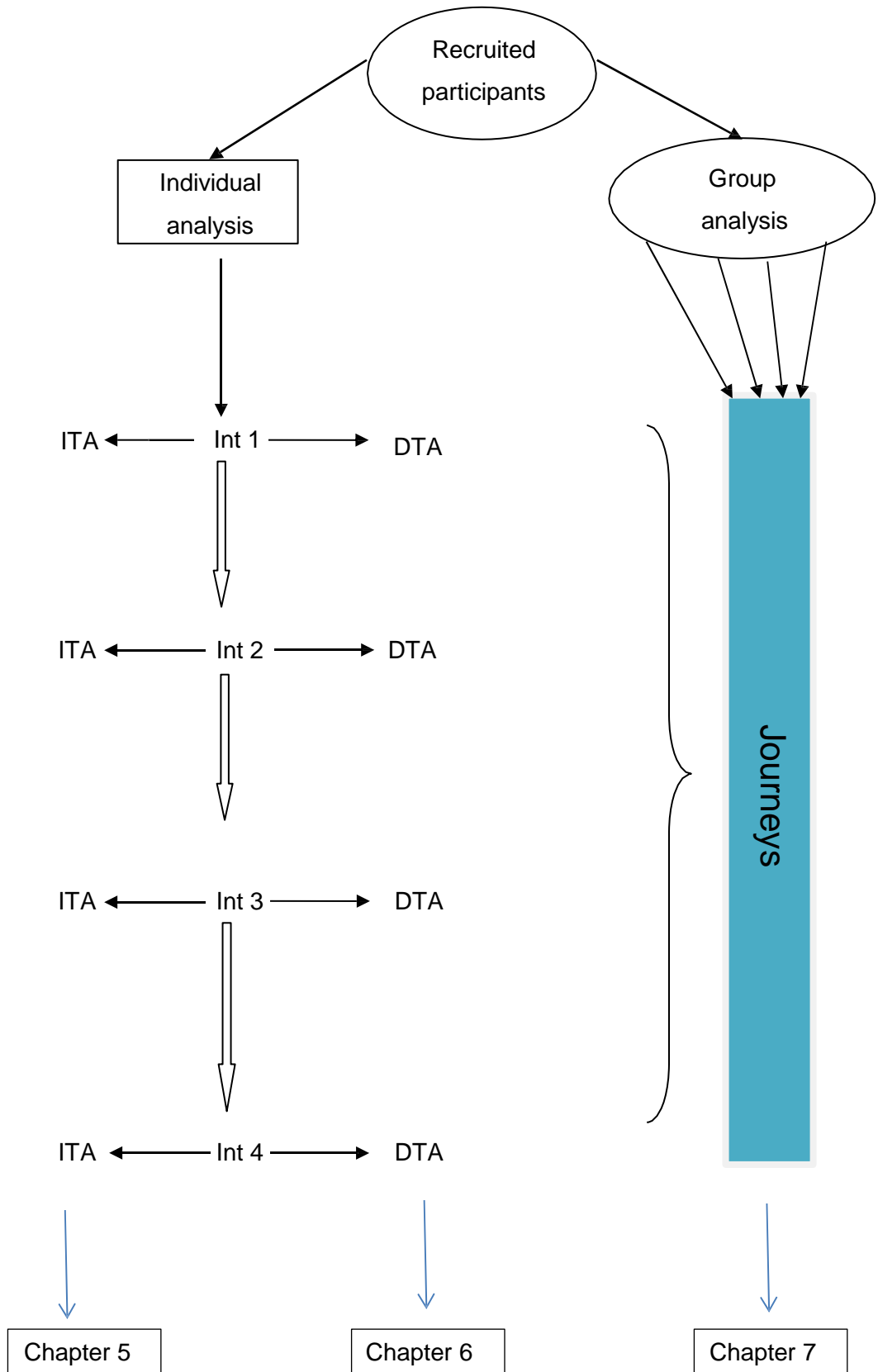
4.9   Formulating the journeys

The analysis was carried out in four steps to elicit any possible journeys that the participants may have taken over the first year.

Step 1: Exploring the quantitative data across all time points

Data across all four time points were examined to find any similarities or differences between participants.

Step 2: Reviewing the quantitative data at 0 and 52 weeks

In order to understand the beginning and end points of pre-diagnosis and one year, data at 0 and 52 weeks were examined for each participant.

Step 3: Proposed grouping of journeys

Having reviewed the scores at the baseline and 52 weeks from the questionnaire data, participants were then grouped on similarities.

Step 4: Integrating the qualitative data

The transcripts were examined across the year for each participant, to review their proposed group, to review any similarities in coping strategies and experiences as described by the group participants. These findings underpinned the proposed labels for the four journey types. Importantly, these journeys appeared to be largely defined not by the journey end, but by the journey processes of coping. The findings are presented in chapter 7. The matrix analysis showed that there was an indication of four possible journeys, and a brief outline of each journey will be then proposed as a narrative, using four patient exemplars (section 7.5).

4.10   Reflexivity

Carrying out qualitative research is in itself a recursive and reflective process; reflexivity by its very nature is a valuable tool for the researcher as acknowledging personal bias can make the research more transparent (Braun and Clarke, 2006). The process of reflexivity is an attempt to identify and acknowledge the limitations or biases of the research and reflective diaries supported this.

4.10.1 Role of the interviewer

The researcher had a clinical role as a specialist nurse based within rheumatology. This potential bias could be twofold. The first is around the interview

itself i.e. whether her professional background would have an influence on the data collection; the second is around data analysis.

When the researcher has a clinical background this may potentially influence the outcome of the interview because the possible researcher-participant relationship (Jack, 2008). There is clearly a potential problem of perceived power imbalance if physicians interview their own patients. Hamberg and Johansson (1999) were family physicians and interviewed some of their patients with musculoskeletal illness who had been victims of abuse. They found that as interviewers they reacted according to three different positions—as physicians, women, and researchers. This awareness of the power asymmetry was crucial to their data interpretation and they found it was possible to reduce it, by discussing it with the participants. Similarly Sword (a GP) described her role as a researcher when she interviewed women about their perceptions and use of prenatal services, describing the ethical dilemma of wanting to provide the women with information in response to the clinical questions and needs that they raised in the interview (Sword, 1999).

Bias will never be eliminated completely as each individual has their own perspective in viewing situations and events by the very nature of their experiences but it should be recognised and can be minimised. Hoddinott, a GP researcher, carried out a number of interviews assessing new mothers' attitudes to breast-feeding. It was determined that she had four roles: GP in normal consultation (A), a researcher (B), known GP to patients from her own practice (C), a GP/researcher to patients from other practices (D) (Hoddinott and Pill, 1997). In role C recruitment rates were easily attained, and rapport was more easily established in roles C and D. However, questions asked during the interview concerning health were answered as though she was acting in a clinical capacity (A), thus adding bias and possibly influencing the direction of the interview.

Whilst trust is needed within the interviewing process it needs to be balanced with objectivity (Hutchinson and Wilson, 1994) in order to ensure that the research process is valid. In collecting the data for this research it was openly acknowledged that the interviewer was part of the research process as researchers are part of, rather than separate, from the data (Hewitt, 2007). The skill of the researcher is to achieve empathy without becoming over involved, this is especially important given the background, knowledge and clinical role of the researcher. However, careful consideration was given to the possible bias and for these reasons the researcher introduced herself as a researcher (not a rheumatology nurse), and made clear to the

participants that she had nothing to do with their potential medical care. It was also a consideration during recruitment as it has been suggested that interviewing your own patients influences the outcome (Hamberg and Johansson, 1999) and increases the risk of obligatory participation with patients fearing that to decline may in some way jeopardise their care or treatment they receive. It was decided that any patients who might be likely to end up in the future care of the researcher in her role as a nurse specialist were not approached during recruitment. The aim was to prevent the interview being used as a clinical session or for the participants to feel that they had an obligation to express certain views when discussing the health service. It has been argued that in qualitative interviews, who you are may determine what you get told (Deverell and Sharma, 2000). However, Richards and Emslie (2000) suggest it is not the researchers actual role, but who the participants "think" they are that affects participants' responses in an interview.

4.10.2 Keeping reflective diaries

Awareness of the dynamics between the researcher and the participant involves an immediate dynamic and continuing self-awareness. In contrast, reflexivity requires a critical self-reflection of the prior knowledge, background, and assumptions of the researcher, and the impact of these on the research (Ballinger, 2003). It is a methodical principle whereby the researcher aims to obtain some level of objectivity and guarantee that their own experiences, potential bias and interpretations are recognised through reflexivity, attempting to limit the way in which bias could potentially influence the results (Grbich, 1999). In this study to address the issue two reflective diaries were kept. The first diary reflected on the actual place of the interview and context of the participants' physical lives, for example where they lived.

The second diary was a reflection on the methodological aspects of undertaking an interview. How did the interview go? What was the researcher's role within it? Did the participants question the researcher about their role? It was a personal log reflecting the thoughts and emotions of the researcher herself, not only with a focus on how the interview flowed, but on interactions what went well, any perceptions before and after the discussion. Keeping a research diary is an essential part of undertaking qualitative research and it prompts the researcher to reflect on different aspects of doing research and her role within the construction of research knowledge (Blaxter, Hughes and Tight, 2001).

While personal identity influences how and what data are produced in all research (Bowling, 2005), in this study it was important to explore the potential impact that a researcher's professional identity had on the research. This was done by adopting a position of professional reflexivity in order to examine how the researchers own professional identity and practices influenced the evolving process of gaining informed consent and the interview data.

The researcher was aware of the possibility that the interview could be seen as a therapeutic intervention. Only one participant actually stated on tape that the interview was helpful to them but the willingness of the participants to talk with frank honesty and their willingness to be re-interviewed at future time points may suggest some gained benefit. The process of the interview cannot be completely neutral and unbiased as the participant and interviewer are entering a mutual exchange, and co-constructing a relationship for the process to work and develop across the 12 months.

4.10.3 Reflexivity and analysis

The profession of the researcher also had the potential to influence data analysis, therefore a rigorous approach was taken to try and ensure the validity of the findings. Silverman (2011) suggest that transcription should be carried out using the same criteria as conversation analysis with the hesitations and pauses detailed, which are shown in the results. Mays and Pope (2000) suggest that having independent assessments of the transcripts can also enhance the reliability of qualitative data and additional skilled qualitative researchers analysing the same transcript and comparing agreement between the two achieve this. For the purpose of rigor four interviews, (two participants at two separate time points) were independently analysed by the researcher and three experienced qualitative researchers where consensus of inductive and deductive analysis was sought. Two interviews (same participant but at different time points) were also analysed inductively by the patient partners to ensure that the interpretation of the themes were accurate from a patient's perspective.

Reflections and the reflective diaries were revisited during analysis and at supervisory meetings. They were used during analysis at first reading and listening of the interviews; this enabled the researcher to contextualise the interviews and acted as a prompt to the interpretation with regards to putting emotions into the interpretation.

4.11   Summary of chapter

This chapter has presented the methodological standpoint and the research methods undertaken to answer the research questions. The following chapters present the findings in three separate sections (chapters 5, 6 and 7) then all findings are discussed in detail in chapter 8. Chapter 5 presents the demographic data of the participants and the inductive findings. Chapter 6 presents the deductive findings based on the illness belief framework. The final results chapter (chapter 7) explores possible trajectories across the 12 months, taking case studies as exemplars to explain the findings.

Chapter 5 Results – Inductive analysis

Chapter 4 described the methods used in this study. This chapter presents the results for the inductive (data driven) analysis by examining the interviews recorded pre-consultation and then examining any changes that occur post consultation. This is then repeated for the 26 and 52-week interviews. Comparisons are then drawn together in the discussion section by reviewing the participant data across the four time points.

5.1 Participant demographics

Upon review of the GP referral letters to the Rheumatology units, 99 participants with potential inflammatory arthritis were identified and invited to participate by letter: 37, 33 and 29 for hospitals A, B and C respectively (Table 5.1); 30 (30%) agreed to participate and of these 17 (57%) were subsequently diagnosed with an inflammatory arthritis. Of these 17 participants with inflammatory arthritis, two withdrew after the first interview, leaving 15 participants whose data are reported here. Fourteen participants completed all four interviews (0, 2, 26 and 52 weeks) while one (Jane) completed all except the 52-week interview (due to a house move).

Of the 13 participants who did not have a diagnosis of IA and therefore did not continue with the study, they were diagnosed as follows: three participants had inflammatory osteoarthritis, two had fibromyalgia, three had polymyalgia rheumatica, one had a reactive arthritis secondary to chemotherapy treatment, one had a type of juvenile arthritis, one had a reactive post viral arthritis, and two were discharged back to their GP with no diagnosis but confirmed as non-inflammatory.

Table 5.1: Recruitment rates

Site	No of invite letters sent	No of participants recruited	No of recruited participants with IA	Withdrew
Centre A	37	17	10	1 (at 52 weeks)
Centre B	33	6	5	1
Centre C	29	7	2	1

There was an even spread of men and women, ages and employment status (Table 5.2). During the first interview three people were on long-term sick leave, although in only two of these cases was it due to their joint problems. During the subsequent 12 months, one decided not to return to work but instead started up her own internet based business from home; the other two participants remained off work.

Fifty-eight out of 59 interviews were conducted at the participant's home by participant choice. Participant interviews lasted between 45 minutes and an hour. Transcribers, who had been verified by the university, transcribed the recordings and the transcripts were checked against the audio recordings by the researcher.

Immediately following each interview, after leaving the participants, the researcher wrote two reflective accounts. The first account was a descriptive observation of the social context in which the participants lived. Although this is a subjective account it was felt that it may add insight and would be helpful when interpreting interview data, especially in the longitudinal journeys. For example, one person on tape described his garden as unruly and pointed out the unevenness of his hedge, as due to his pain it had to be cut on two separate days, the garden looked well-kept and the hedge trimmed evenly The second detailed the interview process, any emotions that the participants showed, or any body language that might be deemed important to remember; and also a reflection on how the interview flowed and whether there were any interruptions and by whom or what

Table 5.2: Demographic data of interview participants

Participant ID	Hospital	Age (yrs.)	Gender	Occupation	Marital status	FH	Time of
Terry	A	52	M	Electrician (SE)	Married	N	26 weeks
Bob	B	60s	M	Retired naval engineer	Married	N	1st consultation
Don	B	Late 60s	M	Retired mechanic	Widowed	N	1st consultation
Nicola	A	58	F	Secretary (NHS)	Divorced	Y	1st consultation
Maggie	A	60s	F	Retired teacher	Widowed	N	52 weeks
Jane	A	34	F	Export officer	Married	Y	1st consultation
Tom	C	40	M	Engineer	Married	N	1st consultation
Fiona	A	40s	F	Ex-Nurse long term sick	Divorced	N	1st consultation
Jenny	A	52	F	Schools Liaison Officer	Married	N	52 weeks
Jacob	A	40s	M	Carpenter (SE)	Married	N	26 weeks
James	A	49	M	Carpenter	Married	N	1st consultation
Cheryl	A	39	F	Shop assistant (sick leave)	Divorced	N	1st consultation
Ian	A	52	M	IT consultant	Divorced	N	26 weeks
Betty	B	70	F	Retired Nurse	Married	N	1st consultation
Sally	A	30s	F	Maître d' (sick leave)	Married	N	26 weeks

SE = self employed

FH = A family history of IA is mentioned

5.2   The qualitative aims of this thesis

1) To explore participants' beliefs and emotions prior to having a confirmed diagnosis of IA.
2) To explore and understand the experience of having a diagnosis of IA.
3) To investigate how beliefs and emotions change over the first year, and which factors influence adaptation and adjustment to IA.
4) To understand the role of illness beliefs in newly diagnosed patients and whether these beliefs influence adaptation and adjustment to IA.

The following section presents the overarching themes and their subthemes that were identified at the first time point of this study, which is between 5 – 14 days prior to the participants first consultation with the rheumatologist.

5.3   Overarching themes from pre-consultation

There are 6 overarching themes and their subthemes: **Experiencing symptoms for first time**, this included pain, swelling, stiffness, exhaustion and sleep disturbances. **The impact of the symptoms,** this included living everyday life with loss of function, changes to people's social life and emotional changes. **Making changes,** this revolved around making life easier or learning through trial and error. **The stigma of being different,** represented by loss of independence**,** work issues and invisibility of symptoms. **Wanting to be normal** was a recurrent theme as was **waiting for the consultation.**

The overarching themes highlighted the physical and psychosocial aspects of living with illness symptoms prior to being seen by the rheumatology team. At this point only two participants had a possible (non-confirmed) diagnosis made by their GP; the others were living with the symptoms without knowing a diagnosis. Although the themes are presented above individually, they are interrelated and often influence each other. For example, Nick's hands were so swollen at one point (experiencing the symptoms) he was unable to drive (impact of the symptoms) so therefore took the train to work (making changes) as he did not want his work colleagues to know how bad his symptoms were (stigma about being different). Going to work was important to Nick as it maintained his normal routine and role (being normal).

5.3.1   Experiencing symptoms for the first time: "I just hurt"

Pain, stiffness and swelling, exhaustion and sleep disturbance were recurrent themes within the interviews. **Pain** was often the first symptom experienced and also the symptom least easy to control at this time and it appeared to have the greatest impact. The descriptions of pain were specific and often visual, using strong and emotionally charged words.

> *"And my wrist was just absolutely excruciating, it was just like a stabbing pain in the actual joint there. I could feel it sort of going – going in, and then shoot – shooting up my arm and into my elbow. Um and I just – it just hurt so much"*   Cheryl

> *"The pain, I mean it was so … it was in there and if someone stuck a knife in and was slowly turning it that's how it felt"*   James

From the early stages people began to experience varying degrees of discomfort. They could differentiate between the more intense pains, through to a degree of tenderness, thus reflecting the fluctuating nature of an inflammatory arthritis.

> *"I can differentiate between different pains and it seems you know if you've got a pain one there and then one becomes sharper, I think probably you focus more on the sharper one"*   Nicola

Whilst the pain initially focused on the patients joints, the feeling slowly encompassed the whole body where the "whole body aches", spreading to include muscles as well as joints.

> *"You're getting a pain in another muscle then and some days I feel like my whole body aches you know"*   Nicola

> *"Just feeling tender. And err, yeah, it's just the general feeling throughout me is just err, you know, this – well it's just – it is almost like I'm a bag of bones, you know"*   Betty

From tenderness to unbearable pain the participants used descriptions of dramatic physical reactions to enable the researcher to understand the consequences of their experiences.

> *"It could easily take your breath away where it hurt that much,*
> *you know you could almost throw up it hurt that much"*　　　James

There was often a feeling of desperation and disbelief about the force of the pain. It seemed that participants needed the researcher to appreciate and believe the intensity of the symptoms. It was as though the participants themselves could not believe the impact of the pain. Although there were attempts to control the pain, the overwhelming impression was that the pain had a significant impact on their physical and emotional health.

> *"I've never experienced so much pain, it really hurt, really, really hurt*
> *and I thought if this carried on and I couldn't get rid of this pain I*
> *think it would drive you insane in the end"*　　　　　　　James

Pain was often at the forefront of the participants' mind possibly due to its impact or related to taking new medication, either analgesics or NSAIDS in an attempt to control these symptoms.

As the conversations developed other physical symptoms became evident. **Swelling**, again an indicator of possible inflammatory arthritis, was an unmistakable symptom that could be clearly described.

> *"Well I started to notice my right hand in particular, swelling and*
> *realised at the same time that I couldn't straighten out my fingers.*
> *They were [pause] considerably curved it didn't seem to allow me to*
> *straighten out my fingers quite as much as, well, I mean it doesn't*
> *matter, because I don't do a lot that requires straight fingers, but*
> *um...it's still uncomfortable sometimes not to be able to straighten*
> *them."*　　　　　　　　　　　　　　　　　　Terry

Stiffness was only mentioned by some of the participants, often it was not recognised as an obvious symptom but one that had to be uncovered during the course of the interview and was only discussed if it had a direct impact on the participant. For example it physically stopped them for carrying out normal activities, as demonstrated by Tom.

> *"Roughly, I don't recall logging it mentally, you know I just got stiff and um.... well I got to a point where I couldn't do anything, literally couldn't even get out of bed"*   Tom

Some participants found stiffness difficult to explain and although the descriptions were physically impossible, the vivid pictures they portrayed illustrated perceived understanding of what was happening inside their bodies.

> *"Um the other thing was um me knees walking, felt like me knees – kneecaps were um loose, if you like. It's like me legs err were just trying – just trying to bend the other way.   That's the impression, that's what it feels like."*   Don

The multidimensional bodily aspects included **exhaustion**, which is also a common symptom of IA. Tiredness was a recurrent theme, with other descriptors including "*exhausted"* and *"being wiped out".*

> *"And it's not just a, "Oh I feel I could do with a little doze," it's like, "OK I've got to sleep now" and I'm just gone for hours and hours"*
>
>   Cheryl

The emphasis from the interviews was that this tiredness was beyond any "normal" state that participants had previously experienced.

> *"I'm started to get really tired, um and not just – not just sort of – oh exhausted, completely wiped out.   You know, I'd come downstairs and maybe do – sweep the floor or something, and then I'd have to sleep. And it was just ridiculous"*   Fiona

This description by Fiona showed the incredulity that participants had regarding this symptom; not just that it existed, but the physical and emotional bearing it had on their life. Exhaustion was also different from the sleep problems participants described.

While **sleep disturbance** was evident, it was not as a stand-alone aspect but often linked with pain.

"I was in so much pain I was really struggling, as I said I was getting two to three hours sleep"   Tom

"I was so tired I just wanted to be able to sleep. The sleep pattern was getting me down because I was in quite a lot of pain"   Don

Participants were aware of changes within their regular routine and despite regular analgesia still struggled to manage their pain, so it continued to disrupt their sleep.

"You'd lie there and then you'd move and the pain would wake you up and 'ouch' you know…They did give me some tablets, a little white one to take at night to stop the pain. I mean last night I slept like a log you know, no problem and I was so pleased about that"   Bob

5.3.2   Impact of symptoms: "I couldn't even use a knife and fork"

The physical symptoms discussed by the participants began to interrupt their daily routines and the impact stopped them continuing with their life as normal (figure 5.1).

"That's when I thought – enough is enough, if I can't work how am I going to survive. And they [the symptoms] can't stop me, I mean I have a young family, and it's the only job I know"   James

Figure 5.1 Combination of symptoms leading to encroachment on life and daily routines
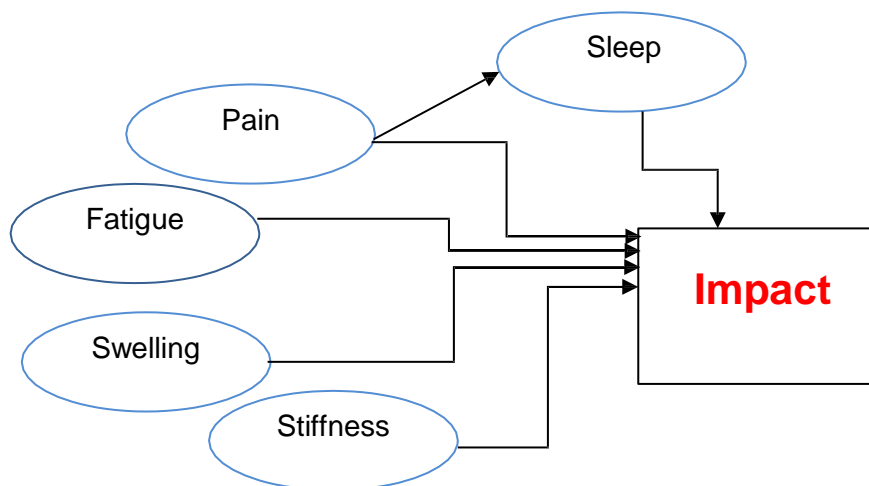
The symptoms affected both emotional and physical wellbeing, and encroached on all aspects of life, personal, work and social. The following section will examine the extent to which the symptoms impacted on participants.

The symptoms cannot be viewed in isolation. Participants described their symptoms in relation to the extent to which they impacted on their daily lives and routines. The participants recognised the **impact** of symptoms through the changes they had to make in everyday life as their symptoms continued. The illness was starting to become part of everyday life and needed to be accommodated into their routines in order for them to continue.

> *"It is, yeah, when you can't finish something yeah. Especially like, you know, as I say, with the hedge just like that. I mean that's a minor – that's just a necessity. But there's a thing that I'd like to go out and do. I mean there's a million things I've got planned to do with the house, and I've got materials to do them, but I'm just, at the moment, I'm just in no position to um – I want to paint the house, but just going up and down the stepladder is – you know, is – you know, is a trial. So um – and yeah I suppose probably a lot – a lot of it is being able to – I mean, as you can see, I mean I like to do a bit of painting. And I used to do a bit of wood carving, well I've got a lot of wood carving equipment, and I like to be able to pass me time doing that, if nothing else. But I'm starting to think to myself, well if me hands get that bad I don't know what I'm going to – you know, I'm not going to be able to do the things I enjoy doing, you know."* Jacob

Since the participants could no longer carry out simple tasks that they had previously taken for granted the **loss of physical function** was felt both at home and at work. Some participants, when asked directly about changes in function, did not acknowledge any had been made in their routine. However, when the questions were rephrased to enquire about specific tasks, such as climbing up the stairs, they acknowledged they had made unconscious changes.

> *"I tend to go sort of sideways, one step at a time, and sort of lever one foot rather than…. actually I avoid going up the stairs. So when I was going up, I would do as much as I could, so I didn't have to go up again"* Maggie

Grip was perceived as a major problem both from dexterity and a strength perspective, with most participants finding that even the simplest tasks became a struggle.

> *"And holding things, I'm quite often holding a cup and when I make a cup of coffee with two hands when I'm carrying it because I'm struggling with grip in the hand, so I'm holding it with two hands, one underneath and one on the handle"*   Fiona

While the consequences of the loss of grip strength and other physical symptoms impacted at work, there was still a determination to continue with the job that was being undertaken.

> *"It's the simple things - I'd do it, but it was just um...I had to admit I used to do it and swear a lot…"come on you've got to do it", I just bashed on the best as I could (pause) I don't know, just pushed on the best as I could."*   Don

Several participants reflected that their decreased grip strength affected their driving ability. This raised several issues including isolation, *"I just can't get down the hill without a car so I can't get about",* family reliance *"my son has to put the hand brake on for me"*, and difficulty getting to work.

> *"I was struggling to move my hands at all, you know my wrists and my fingers were swelling up so it was getting a real struggle just to get to work"*   Terry

This specific loss of function showed how having joint problems forced some people to change their priorities and change the way that they carried out activities. Changes not only had practical implications but also restrictions in terms of socialising.

Participants experienced significant **changes to their social life**, including reduced socialising and opportunities for social interaction. The changes were due to physical limitations of the new bodily symptoms. One concern was not being able to accept the limitations caused by the new symptoms, and declining invitations to socialise. For example, Jacob no longer played darts for fear that his grip would let him down.

> "*Well I'm not – I'm not – I didn't really socialise a lot anyway. I mean I would occasionally just stop in for a – for a couple of pints. And obviously when I was playing darts, and I'm not now, so I'm not going out for that, and I used to just practise at home upstairs, you know. But I've tried that and – you know just hurts too much*" Jacob

> "*I try to avoid [social] circumstances, but I have to accept that this is where I'm at, this is what I've got and I've got to try and get all the best I can for me. My friends don't understand so I hide from them, I never commit to doing anything now*"　　Nicola

In extreme instances, it appeared that the participants felt the symptoms had begun to re-define who they were as a person with profound challenges to their self-confidence. The most powerful example was Cheryl who was just beginning to start "liking herself" after an acrimonious divorce when her IA symptoms developed, and she "hated what she had become".

> "*So I do, I distance myself from people. And a couple of my friends, other friends, couldn't – couldn't grasp that, they couldn't get their head around it. Um so I'm aware that I'm doing that. Um I have become – I – I know that I've become more insular, don't want to go out quite so much.*"　　Cheryl

Dealing with their symptoms and how these impacted on life restrictions were also influenced by the emotional response of these participants.

All participants experienced an **emotional response** including anger and frustration, and this is discussed within illness perceptions (section 6.1.6), however, the way that they chose to deal with these negative emotions differed greatly. A number of participants felt the condition caused them embarrassment and acknowledged their perception that they were changing.

> "*Yes even if there was nobody about it was really embarrassing, I was hating myself for getting like that you know. I was.....thinking you know, what's the matter with me sort of thing.*"　　Terry

"I hate – I hate what I've become"   Cheryl

In contrast, there was a very pragmatic, almost resigned attitude from those who were retired, which may be due to their different expectations of life based on their past life experiences or due to what is important to them as individuals at the time of their interviews.

"Nothing much I can do about it really, just to make the best of it, take the medication and I mean...I'm in the later years of life now, seventy five."   Betty

Underpinning the interpretation of the interviews was often a feeling of sadness. This seemed to be for life that had not yet been lived, the perceived unfairness of circumstances. The concerns acknowledged by the participants were focused on their personal perceptions of what they considered to be important.

"I just um – but I want to be so much more positive than this, and that frustrates me – sorry. So um I want to be able to just carry on and do as much as I can, but I can't seem to do anything um...like a normal person does"   Nicola

"Um I have become – I – I know that I've become more insular, don't want to go out quite so much. I've hate what I've become"
                    Cheryl

There was variation in how participants tried to maintain some emotional shield. Several participants tried to minimise the emotional effect by using a downward comparison. The theory of downward comparison (Wills, 1991) posits that persons experiencing negative affect can enhance their subjective well-being through comparison with less fortunate others, the process occurring on either a passive or active basis.

"I mean I really know there are people a lot worse off than I am, (thank you....) you know I see, like ... you see these poor soldiers coming back with arms missing that policeman there they've blinded by that...person.... um...and I think how terrible that must be and life, I mean at least I can see"   Terry

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However, others dismissed the value of downward comparisons as unhelpful and irrelevant.

> *"Okay you can have great sympathy with people that are a lot worse off than you but that doesn't and shouldn't make you feel better"*   Cheryl

5.3.3   Making changes: "being good to myself"

This theme relates to the participants wanting to cope both physically and mentally with the imposed changes by taking action (making changes). Some participants were decisive in recognising their limitations when planning their life. Others went further and began adapting their living and/or working environments; and two participants who had other medical conditions had already made practical changes at home. These practical changes were often the start of participants adopting strategies to control their symptoms in order to minimise their restrictions.

> *"I even avoid things like chopping, where you have to put pressure on these fingers, these are the fingers which hurt, these are the major fingers I would say, each of them is inflamed, I'm not a big fan of buying stuff which is already chopped for you but I started looking at options like that and if I have to give [daughter] some soup from the carton I bought in the shop pre-made well then I have to"* Fiona

Although the symptoms were still relatively new to most participants they were finding ways of managing their illness to maintain their lifestyle, within their limits.

> *"I've found that if I push myself to the end and I think "I've got a pain now," it's too late, I've really done the damage then you know. I know that I'm gonna be in agony, so now I don't do that anymore, I just, I do things as much as I can and then oh that's enough."* Sally

Some participants had begun to think through their activities and even pre-plan for them, others learned through experience by repeatedly "*overdoing it*". Those that

had begun to actively change from the start of their joint problems had previous illness experience, such as hip problems or diabetes. The changes they made related to everyday management of daily living, including adaptations at work and in the house, and also positively maintaining the current levels of activity with a belief that positive management would be better for the future.

> *"I do break things down into chunks, I know I can't do everything in a day, so I would do something for quarter of an hour, or I'll do something for half an hour and then I'll stop before the pain comes on"*   Jane

Several participants spoke about **making life easier** for themselves using a number of strategies to minimise the impact of their disease. This suggested that these participants were beginning to adapt to their illness even before they had received a diagnosis.

> *"I know I wear clothes with no buttons, everything is elasticated even my shoes are like Velcro and stuff"*   Fiona

Women appeared to use preventative self-management strategies in advance, compared to men, who at this stage tended to self-manage only after they found their symptoms stopped them from achieving their goals.

> *"So there's a thing that I could do there I know that's been bugging my mind, but I have got a slow cooker, I have got a rice cooker, so I don't have to lift heavy things off the cooker now."*
>   Fiona

> *"I just reach a point and I'm exhausted and have to put the tools away".*   Jacob

Participants reflected on how they developed an understanding about their joint problems through **trial and error**. It included trying to control the symptoms and also attempting to continue with their life activities.

> *"Um I've tried hot milk, tried whiskey…. Um I'm reluctant to take sleeping tablets, purely because I want to be able to function the next day. And I've had – I don't want to be waking up feeling groggy"*   Bob

> *"I've learnt now, to say no - don't particularly like saying no but I need to sometimes, you know, to look after myself."*   Jane

The combination of active management and trying to maintain a balance of symptom control and activity, promoted a positive sense of control with participants choosing to *"be nice to oneself"* and rescheduling outings with friends if they thought it would be beneficial "*normally I would struggle on, but now I just tell them I can't do it".*

> *"My work colleagues take the mick but every day we go out for a walk and they'll say to me "is it an uphill day?" I'll never not go now"*   `   Tom

Trial and error also included the management of symptoms. Sometimes this was guided by the medical team, "*naproxen – just brilliant*" and at other times the participants tried whatever means they felt were appropriate.

> *"I tried gel packs, heat – I tried cold, cold packs and I thought – well this isn't working, let's go back to cold you know – that kind of thing. Tried um strapping it with a bandage, makeshift sling, that did relieve some of my pain, haven't got round to swimming that's my next thing to do"*   Jane

Diets, honey, vinegar and cod liver oil were all experimented with, but improvement was negligible. However all participants experimenting with these were reluctant to stop as Terry explained, *"I don't believe it's doing anything but I'm not changing just in case."*

5.3.4   The stigma of being different: "I hate being a burden on people"

The stigma, that is the shame attached to something being socially unacceptable, for the participants was based on their perception of becoming dependent on others.

The loss of independence was a constant fear to several of the participants who described a fear of losing independence and becoming a burden to others. This was a significant theme especially for those participants who were the main earner or carer within the family.

> *"I'm very independent, and then having to rely on my kids for just the most ridiculous things, and I hate being a burden on people"*
>
> Cheryl

> *"…. it's that loss of independence, you know, I can't do it myself, I need somebody to do it for me or with me"* Terry

Work issues included fear of change or loss of employment, however the main subtheme within the work category was being different.

> *"I just can't seem to manage everything I should, I mean I can't even lift more than one set of notes...and nobody really cares. I mean all they care about is whether I pull my weight at work – what good will I be if I fall behind"* Nicola

> *"They want to move me from where I work to another area of the store, they say I'm not quick enough. I mean they don't have a clue. Moving me to an area where I have to stand all shift in a different team...well they're having a laugh if they think that's better for me. I want to stay with people I know not moved to another team I mean why should I have to explain to people that don't know me that I've got something wrong"* Cheryl

The response from family, friends and work colleagues varied as the participants' struggled with others' perceptions of the symptoms. Often the **Invisibility of symptoms** caused disbelief and lack of support. Participants described a lack of understanding from others as the participants struggled to come to terms with the varying symptoms. Many people who came in contact with the participants remained judgmental.

"One of the blokes at work made a comment about me because I went down the flight of stairs from Level 9 to Level 8 and I could do it and he went, 'oh you're amazingly mobile today' and I thought how dare you, he never speaks to me any other time, never"

Nicola

This recurrent theme was indicative that the participants believed other people really did not understand the aspects of change, which had occurred due to symptoms and the impact that it was having on them as individuals.

"I don't think she appreciates how much pain I was in. I don't get a lot of sympathy off my wife so I don't say too much about it … I think that's just her way, I'm not saying that she doesn't care because I'm sure she does but…."   Terry

Initially it appeared that people were supportive and empathic, but participants believe this wore off when the condition continued.

"And they're probably quite selfish in the fact that the novelty seems to have worn off for them. I know that sounds awful but, you know, to begin with they were all really supportive and, "What can we do for you, mum? Does anything need doing?" And now it's like, "Oh well, it's been 3-4 months, you're doing better"   Cheryl

There were many instances where participants commented that people judge others on external signs of illness but that pain, exhaustion and lack of functional ability are difficult to describe and are not visible.

"Um err the other thing, I suppose, is um the fact that outwardly I look completely, you know, able-bodied, you know. And um it's – it's trying to explain to people like, you know. Especially, as I say, when I went to the site and he said, "Well I'll give you something light to do." I said, "There's probably nothing light enough." And it looks as though I'm sort of shirking, trying to shirk something. So um I want to be able to just carry on"   Jacob

Participants' perceptions of what others were thinking about them had a profound effect on how participants viewed their symptoms, and also how they dealt with social interactions. Jacob's perception was that people might see him as "shirking" yet he desired to work. It is difficult to know if his perception was based on actual comments from colleagues or his perceptions of what was unsaid. Some participants used withdrawal from social encounters as a form of self-preservation.

> *"So I do, I distance myself from people. And a couple of my friends, other friends, couldn't – couldn't grasp that, they couldn't get their head around it. Um so I'm aware that I'm doing that. Um I have become – I – I know that I've become more insular, don't want to go out quite so much. I hate – I hate what I've become"*   Cheryl

Other participants, as shown below, found other people's views frustrating and their wishful thinking was for an easier way to communicate with others. This links with the invisibility of symptoms where people wanted their symptoms to be recognised.

> *"Or an L.E.D. flashing where it's actually hurting at the time...you know and a group of L.E.D's so (1) is reasonable and (2) increased pain, you know, whatever...um...because it is like that and some...[wife] will say what's that and I say oh nothing, but I'm in....pain."*   Terry

 5.3.5   Wanting to be normal: "I just want to be normal"

This theme was important for several of the participants and underpinned their choices as they continued to feel the impact of the symptoms, being reflected in emotional experiences and practical aspects of change.

> *"I couldn't open a bottle of wine anymore. Not with these [hands] um...I know we can all live without drinking wine, but it's err...something that normal people do"*   James

Functional aspects of living were often contextualised within the participants' emotional health, and participants related this to their personal vision of normality.

> *"But the embarrassing thing for, well what I feel should be a fit and able man, yet I can't get out of a simple thing like a bath"*
>
> Bob

There was a constant appraisal of what was important to the participants and their own perception of what is normal for them, from physical normality *" I don't want to feel old",* to acknowledging that the restrictions define what you can achieve *"I want to be normal but I can't keep up".*

> *"I was trying to do too much just trying to carry on normally and do the normal things I used to do but now it's like on the weekend I slowed down"*
>
> Tom

Overall the findings suggest that even before the diagnosis the physical symptoms (such as pain, fatigue, swelling and for some participants, stiffness) are having a major disruption on their daily lives, from lack of sleep to involvement in their work and social situations. There were three compelling factors: the symptoms that led to seeking help (5.3.1), the impact of these symptoms on the life of the participants (5.3.2) and the stigma of being different (5.3.4). These meant that changes that had to be made (5.3.3) (see figure 5.2). Changes could be triggered and affected by the lack of understanding of others, the reliance on others and work issues, depending on the personal importance to each individual. This was underpinned by the disruption to perceived normality (5.3.5) and fed into beliefs about their consultation (5.3.6). This is demonstrated by placing these themes in the context of the participants' perspective as shown in appendix 18.

Terry summed up how living with his joint problems encompassed these factors:

> *"Um err the other thing, I suppose, is um the fact that outwardly I look completely, you know, able-bodied, you know. And um it's – it's trying to explain to people like, you know. Especially, as I say, when I went to the site and he said, "Well I'll give you something light to do." I said, "There's probably nothing light enough." And it looks as though I'm sort of shirking, trying to shirk something. So um I want to be able to just carry on, I'm a very active person normally I'm out and about doing things you know and this was holding me up terrible."*

Figure 5.2 is based around the issues discussed within the first interviews. However the focus at this point is the forthcoming consultation and the participants' perspectives and needs from this forthcoming event.

<u>5.3.6   Waiting for the consultation: "I'm desperate for an answer"</u>

There was an overwhelming need to be believed and to have some form of legitimisation of the symptoms. From the interview data the main focus was not around what would take place in the consultation, but rather what the outcome would be. There was a common thread that people had not thought about what

would happen during the consultation with an "*I've got no idea what's going to happen"* response*.* There was overpowering sense of anticipation and hope of solving the problems interlinked with the receiving of a diagnosis.

> *"So I don't, I don't know. I just – I wish – I'm hoping that he'll be able to say to me on Friday, "This is what it is, and this is what we'll do, and this is how you cope with work, um or not, as the case may be."I – I don't know, that's what I'm – I'm struggling with"*
>
> Sally

Much emphasis was placed on receiving a diagnosis but this was accompanied by fear *"I am scared that he's not going to be able to give me those answers"*, something that is almost incomprehensible for most people.

> *"I need an answer, I can't believe he won't tell me straight away, that would be awful, I really couldn't bear that… not sure what I would do if that happened"*
>
> Jane

There was a rationalisation that the diagnosis would be the start of the road to recovery and having a diagnosis would enable people to return to their previous lives with some level of normality.

> *"I'd like to think that they can actually pin point exactly what it is I've got. Because at the moment it's all scratching their heads it might be this or it might be that. Um...I just don't know. I would like to know um...and hopefully they can find something to either cure it or make it more bearable so I can return to work and do things"* Terry

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Summed up by one participant, a common sentiment throughout the interviews was simply a need for some answers.

> *"I'm really desperate to find an answer for obviously because I don't*
> *want to be ill."*   Maggie

Figure 5.2 Pre-consultation pictorial representations of inductive results

Personal experience

Experiencing symptoms for the first time

Impact

The stigma of being different

Changes to social life

Everyday life with loss of physical function

Emotional response

Invisibility of symptoms

Work Issues

Loss of independence

Making changes

Trial and error

Making life easier

Waiting for the consultation

Wanting to be normal
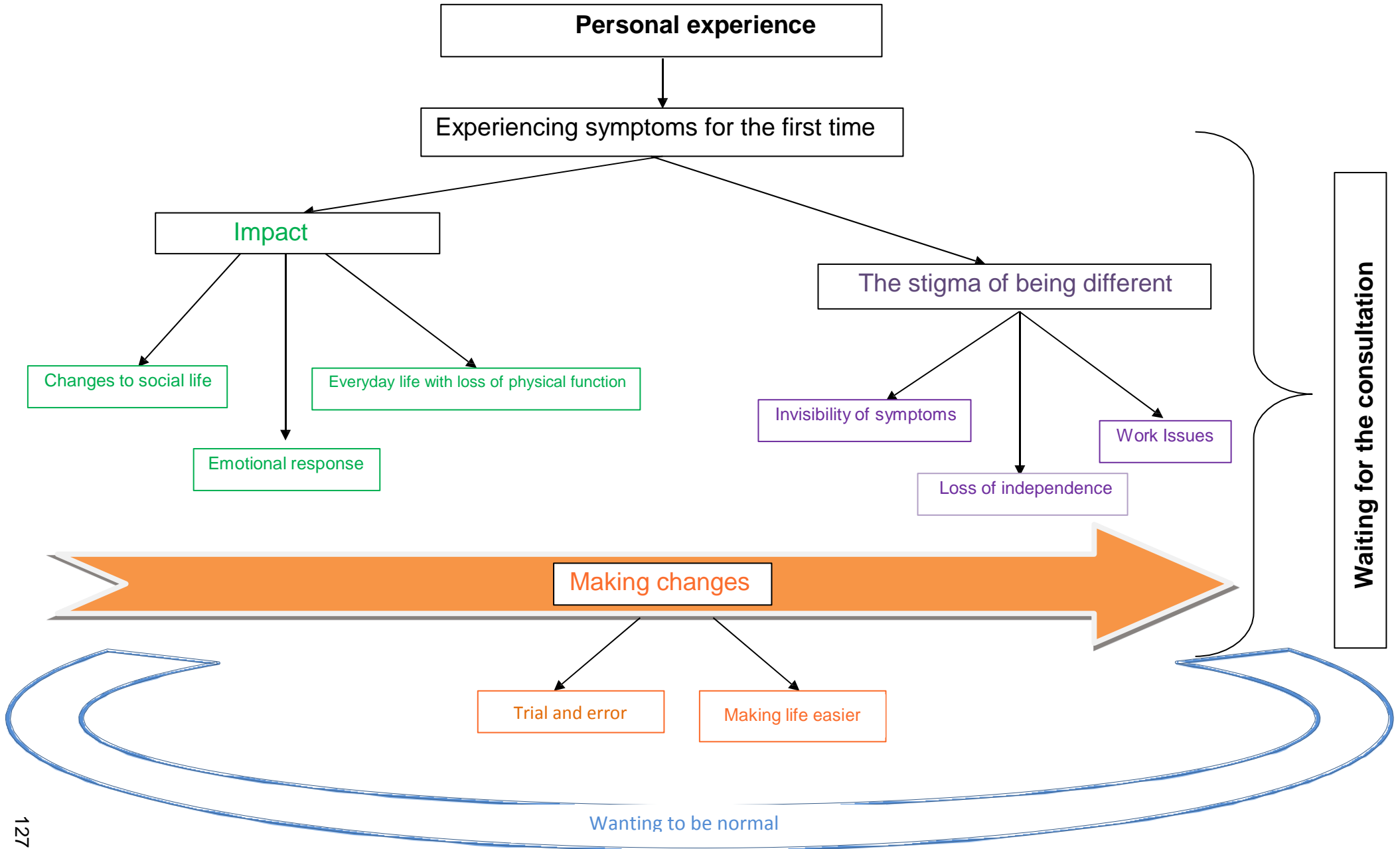
5.4   Overarching themes from post-consultation

The majority of themes found in the pre-consultation analysis were repeated in the interviews that took place post-consultation. These included the themes of experiencing symptoms, impact, stigma and wanting to be normal, and are not revisited in this section as there was found to be very little change from pre to post consultation within these themes. This may be as the time between each interview was approximately four weeks or it may be that the focus from the participants' perspective was on receiving diagnosis or even if the diagnosis was not confirmed at this stage (six participants) the validation of being seen by a specialist was the important factor in these post-consultation interviews.

However, in the post-consultation interviews the new themes regarding the influence of this meeting were identified as **validation of symptoms, gaining information, starting new treatment** and **hope for the future**

5.4.1   Validation of symptoms

Despite being given a diagnosis of inflammatory arthritis and the potential problems that this may bring, the overall feeling was one of optimism. Although the reasons for this are unclear at this stage and may be linked in with hope for the future (5.4.4), it may simply be the fact of finally having a label or being listened to and believed, especially from the younger participants, as Cheryl suggests:

> *"Because I feel um probably more confident. I know that sounds really silly, but now I know what it is I'm not scared any more. I have an answer now, I know – I know what I'm dealing with."*   Cheryl

The consultation legitimised the situation for all the participants. Even those who had not received a definite diagnosis felt more able to handle the situation and less stigmatised at being different.

> *"I can explain things now to people at work, my manager – even they may help me by taking the pressure off a bit, it helps just seeing someone, even if they're not sure at least they can advise me"*   Jenny

Participants found that they had to re-evaluate their priorities and come to terms with a diagnosis. This may be due to legitimising their symptoms or new knowledge about their symptoms. These reasons are discussed in depth in the discussion.

> *"My priority has changed. You know, losing weight, which is – I've always known that I've been overweight, I'm not stupid, but it just never – it was never important before. I would have been quite – quite happy to have ended my days as a fat woman, just because I couldn't be bothered. But now I've – I've had – I've got to you know, it could make so much difference to my life. Or even if it just makes the tiniest bit of difference, relieves my pain just ever so slightly. I can't be that selfish anymore."* Cheryl

The consultation provided validation about being sick and being believed. The legitimisation of the condition enabled a reviewing of thoughts and beliefs and positive reinforcement of their illness enabling the participants to enhance their self-efficacy, therefore improving their confidence.

> *"Now I know that I'm not going mad, um I'm a lot more – a lot more positive, and my attitude's a lot more positive. Yeah, I feel a lot more positive. Joined weight watchers, Fat Fighters, as me and my friend call it. It's our first session tonight. So um, bless her, she's decided that she's going to support me, and we're going to do it."*
>
> Cheryl

5.4.2   Gaining information

Where the diagnosis was certain it was reinforced by written literature provided by the doctor. The news was portrayed in an *"optimistic"* manner and "*she obviously knows her stuff*" enabling confidence in the consultant and also in the actual information gained. This was a shift in how the participants gained and understood information, and they were given guidance as to where further information could be sought. At the time of the second research interview only one participant had met with a nurse (focused on medication), and two had had physiotherapy sessions, although this was in the community (pre-arranged by the GP).

There was also a perception of hope by the participants when meeting other members of the team, from:

> "*Because in my experience it's always a lot easier to speak to nurses than it is to doctors anyway. They're a lot more um – what's the word I'm looking for? – down to earth.*"   Nicola

Through to the management of the disease treatment

> "*I'm also going to see the rheumatology nurse and she's going to be keeping tabs on my record regarding the blood etc.*"   Bob

5.4.3   Starting treatment

In between the consultation and the research interview, most participants had started medication for their IA (11 participants). Although the participants themselves did not associate their feeling more positive with starting the medication at this point, it should be noted that those who felt the symptomatic relief also felt that their general wellbeing had improved. In fact the three participants who received an intramuscular depomedrone (steroid injection) at the consultation felt immediate benefit and therefore a change in attitude. There was, at this interview, no reference by the participants that this may be a short-term remedy.

> "*It's like a wonder drug, ok – so I'm not perfect but I feel that I can go back to work, I know that I have to take some tablets as well but we'll see what happens with them later*"   Jacob

There was some readjustment to all the changes, which included coming to terms not only with the diagnosis but also the impact of the medication and the disease itself.

> "*I've still – still got a few um worries about maybe the future, you know, whether or not it's all going to go to plan with er – with the treatment. Whether it's going to be effective and whether or not I'm going to wake up er one morning and, you know, not be able to get out of bed or, you know.*"   Maggie

5.4.4   Hope for the future

"You know, even today meeting with the nurse, she's – she's um, you know, pretty much told me that, with the medicine they can control it, and I wouldn't – shouldn't expect any – any more um or any worse than I've already experienced."   Bob

The impact of the disease was still evident but as Bob states he has become more positive with a shift towards a positive outcome for the future. This was emphasised by Terry.

"I mean I'm more positive about it now because like I said the difference between when I saw you last and the differences when we came back from being abroad, I mean I had days when I couldn't get out of bed and then I was very worried, I've got to be thankful for that, so that's a lot better."   Terry

"I think it just comes down to having a good mental attitude and I think my attitude's changed."   Jane

Within the hope and positivity there were still some indications of wishful thinking by the participants who has received a diagnosis. This contradicted previous comments in the interviews of the positivity of receiving a diagnosis and is demonstrated by Tom.

*"I sort of guessed, wish I was wrong through…. Suppose….It's OK –
I sort of knew – so I can get on with it now, I know for sure what I'm dealing with, so that has to be good"*   Tom

However, there was still a hope for a cure or at least a treatment that would be free of side effects and be effective.

"I'm kind of upset because you always want … you always don't want it to be so you're sort of like okay I'm going to have to come to terms with … you know really come to terms with this now so …well that I've got arthritis and I'm going to have it for the rest of my life so you always hope there's going to be a cure there so you

know it's not going to be that until … I'll be better at some point."

Tom

This section has presented an overall qualitative in-depth analysis of interviews from participants referred to and seen by a rheumatologist. The findings pre-consultation included experiencing symptoms of inflammatory arthritis and the physical and psychological impact experienced by these participants.

The main changes post-consultation in this rich data set are those shown in mental attitude, that despite receiving a diagnosis for a long-term potential life changing illness, having a name for the illness or being recognised as having symptoms and knowing that with medication the disease was more controlled was seen as positive. The stigma of being different had been reduced by the actual act of the consultation, of being able to legitimise their symptoms by a specialist review. This enabled the participants to become more positive. Post-consultation the group were not only more informed about their illness, but also seemed more willing and better prepared to be able to absorb more information. Fears about the medications risks and side effects were evident, however so was the readiness to take "anything" that would help. Living with a long term condition involves a reiterative process showing that any illness that is embedded in daily lives can be disrupted by not only the changing symptoms but also by society's perception and the individual's experiences.

This section focused on inflammatory arthritis and the disruption that an illness brings pre and post-consultation. The next section describes the changes over 26 and 52 weeks.

5.5   26 week interviews: Overarching themes

By 26 weeks the analysis identified **change** as an underpinning theme. The changes identified were enforced or subconscious, physical or psychological. The original themes of experiencing symptoms and their **impact** were influenced by **listening to my body**. **Making changes** was altered by new thoughts and actions. The stigma of being different was altered by the **influence of others**, while **disrupted normality** added new concepts to wanting to be normal. This section presents these changes (table 5.3).

Table 5.3: Comparison of the themes

Pre-consultation		Consultation	26 weeks (underpinned by change)	
Theme	*Sub-themes*		*Theme*	*Sub-theme*
Experiencing symptoms for the first time	Pain Swelling Stiffness Exhaustion Sleep disturbance	Hope for the future	Listening to my body	Recognising the symptoms Rationalising the use of medication
Impact	Loss of physical function Changes to social life Emotional response		Impact	Isolation Wishful thinking
Making changes	Making life easier Trial and error	Starting treatment	Making changes	Pacing Rethinking things New me
The stigma of being different	Loss of independence Work issues Invisibility of symptoms	Gaining information	Influence of others	Support groups Other people's perceptions
Wanting to be normal		Validation of symptoms	Disrupted normality	Battling on Re-negotiation

5.5.1   Listening to my body: "but when they do flare up it's quite difficult to do a lot of things"

Listening to my body expanded the original themes of experiencing symptoms and the impact that the illness had on the participants, through recognising the fluctuating nature of IA, the effectiveness of the medication, how participants reasoned their use of medication and its appropriateness in controlling their symptoms. The recognition led to changes being made to managing the symptoms which altered impact (section 5.5.2).

Participants started to be able to distinguish their illness by **recognising the symptoms.** There was a noticeable improvement in the symptoms experienced by all participants with the descriptions becoming less vivid than in interviews six months earlier. There was also an acknowledgement of elements of control and how the symptoms could be improved by actively incorporating self-management strategies. Participants started becoming more aware of their body and its needs, and using therapeutic strategies that might improve symptoms, including the use of exercise.

> *"And occasionally I – I haven't had much problem with wrists, but when they do flare up it's quite difficult to do a lot of things.   And walking, first thing, is awful.   But I'm pretty sure that the more, you know, the more I keep moving, the better it is.   And certainly by midday I'm okay, as a rule "*   Sally

> *"I've still got some slight problems with shoulders first thing in the morning when I get up but that goes off fairly quickly as my arms get exercised"*   Bob

There was an inextricable link between symptoms and the use of medication, in both trying to gain and maintain control over their symptoms. Participants began to recognise the effect that the medication was having.

> *"Definitely the swelling is the main thing, since starting this [combination therapy] the swelling is, you know, it's so lovely to not have that, I was finding it frustrating because like trying to*

> *wipe your own bum, or if you touch something and it just - your*
> *fingers hurt"*   Cheryl

At this time there was evidence that patients weighed up the risks versus benefits
and started **rationalising the use of medication**. They made choices between the
potential benefits and side effects of medication. Participants began to rationalise the
use of the medication.

> *"Well I just felt really, really tired. Unless I was still having the flare*
> *up, because I was so terribly tired all the time, I felt sick. People*
> *even noticed I had bags under my eyes, and quite black bags. And*
> *I'm sure it was the drugs, my body adjusting to the system, you*
> *know, to the difference of taking these things. And as I said, it took*
> *a long time before I actually really noticed a difference in my*
> *symptoms. They said after maybe six weeks or three months, and*
> *for me I think it took four, a good four, coming up to five months*
> *before it started to kick in and make me feel better."*   Fiona

A majority of patients were on both NSAIDs and DMARDs at this stage. There were
three participants who were not, one through choice, and the others being
maintained on steroids and NSAIDs alone. The benefit was beginning to be seen
by the participants as they started to get their symptoms under control.

> *"It has made a difference to my quality of life. Still stiff in the*
> *mornings, and my feet are a problem, they swell all the time on and*
> *off, and they hurt at times, well more often than not actually. But other*
> *things, it has made a difference to certain of my joints, and that's*
> *good, so I've been very pleased with the regime, um yeah"*   Fiona

The side effects for one gentleman became so problematic that he was admitted
into hospital with severe epistaxis, causing disruption both bodily and to life in
general.

> *"That was when I was in hospital and they gave me these tablets, I've*
> *forgotten the name of them now, begins with an 'n' [naproxen] and it*
> *thinned the blood down so much that I kept bleeding and I couldn't*
> *stop it and I spent five days in hospital"*   Bob

The side effects also created fears about future medication, but as Bob summed up it appeared to have a detrimental effect on the arthritis as well.

> *"I lost a bit of weight on that … when I had that blood thing, I lost about a stone I think it was. It really done me that did, it was then that the arthritis seemed to come on worse you know, it seemed to do a lot of damage physically and mentally. Mentally because you're always nervous about your nose bleeds. Now he told me for the pain here to use Paracetamol because it will not affect the nose, some of these tablets you take they tend to thin the blood like aspirin, which I've been scared to take you know because I don't want to thin the blood. But they said Paracetamol won't thin the blood but I'm still not that confident and I haven't been taking any"*   Bob

Unfortunately side effects became apparent for three other patients. In two out of the three cases the side effects were tolerated as the medication began to control the disease. This demonstrated the risk versus benefit decisions that the participants had to make when dealing with unpredictable medication and fluctuating symptoms. For example Cheryl continues to take her medication despite side effects.

> *"Because I was getting really bad mouth ulcers. Um I've had one for about three weeks now, probably a bit longer. It's only just starting to heal. Um which is a bit of a pain"*   Cheryl

Despite many participants reporting that their symptoms had improved there wasstill a feeling of living with this *"inconvenience"* as participants struggled to place the impact of their arthritis within their own personal situations.

5.5.2   Impact

In these interviews the physical impact of the arthritis remained an issue but was less prominent than in previous interviews. However, what was increased was the psychological impact. There was a feeling of **isolation** for several participants. This appeared to be for two main reasons, psychological change and physical restriction. Psychological change, as described by Terry, was due to feeling the need to

concentrate on dealing with the arthritis in his own way and therefore he stopped himself socialising.

> *"But I was sort of like, "Oh no, I don't know if I" – and a lot of it as well is, I don't know if I want to go out. I've become very….sort of iso – no – yeah probably isolated"*   Terry

The physical aspect of arthritis also meant that lifestyles had to be changed and this led to isolation imposed by the impact of their physical restrictions.

> *"Because you get quite isolated with this thing. Oh I did do in the winter when I was at my worst. You're not even er confident enough to arrange to go out, in case you're as miserable as sin anyway. Um so yeah, that was quite limiting really as people don't really understand and I won't ask for help"*   Maggie

This psychological impact continued as participants tried to remain positive but the theme of **wishful thinking** was raised as coming to terms with the diagnosis continued. Despite understanding and beginning to come to terms with a long-term condition, even the most accepting of participants hoped for a "*magic wand*", a "*cure*" or just a simple way of being able to maintain their lifestyle.

> *"And I wish there was a pill, er an injection you could have two or three times a year, but apparently you can't. It thins the skin or something, doesn't it? And again, there's other side effects, isn't there? I would like to – to be doing fitness things, such as running and, you know, exercise. That is definitely out of the question, and I'm lucky if I can walk at the moment, let alone any distance. Um and then I do get a little bit stiff afterwards, and I don't know whether that's because I haven't been able to use my joints or it's a result of this and I've just got to build it up again. But having the energy to be able to do it in the first place would be – would be a good start as well"*
>
> Terry

> *"If I knew what would take it away permanently, I would do it, whatever"*   James

There was often a psychological battle between wishful thinking of *"I – I just – I just want a little bit of me back"* (Sally) and feeling relieved at a diagnosis that was perceived as non-life threatening.

> *"And I just think, oh I know life's hard, and I know this is horrible, but surely there's a lot more that we – you know, we're not dying, it's not a terminal illness. It's a pain in the arse. And I – I do still crave my old life, and I would do anything, I literally would do anything to go back a year and be how it was. But I can't. So you've just got to get over it"*
>
> Cheryl

5.5.3   Making changes: "I'll now stand back"

These negotiations around medication choices were the beginning of a shift towards accepting and making changes. At this time point participants were beginning the process of renegotiating aspects of their lives.

Some participants **began pacing.** Like Jane, they were beginning to identify certain trigger factors and despite the difficulty in asking for help, had begun to be more assertive in stating their own needs to pace.

> *"That's right, yeah, work stress I've tried to minimise. Um in the past I would have just said, "Yeah I'll do it, I'll do it, I'll do it." Now I'm sort of saying, "No OK, I'll stand back and let somebody else take that on"*
>
> Jane

These were practical changes of pacing evident across the participants and in all areas of their life. Jacob emphasised, like Jane, pacing within the work environment.

> *"I need to think about my work, if I overdo it I just struggle to keep going for the week"*
>
> Jacob

The fluctuating nature of the arthritis caused a **rethinking** of both mental attitude and physical activities; there was a sense of participants having to reassess their day-to-day thinking and plan.

> *"I never seem to wake up and think, "Right, I've got loads of energy this morning, let's get this, this and this done," that never seems to happen anymore. It's err a case of, "What have I got to do today?" (Laughs) and try and do it that way. But er mobility-wise it's gone, any problems that way have alleviated."*   Sally

> *"Just have to take on jobs that don't need an early start, I can't use the heavy hammer you see either so have to think before I accept a job"*   Jacob

As participants continued to psychologically adjust their mind-set they talked about cognitive changes such as accepting the arthritis for the illness they perceived it to be. In fact they reasoned that as an illness it *"could be worse"* with several participants comparing it to cancer.

> *"And this has just put it all into perspective. Like I – you know, like I said, I'm not dying. I haven't been told that I've got terminal cancer or whatever and these are my last six months. I've just had to make adjustments. And it's, you know, it's not all bad"*   Cheryl

> *"I said, "Well it's not as though I've got cancer, you know, someone who has got that, you know, that is very, very serious, and you can't necessarily learn to live with that, but you can learn to live with what I've got."*   Terry

IA may necessitate changes in mind set and attitude, redefining a **new me**. During the interview the participants were asked if they could think of any positives that had arisen from having been diagnosed with arthritis, or within the changes that had happened. About two thirds of participants could not think of anything positive from having IA. However, some women believed that they had changed through the process of adapting to an illness, forming a new 'me' which incorporated being more confident in saying no and developing empathy with others. Commonly the people who used empathy with others also used downward comparisons although this was not exclusive.

> *"This is who I am now. If you don't like it then that's not my problem, jog on; I'm not making any apologies for the fact that I've got this*

illness. I'm more sympathetic to people now. I'm not so um quick to
judge."   Cheryl

"So yeah it's er – it's quite tough. But also, you know, on your other
hand you think well, you know, I am lucky, I can do a lot more than
what other people – do you know what I mean?"   Fiona

5.5.4   Influence of others: "you don't want their sympathy"

Participants talked about their own self-care strategies, which, as was the case for the time of diagnosis, often included trial and error. However this was now expanded by an acknowledgement that managing IA was influenced by others. **Support groups** were recognised at this time point as being a valuable source of information. Participants had not sought those out but were advised by their OT to attend, or they were invited to attend therapy and the support groups were automatically part of the therapy regime. The informal environment included the sharing of information within an empathic audience.

"And we sit round a table, you know, hands in the wax gloves like this.
(Laughs) And – and you swap information that way, and that's a good
thing"   Maggie

Those who experienced a group support felt the benefit of shared experience; those who did not experience it felt unsure whether it would be beneficial for them.

"Ooh no, wouldn't feel comfortable talking about this in a group,
what would I gain?"   Fiona

One man had participated in a focus group for research and was firm in his opinion of groups, not because of gender but because of his life and his perceptions of his normality.

"No it wasn't any benefit, how can they say it's the same for them, I
stood out as being different, I need to work, I'm relatively young, they
just didn't get it"   Jacob

There was a continued recognised battle with **other peoples' perceptions**. As the participants tried to control and manage the symptoms, the invisibility factor of family and work colleagues not seeing the symptoms persisted. This recurrent theme still emerged as important as participants struggled with psychological adjustment.

> *"Sometimes it's a lack of – you don't want their sympathy, you want the time, or given the consideration for that. You know, you don't want to stop because you know stopping's bad for you anyway, you've got to keep active and doing things. But you would sometimes like people to be a little bit more considerate of, you know, of the situation, especially family. And my elder son, sometimes he says to me, "Oh you're just lazy," he says, "you're not old."* Nicola

5.5.5 Disrupted normality

At the 26-week interviews participants began to acknowledge that the normality that they wanted pre-consultation would continue to be disrupted as the impact continued and as changes occurred. The unpredictability of the illness and the necessary changes (5.7.2) fluctuated as participants struggled to accept a new normality.

> *"Some days I think I'm doing OK – other days I feel old, an old man, I'm not even 50!"* Tom

> *"I need to keep some normality, I dive and I want to keep doing that for as long as I can, and as long as my hands stay as they are I'll be ok, but when they swell I worry"* Ian

The process of adjusting and adapting to achieve a sense of normality seemed to be continually changing as participants began **battling through** or starting a process of **renegotiation** through the 26-weeks. Accepting the restrictions of the illness became an individual battle for some participants, with a reluctance to give up their normal way of living and achieving things, which led to a determination to

keep battling through. Certain personality attributes started to emerge as participants demonstrated their individual ways of coping and managing.

> *"Because there's a certain amount of pig-headedness um in – in me generally that er, you know, until it gets to a point when I really am in discomfort then I'll keep trying to do things, which probably isn't a good thing"*   Terry

> *"And I do push myself through the boundaries of doing it to be independent. So I'm saying to them, yeah, I do those things, but I struggle doing those things. Do you know what I mean?"*   Fiona

> *"So well it's not – yeah, for me, it wouldn't be a matter of giving up, you know, that's – that's – that is fundamental to me really, um I am not one for giving up."*   Ian

This "battling" and stubbornness were underpinned by hope and an unrealistic desire for the illness to be temporary or easily controlled. If battling through failed or if symptoms made it unfeasible to even contemplate then a process of **re-negotiation** occurred. This can again link with making changes (5.5.3), however it is the impact of trying to re-negotiate life to make the changes that disrupts normality.

> *"Sometimes I just can't do it… I'm the main bread winner so I have to change, yet I can only do one thing – boat making is all I know, all my friends and mates live and work around here [riverside] I'll stick out [as not normal] if I can't continue, but it's my wife – I have young kids you see so I'm going more into selling rather than sailing – it's a compromise but makes all happy I suppose"*   James

The process of re-negotiation was also seen as a way of combating disrupted normality. Two participants changed the way that they cooked to enable them to continue to have friends round; one participant changed her working hours to enable her to leave work half an hour earlier so that she could continue to pick her child up from school without having to hurry when her feet were bad.

5.6 Summary

At the 26-week time point participants described how they began to recognise the symptoms in context of their activities and life. Another theme was the influence of others including support and others' perception of IA. Through further analysis this was influential with making changes to begin to live with the IA. Further disruption was linked with the physical and mental isolation imposed by the impact of their illness and the optimistic bias, or wishful thinking, which was separate but balanced on the reality of the disruption i.e. illness had disrupted their perception of normality (figure 5.3). Although there was a shift towards change, this was an ongoing process, which was based on the realisation that normality would be redefined within the individual's perception of their disease severity. As the psychological shift continued towards change and coping within both emotional and physical concepts of well-being, the participants' emphasis was focused on the importance of listening to their body. Analysis of the 52-week data will review whether after having established change at 26 weeks, people reset their normality and if this new normality is maintained or managed.

Figure 5.3 Diagram to show personal experience at 26 weeks

Personal experience

Influence of others

Support groups

Other people's perceptions

Listening to my body

Recognising symptoms

Rationalising the medication

Making Changes

Pacing

Rethinking

A New Me

Impact

Isolation

Wishful thinking

Disrupted normality
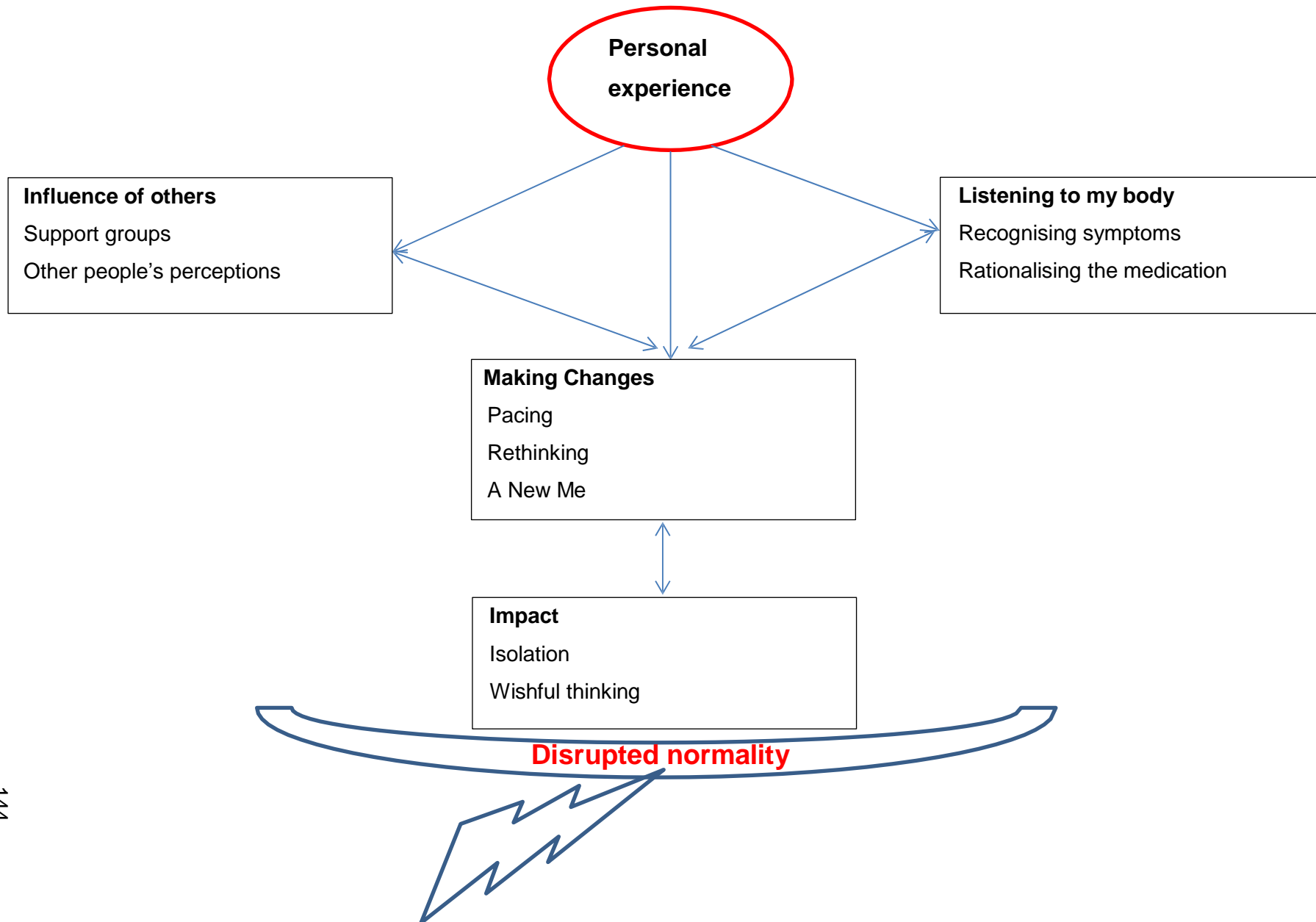
5.7   52-week interviews: Overarching themes

The next section reviews the findings at the 52-week time point. Similar themes continued; the improvement in symptoms and recognising a flare, work issues and the impact of the illness, therefore only the differences and changes are described in detail. The main change was **acceptance,** which involved the illness and around coping strategies. These included acceptance of the illness as part of life by learning to live with the symptoms and their impact and renegotiating on a day-to-day basis and in the future as the process of adjustment and adaptation continued. Table 5.4 shows the themes and subthemes across the 52 weeks.

Table 5.4: Themes and sub-themes across the 52 weeks

Pre-consultation		Consultation	26 weeks		52 weeks	
Theme	*Sub-themes*		*Theme*	*Sub-theme*	*Theme*	*Sub-theme*
Experiencing symptoms for the first time	*Pain* *Swelling* *Stiffness* *Exhaustion* *Sleep disturbance*	Hope for the future	Listening to my body	*Recognising the symptoms* *Rationalising the use of medication*	Listening to your body	*The significance of the diagnosis*
Impact	*Loss of physical function* *Changes to social life* *Emotional response*	Starting treatment	Impact	*Isolation* *Wishful thinking*	Impact	
					Acceptance	*"Getting your head round it"*
Making changes	*Making life easier* *Trial and error*	Gaining information	Making changes	*Pacing* *Rethinking things* *New me*	*Making changes*	*Battling through* *Positive renegotiation*
The stigma of being different	*Loss of independence* *Work issues* *Invisibility of symptoms*		Influence of others	*Support groups* *Other people's perceptions*	*Social support*	*Invisible symptoms* *Fluctuating support*
Wanting to be normal		Validation of symptoms	Disrupted normality	*Battling on* *Renegotiation*	*Personal normality*	*Changing pre-conceived ideas* *Coming to terms with change*

5.7.1   Listening to your body

Although this theme remains constant throughout all the interviews over the 52 weeks at this point there is a move towards an acceptance of the fluctuating nature of the symptoms. At the end of this first year participants began to understand the significance of the diagnosis given at the consultation, and the prospect that the medication which they had been managing (26 week interview) would be long-term. Even at week 52 **the significance of the diagnosis** was still as pivotal as the day that participants were told, and this was demonstrated as participants were asked to reflect back over the previous 52 weeks.

> *"My life was just – and then this, it was just like a great big – almost like a stop sign, and it was just like, "Well what do I do now? Where do I go? What do I do?" I felt like all my options had been sort of taken from me almost. I mean I've always been one of these people that I just need time to deal with things in my own time. And I always know that I'm gonna be alright, but I just need time to get there myself.   And the more somebody says to me, "Oh get on with it, get on with it," the more I sort of dig my heels in and think, "No, arseholes, I'm gonna take as long as I need to." And I think I've finally got there. I know that life is shitty and everything changes. I know that anyway. I just live for – I live for today and tomorrow"*   Fiona

Accepting their diagnosis and valuing the identity that a label can bring suggests that these participants were moving towards acceptance of their symptoms

> *"At least I can say, "Well I've got these problems," and there's a label on it, and people accept that. And that is a big, big thing, because then you don't feel like crying because everybody thinks you're lying, or you think that you're mad, there's nothing wrong with you, and you're aching, you still don't know why you're aching or why you've got these pains or why it comes and goes. Because that's another thing, even you're very aware that it comes and goes, it's not always constant……. And sometimes it comes with a vengeance and you're wiped out. And other times it's just chronic, but you can cope. But it still brings you down"*   Nicola

5.7.2 Impact

The above quote from Nicola also focuses on the impact that the IA continued to have in everyday situations. This theme continued to be recognised by each participant, from daily situations as described by Maggie to more long term impact by Ian.

> *" I still can't do what I want when, I need to think before I plan. I'm still not looking forward to the winter either as I'm less mobile now"*
>
> Maggie

> *"OK so at the moment I can still work – that's great, but sometimes I struggle to actually drive – that's a real nightmare. As long as I can dive – that's my passion, if I lost that I would struggle"* Ian

5.7.3   Acceptance

Accepting the illness was interlinked with the way participants perceived the impact of IA, how they were coping and managing, and by the symptom control.

> *"Now it's under control I feel quite comfortable with it"* Don

> *"If it [IA] stays where it is now, I can't see any problem with it"*
>
> Bob

> *"They said um straight away that it was lifetime. So I knew that there wasn't a cure. Yeah I suppose they – well they can't really say, "We'll – we'll make sure it – it levels out," 'cause it doesn't always, does it?"* Maggie

The participants were aware of the fragility of their symptom control and reliance on the medication. Even with acceptance there was still a process of coming to terms with the impact and the unfairness of the condition, as participants became more aware of the permanent nature of the situation. There was a continual movement between acceptance and disillusionment, causing a constant reframing of the situation.

"I don't know. I think I've just given myself time to accept it. It's all well and good people saying to you, "Oh, you know, it's just a – it's not gonna kill you, it's not any of this, it's just, yeah, it's a really awful illness and, yeah, it's debilitating, and all of these things but, you know, you're just gonna have to" – it's all well and good saying that to somebody, but actually being able to – some people come, I'm sure, come to terms with it a lot quicker than I have. But again I'm sure that there's people that are still years down the line of their diagnosis thinking, "Why?" Um I'd be a liar if I – you know, some days I don't think, "For Christ's sake, you know, why can't I wear high heels anymore?" And, you know, I can't run – I mean I didn't run anyway, but I can't run after the dogs or do anything like that"

<div align="right">Cheryl</div>

5.7.4   Making changes

There was a mind shift in the way that participants developed their coping mechanisms to deal with their IA. This constant behavioural adaptation and psychological adjustment fluctuated between battling on despite symptoms and the process of taking back control.

Positivity was seen as a benefit when renegotiating aspects of life that needed to be changed and adapted. However there were also certain areas of conflict where positivity caused participants to "**battle on.***"

"I am very positive in – in the fact that I can – I don't actually let anything stop me trying, you know, to do something, you know, I'm always, you know, active, and I mean to go on that way. But I don't – and I don't know, I suppose it could come back to that degree. I mean I don't – there's no guarantees with anything. So – but I don't actually um let it stop me sort of, you know, moving forward"

<div align="right">Betty</div>

Some participants started to accept that pacing themselves and planning were to be incorporated into their lives in order to maintain their personal normality and started

a process of **positive renegotiation,** where they could perceive a benefit of pacing and planning within their activities.

> *"Yeah, as long as I, you know, as soon as I start to feel a bit of a –you know, a bit of pain, or I feel tired, I think, "OK now it's time to stop." Whereas before I was in complete denial and I was pushing on and pushing on"* Sally

> *"I just carry on as normal, but I'm mindful that if I use my arm … too much, then I may get pain, so then, in a way I suppose I'm restricting or limiting the activity that I might do, so I might not be as vigorous at doing the activity, or I might erm, space it out more or … in order to do that. If I do have a pain in my shoulder then I'm erm, using nurofen as a way of controlling it, paracetamol at times"*

> Jacob

Although this dilemma between battling on and renegotiating showed internal control, there were external factors that also influenced how participants perceived and managed their illness. One constant throughout the 52 weeks was the external influences of social support; this came in both positive and negative forms.

5.7.5   Social support

Whilst the participants began to accept their symptoms they still struggled to accept the impact. Their acceptance of the situation was often better than their family or friends who perceived the symptoms as "invisible" and therefore non-existent.

> *"Well he [partner] – he just – he couldn't get his head around it all. He's just – he was a bit like my friends really, it's like, "Well there's nothing wrong with you really, why are you – why are you in bed? Why – why do you need to sleep so much? He couldn't see anything"*

> Cheryl

This perception of **invisible symptoms** by friends and family often caused **fluctuating support.** In both Cheryl and Terry's situation, the support that they received varied throughout the 12 months, fluctuating between overwhelming to none in Cheryl's case and in Terry's from none to partial. The participants perceived

that their family and friends did not consider their needs. This was a similar situation for a further 4 participants. Terry explains the dilemma about the lack of understanding;

> *"And no one does. I mean 'cause to look at me, I look fine. I know I do, I look, you know, good, pretty good for my age. And um – and it's– and I know if someone says, "Oh I don't feel well, I've got a headache," or, "I don't feel" – you can't see that pain. You'll only see it if they've got a broken arm or there's blood pouring out of a part of the body, you know, then you know. Or if they're er – got a really bad fever or – or sort of desperately ill with something like cancer, with hollow face and grey and at death's door. But a lot of people that have got pain in their joints and arms and legs, unless it's the visual type of arthritis with the big swollen, you know, fingers turning one way and the other, you can't – you can't see it"* Terry

5.7.6 Personal normality

The mind shift over the 52 weeks was a process that involved participants becoming more flexible about recognising and adapting to their illness. Being able to change developed over the 52 weeks and this included a **change in pre-conceived ideas.** It involved a re-evaluation of the participant's overall situation, often dispelling myths or pre-conceived ideas.

> *"Um 'cause I – I think so, because when I first got diagnosed I thought that was the end, (laughs) um I wouldn't, you know, be able to walk the dogs, I'll be – in a year or two I'll be in a wheelchair or something you know, with a lot less capacity to do things. And now it's really good. I think I don't really think about it much anymore"* Cheryl

Change encompassed physical and psychological shift as participants started **coming to terms with change**. The participants discussed how change was about physically managing, not just the symptoms, but also the daily impact and restrictions of their IA.

"I probably don't do very much at all, if I have got, I know that I have got to rest and that is it, so I probably don't even get to the stage now of attempting too much, only when I have got to and try and rest in- between. It's in the back of my mind, but now I think, "Well I'm going to do this," and I get on and do it.   Whereas before it'd

be, "Oh perhaps I shouldn't do that because I might not be able to"

Jacob

By 52 weeks there had been a mind shift, which encompassed emotional and psychological change as participants began to come to terms with the illness in renegotiating and learning to live within their capabilities in a new **personal normality.**

"But I do sort of feel a bit naffed off, but I'm not lying in a pit of despair anymore. I know my capabilities and my – my limits now, and I don't exceed them anymore"   Ian

"Emotionally I feel in a better place as well. That was the – that was the worst thing for me: I just couldn't get my whole head around what it had done to me. Not – not the physical sort of implications more so, but the mental and emotional, you know, what it had robbed off me. And, like I said to you before, I'd find myself, for the first time I'd felt comfortable, and I felt really content in myself, and then this happened – I'm not feeling quite so angry anymore. I'm quite – I'm not looking on it as a burden anymore, it's just something that's part of me now"   Cheryl

As the participants reasoned their diagnosis and rationalised the impact of their condition they realised while control was important at 26 weeks, by 52 weeks it had been replaced by acceptance and flexibility.

"It's just – it's just um taking it at face value and sort of saying, OK, well whatever happens, happens, and sort of being flexible with it, letting it not define you as a person, sort of move with it"   Ian

In this reflection Ian shows acceptance of the situation within his own re-defined personal normality, acknowledging the difficulty of the situation yet seeing flexibility as a pragmatic approach rather than a failure.

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Figure 5.4 is a pictorial representation of the interpretation of the interviews. At the 52 week point making changes (section 5.7.4) had moved towards a process of renegotiation, a balance between battling through and taking control. The influences appeared to be from other people (section 5.5.4) with the invisibility of symptoms continuing to impact on the level of support. The overall shift from pre-consultation to the end of the 52-week interviews appeared to be acceptance with adjusting and adaptation the processes that came in the form of the fluctuating renegotiation between taking positive control and battling through to maintain some individual normality.

Figure 5.4 Pictorial representations pre-consultation to 52 weeks

"There is light at the end of the tunnel. And don't let it get you down, because it will get better, it will improve"   Cheryl

Personal experience

Social support **Impact** **Listening to your body**

Learning to Live with IA

Battling through

making changes

Positive renegotiation

Personal Normality

Acceptance
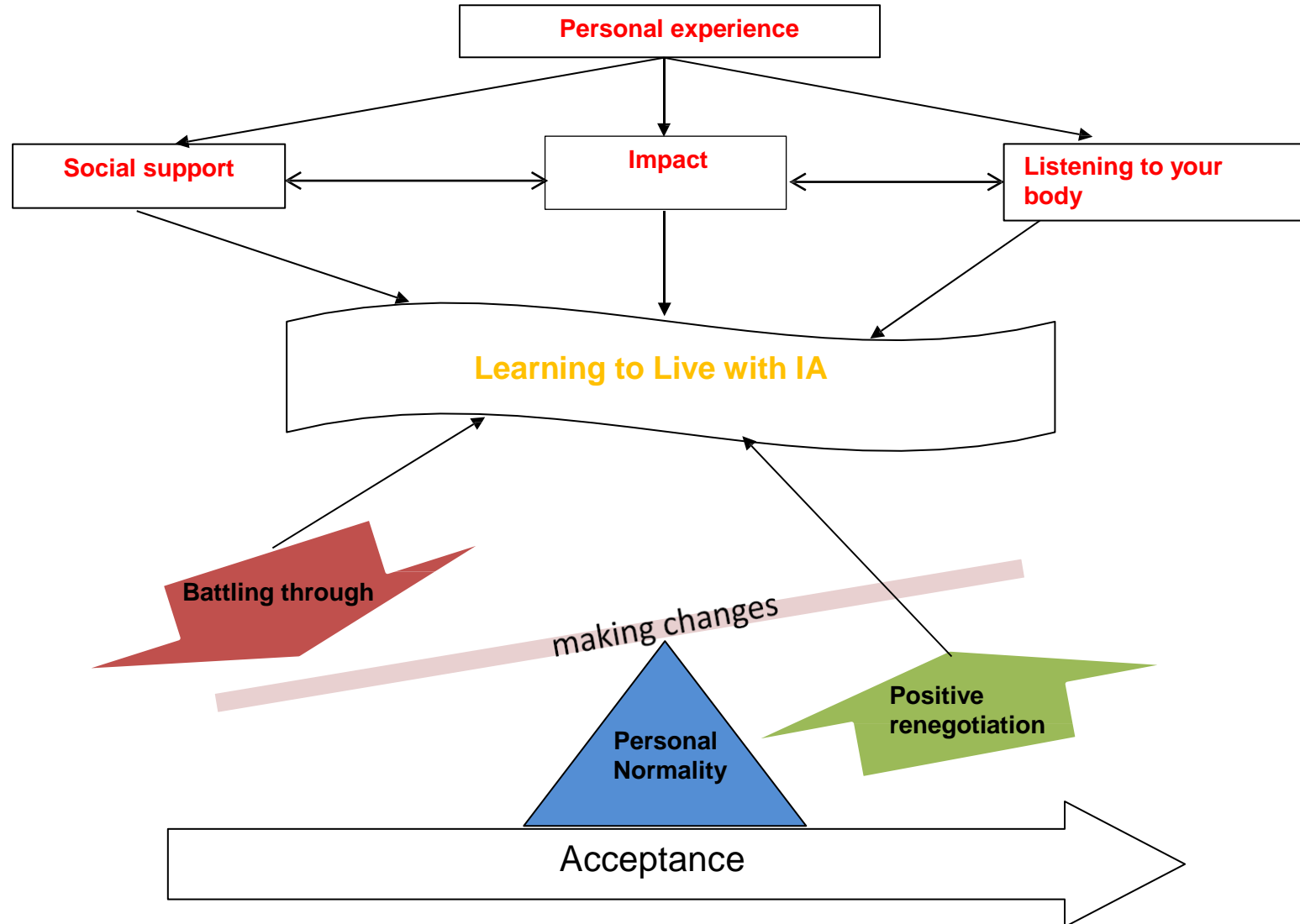
5.8 Discussion

This section will discuss the findings from the inductive analysis pre-consultation (5.8.1), then post-consultation (5.8.2), and finally to any change over the 52 weeks (5.8.3). It is impossible to explore all individual themes, so the themes chosen are those salient to the majority of the participants.

5.8.1 Pre-consultation

Symptoms were clearly depicted and described vividly, often using visual references by all participants. Insights into how participants described their symptoms and the terminology used may assist in understanding the importance the participants placed on each symptom. An example of this is fatigue. The description of exhaustion was evident throughout the interviews yet the term 'fatigue', which is now a recognised symptom, was never used. There may be several reasons for this; fatigue may be a medical term and not known as a general descriptor or more possibly a term heard and used by people with long term arthritis (Nicklin *et al.,* 2010). This impact of the symptoms was displayed in all aspects of everyday life with loss of physical function and change in social life compounded by an emotional response. Compared to those without pre-existing long term conditions, participants who already had other medical conditions were able to accept functional changes; they had already begun to reprioritise and reconceptualise their response to their joint symptoms. Awareness of this shift throughout this process may be beneficial for HCPs in guiding patients through self-management. This in turn may promote highest perceived quality of life for each individual (Brown *et al.,* 2008). The fact that some people can do this from the start is surprising, but will aid the perception of normality.

Threat to normality at this stage was recognised in loss of physical function and change in social life. Normality was a recurrent theme across all participants. Normality was recognised with negative cognitions, as if not being normal constituted failure or failings. Bury (1982) recognised disruption based on the experience of people with RA; this disruption caused people to rethink their assumptions and behaviours. In this current group of participants the disruption had caused a rethink but not yet a shift or change of behaviour. The context of normality was related to personal expectations, perception of role changes and functional "normality" such as disruption in work. In the two participants who had already experienced a shift in their perception of normal routines, these experiences could be conceptualised as "biological flow" rather than disruption, (for example Tom continued his daily lunchtime walks with his work colleagues but changed the route

to avoid hills). This is an example of biographical continuity where previous illnesses have been experienced and therefore disruption is minimised (Faircloth *et al*, 2004). Knafl and Deatrick (1986) identified a key component in the normalization process, which is to "acknowledge the impairment is present". Pre-consultation participants acknowledged and described symptoms and their effect on life and this concept of normality will be revisited at the 26 and 52-week discussion section to see if any changes occur.

The interviews were highly charged with the emotions swinging from despair to hope, from frustration to optimism. Emotional health is shown to be important across a variety of chronic illnesses at various stages with the ability to express emotions assisting adjustment (Bonanno *et al.,* 2004). Even at the early stage of the disease the way that a person responds emotionally to their symptoms and the impact on themselves and their families will determine what coping strategies they use to manage their disease. Both male and female participants, across all ages demonstrated signs of helplessness and emotional distress, which is contradictory to findings by Camacho *et al.* (2013) who suggested that helplessness was more apparent in the younger aged participants (although their median age was 57.2 years). However, in this study helplessness was related to other factors rather than age, for example social support and other people's perceptions. There was no difference in emotional distress across participants when physical ability was considered, however helplessness was associated with perceptions of pain.

The link between pain and helplessness was also found in a study by Bhat *et al.* (2010), who reviewed data from 391 participants with arthritis in two randomised controlled trials and found helplessness did not predict disability but did predict pain. This may be an important clinical issue, as if emotions are addressed early in the clinical consultation there may be a possibility of influencing the long-term adaptation and adjustment and management of symptoms. This theme will be further explored to observe changes or differences across the group in the discussion (8.4.5).

The stigma of perceiving themselves as different led to the importance of social support and other people's views. The vivid descriptions emphasised the need to be believed, either by family or medical team. There was a belief that if the diagnosis is known, the problem could be rectified, or dealt with and may be even eliminated. However this belief was not supported throughout the 52-weeks as despite a diagnosis the stigma of being different and therefore not normal continued. Active and verbal reassurance from support networks, including the team, friends and work colleagues was shown by the participants to be important but not necessarily given or positive. Self-perception is how you see yourself (Alicke, Dunning and Krueger 2013). It encompasses self-efficacy (the belief that you can do something if you want to), and

self-esteem (or self-worth). It may be based on a personal expectation but can also be influenced by upbringing and external influences, which includes other people's views and support. Supportive close relationships are important for health generally and may have more of an importance in chronic illness and therefore for the health and well-being of participants with IA (Kasle Wilhelm and Zautra*, 2008*). Problematic support can come in two forms; unrequested (or overbearing) or completely inappropriate; neither fit the needs of the person and therefore may lead to added stress or emotional discourse, which in turn have been associated with increased depression in women with established RA (Evers *et al*, 2003). The literature is sparse when looking at prospective social support needs over the first year, and it may be that support needs change depending on the disease and also depending on the path people take to adapt and adjust. This theme is examined at the 26 and 52 weeks (section 5.8.3) and also within the journeys (chapter 7), and discussed fully in chapter 8.

5.8.2 Post-consultation

The same analysis was carried out on the second interview with the same participants after the rheumatology team had seen them for the first time. The mean time was 14 days after the consultation, at which point 12 (87%) of participants had received a probable or definite diagnosis of IA, of whom 3 were waiting for confirmation from x-rays and ultrasound. Ten participants (67%) had also received treatment. The main emphasis of the second set of interviews was the consultation and its outcome. Receiving a diagnosis can be one of the many turning points in the lives of people with chronic disabilities (Radford *et al.,* 2008). Solari, in a qualitative study with MS patients, reported that all the patients they interviewed experienced the moment of diagnosis as "powerfully evocative and unforgettable" (Solari *et al.,* 2007).

Receiving a diagnosis appeared to have had a positive effect on this current group of participants and those who demonstrated higher levels of helplessness at the initial interview with "*overwhelming feelings of despair*" or emotional release "*I could cry*" seemed to take the diagnosis from a positive viewpoint. The shift in the emphasis post-consultation was one of relief of being believed (despite being given the diagnosis of a long-term condition) and being able to label the condition. The feeling of uncertainty pre-consultation shifted to one of relieving some angst. Receiving a diagnosis of a long-term condition may be a traumatic event for any individual and can have a significant impact on both the psychological and social aspects of their lives (Newman, Steed and Mulligan, 2004). Significant turning points can emerge with meaning acquired to belonging, doing, and understanding the world

within the context of self. Meaning in the context of chronic illness is as important for participants and clinicians as is the treatment of symptoms (Ironside *et al*, 2003).

In this particularly emotive time the consultation underpinned a positive message both in treatment terms and outlook. It brings about closure of the diagnosis and the start of a long-term relationship both with the illness and the specialist team. Although all clinicians provided clarity in terms of diagnosis there was not in all cases a definitive treatment plan started. In two cases the participants had to wait to see the nurse before they started their medication and a delay in this appointment (3 weeks with no treatment for one patient) led to emotional distress and frustration. However, even for those who started treatment, the establishment of medication appeared to be not as important as receiving the diagnosis. The advent of aggressive treatment of IA has led to more recent optimism within the consultation and this was portrayed to and perceived by the participants, which may be an important aspect in their journeys. Hehir *et al.* (2008) reviewed the need for nurse support at the onset of rheumatic disease, stating emotional support to be the overarching theme that underpins other needs in relation to coming to terms with the arthritis. However, this paper does not indicate the timing of these consultations in relation to the time of diagnosis and in the current study only 2 participants were given follow up by nurse specialist at the first consultation and this was described by the participants as purely to start the medication regime. All participants were complimentary about their consultation with no questions raised or unclear understanding. It may be that emotional support is needed at a later stage.

Not receiving a definite diagnosis at the first consultation was described in five post-consultation interviews; the challenge for the team is to support the participant through this time. Australian participants with CFS highlighted the enabling aspect of receiving a diagnosis; a label enabled them to understand their experiences as coherent and meaningful and they saw it as an essential precondition for coping (Woodward *et al.,* 1995). In a similar study with fibromyalgia participants (Undeland and Malterud 2007), the initial response to getting a label for their illness was relief. However, in the eyes of several of the female patients, they felt that, even after their long term diagnosis was confirmed, their condition was still not viewed as a legitimate disease by many people. Werner and Malterud (2003) showed that women demonstrated "hard work", that is they used techniques to make symptoms socially visible and physical when consulting a doctor as they struggled to maintain self-esteem and dignity. There was a recurrent theme that the participants in this current study needed to be believed, for them to get recognition from their work colleagues and families to stop them from "feeling like they were going mad".

5.8.3 26 and 52 weeks

At 26 weeks experiencing symptoms changed into *listening to the body* and *recognising the symptoms* as participants began to understand the condition and its implications. It was all about making changes and rethinking the whole concept of the condition and new me. Normality became more disrupted despite the shift in pacing and planning, which suggests that adjusting and adapting may happen by necessity and does not necessarily mean acceptance.

At week 52 the participants began to accept the symptoms and a process of negotiation began with two distinct mind sets: "battling through" and "positive renegotiation". Both mind-sets were demonstrated across all participants at different times.

Kralik (2002) talked about transition in her qualitative study that focused on participants with RA; the patients' purpose was to "create order from chaos". The study showed that the process of this transition is an ongoing iterative process that involves continual interpretation of a person's situation starting at the point of the symptoms. However the main difference in the current IA study is that the transition is a balancing between trial and error, and taking positive control (pacing and planning). This therefore suggests that there is a process occurring towards coming to terms with living with IA and the process is based on individual life context and is complex and multidimensional. This supports the qualitative findings by Taylor (2001) who explored self-care within arthritis. Although not a longitudinal study, it revealed the highly contextual nature of the way in which people learn to incorporate arthritis into their everyday life.

The data produced from the participants within this thesis have shown that when illness occurs, the impact on an individual's life requires coping responses starting at the beginning of the symptoms. The participants demonstrated a coping mechanism as "enduring," which is defined as the way the person gets through the immediate reaction with a focus of hanging on and protecting themselves. When the level of knowing about the illness is limited to awareness without full comprehension then the person enters the stage of enduring (Taylor, 2001). They then move through this process as they begin to learn to live with the illness, adjusting and adapting and adopting coping strategies in the various stages of uncertainty. The end result of learning to live with it is a form of acceptance as was the findings in this study. Acknowledging personal difficulties and working to overcome them rather than having no coping at all may occur at different times and in different ways, for example Nicola within weeks of her symptoms developed different ways of cooking to assist in activities of daily life, whilst Jacob persevered in his job until it was physically impossible for him to hold the necessary equipment then began to find

ways to assist in his work. Inventiveness is an aspect of this and a form of coping e.g. finding innovative ways to solutions (Rogers-Clark, 2002); however the first aspect is to confront the symptoms and the illness. Confronting illness is probably one of the most significant life challenges a person is likely to face (Martin-Macdonald and Rogers-Clark, 2005) and these participants have shown through their interviews an ongoing process which begins before the point of diagnosis.

5.9 Across the 12 months

This study has shown that the personal experience of each individual throughout the 12 months was primarily influenced by others, the confronting of the unpredictable nature of IA and by the realisation that learning to live with IA meant listening to the needs of the body. This led to a determining of personal normality and recognising what was important to that individual: for Ian his sailing, for Cheryl her work life balance. This renegotiating was balanced precariously on the triangle of perceived normality (figure 5.4), which changed across the 12 months from desperation to be perceived as being normal, to recognising a disruption, and finally learning to live with it by changing pre-conceived ideas of personal normality as people moved towards acceptance.

This supports the shifting perspective models of fluctuating illness (section 2.7.3) (Paterson, 2001), which depicts the experience of chronic illness as constantly changing perspectives about the disease in order for people to make sense of their illness. However, the data from this study also show that the symptoms were not the only confounding factor, but the person's experience and adaptation was affected by the influence of others across all aspects of life: social, medical and work. The participants began to mediate the physical and emotional impact through a variety of readjustment and coping strategies. The importance of normality was raised throughout the 12 months, which supports previous findings in RA, in which six different typologies of normality were highlighted (Sanderson *et al.,* 2011). Patients began to make cognitive adjustments in order to mediate the impact and reprioritise their personal normal. This included accepting and learning to live with it by making adjustments of their expectations and also making social comparisons. Social comparison is a coping strategy that is particularly useful when a person is unable to change their situation. The patients in this study used downwards comparisons, which involved comparing themselves to a less advantaged, often less fortunate patient (DeVillis *et al.*, 1990).

The combination of social support and invisibility of symptoms created barriers for participants to receive the practical, social and emotional support for

self-care making it harder for patients to attain their health and behavioural goals (Rosland and Piette, 2010). Actively engaging personal support networks of patients be it work colleague, friends or family may change this self-management environment in ways that facilitate patient success. In family goal setting programmes (Rosland and Piette, 2010) this incorporates the role of the person who is ill and their needs, allowing members to choose goals that support and enhance the person's self-efficacy. Although an American concept and with mixed results for patients with rheumatic diseases, family goal setting reinforces the importance of being valued by family members even at the early stages of the disease, and an increase in understanding may promote self-esteem.

Holtzman, Newth and Delongis (2004) found that support indirectly influenced pain by encouraging the use of particular coping strategies. Although this does not specifically concur with the findings of this study what has been shown is that social support can have both a positive or negative effect on other aspects of coming to terms with a long term condition. Invisibility of symptoms continued throughout the 12 months (*"They don't get it as they can't see it"*) and influenced social isolation (*"I can't keep up so I just don't bother"*) and negative or passive coping. Whereas if social support is adequate coping becomes proactive *"They know if I have to rest then I rest"* but *"it doesn't stop me from doing anything".* If, as suggested, by week 52 social support is still as important as in the early months and self-management goal setting is seen as a potential method of promoting self-care (Rosland and Piette, 2010), through promotion of confidence and self-belief, then early intervention should encompass support networks, as the confidence that a person has to change their behaviour is linked to self-belief. Self-belief is a term that encompasses both strategy (self-efficacy or self-confidence) and self-esteem, (Mruk, 2006).

Bandura (1986) argued that self-efficacy beliefs are important mediators in how and whether people feel in control of their lives. Self-efficacy beliefs differ from person to person, based on past interpretations and present day interaction with their environments and other people (Stretcher *et al,* 1986) and are a fundamental principle of Bandura's social cognition theory. These data reinforce the importance of interaction with support networks, and beliefs are analysed in the following chapter.

As well as redefining normality, participants also showed the need to be able to redefine self. Redefining the meaning of self by "learning to live" with an illness was determined in this study by a process of acceptance and taking control with battling through and renegotiation to feel well. Beaton *et al.* (2001), found three definitions of feeling well in her qualitative study of people with RSI (although the focus was around pain). Her participants adapted to the existence of their illness and

the impact on their lives not just by changing but by accommodating or acknowledging the symptoms as part of their lives, by a process of battling through. In this study the "accommodating" was encompassed in a process of negotiation balanced with "battling through" and underpinned by normality.

5.10   Chapter summary

The data have shown the changes in the first year of being diagnosed with a long term illness. The results show how vital longitudinal research is when assessing the needs of newly diagnosed patients and this is discussed in chapter 8. This demonstrates that during the first year these participants changed in their approach to managing their symptoms and readjusted parts of their lifestyle according to what they felt was important for maintaining their individual normality. It was a continual iterative path where participants were adapting, adjusting and renegotiating within their own individual contexts. However there were differences in the timing of the mind shift and although the end point was a form of acceptance the themes indicate the different processes between the participants.

One reason for these differences is that people may have different illness beliefs and it is these illness beliefs that may influence change. The following chapter presents data from a reanalysis of the transcripts deductively across all four time points using a framework based on illness beliefs.

Chapter 6 Deductive analysis

As part of the hybrid analysis this chapter will present the findings from the deductive analysis examining the illness beliefs of the participants at each time point across the 52 weeks. Deductive analysis will utilise a framework of illness beliefs based on the work by Moss-Morris et al. (2002) as discussed in the methods chapter 4 (section 4.8.2). Table 4.2 replicated below.

Table 6.1: Framework used for deductive analysis

Belief	Working Definition
Causal Beliefs	Person's beliefs of the cause of their illness, this could include distal causes and trigger factors. There may be more than one causal belief per person.
Coherence	Person's overarching belief about how all the parts of their illness fit together (or not) to form a coherent picture.
Consequence	Person's beliefs about personal future impact of their condition.
Control - personal	Person's beliefs about what they can do to help regulate their condition. This can be high levels of control (e.g. "there is a lot I can do") or low levels (e.g. "there is nothing I can do about it").
Control - treatment	Person's beliefs about the effectiveness of their medical treatment (both negative & positive).
Emotional Response	Person's belief about how they respond emotionally to their symptoms or illness.
Identity	Person's belief about the process of matching symptoms to an illness label.
Timeline – acute or chronic	Person's belief about whether the illness is short or long term.
Timeline – stable or fluctuating	Person's belief about the variability of the symptoms.

The results of the deductive analysis will be presented for each illness belief at each time point. Chapter 7 will combine all inductive, deductive and quantitative findings and illustrate different journeys across the 12 months, while the main discussion on the links between illness beliefs and the participants' experiences and trajectories across the 52 weeks is presented in chapter 8.

6.1 Pre–consultation

6.1.1 Causal beliefs

Causal beliefs can be either trigger factors, perceived as being immediately responsible for the initial symptoms of an illness (for example stress), or distal factors which are considered as the reason for the occurrence of an illness (for example familial traits). When participants were prompted to think about any possible reasons for their symptoms, some felt *"it just happened"* and could not elaborate. Other participants could identify trigger factors, including six participants who identified more than one. In these first interviews, before diagnosis, participants did not consider distal causal factors even when prompted.

Stress and infection were the two main trigger factors thought by the participants to have contributed to their joint pain and "flare". These were described generically and often asked as a rhetorical question, indicating that the participants were looking for confirmation.

> *"Do you think it could be through stress? We've had a lot of stress with our older daughter"*   Tom

> *"I'm kind of thinking well it's my kidneys or is it stress which caused it?"*   Betty

> *"I mean I've had various thoughts on maybe it was a reaction to err...something I got bitten to....bitten by in the tropics, em..... You never know, some treatment and it'll go."*   Terry

 Work was a recurrent causal belief and was often described alongside the impact of stress, however stress in these circumstances was described as an external physical event for example, as Nicola and James describe, stress on joints:

> *"I have to consider the fact, I started work at 14. I've been typing years, banging away at a heavy typewriter, when I was young you know they weren't like that. Lifting heavy files all my life"*   Nicola

> *"I put it all down really just to stress injuries from work, from the nature of my work"*   James

The participants who mentioned the relationship between their work and their joints all had physically demanding jobs that they had been employed in for at least 10 years.

It was difficult to ascertain whether there was an underlying element of self-blame within these particular trigger factors, such as choice of work. However, further exploration showed that even with hindsight the participants would have made the same choices regarding work.

Other personal issues were linked with trigger factors, as Cheryl demonstrates with concerns around her weight.

> *"I thought it was because I was walking everywhere and I'm on my feet all day at work. And I am more rotund shape so I'd think I'm obviously carrying extra weight that's going to have that sort of issue."*   Cheryl

Injury was a recurrent causal belief, although it may be that events such as injury could just be easier to recall than subtler trigger factors.

> *"...started where I assumed I'd hurt my knee getting out of the car. And then following on from that, where I was trying to sort of yank myself up and down the stairs, because my knee was hurting, I ended up with hurting my shoulder"*   Fiona

> *"I hurt my back, just one of those things, um went on holiday, came back, hurt my back had been at home a couple of weeks off work because I wanted it to strengthen up and then I woke up one morning and my whole body was just completely throbbing, every joint in my body was just throbbing"*   Jenny

The beliefs about causal trigger factors may be linked to participants trying to legitimise their situation, or it may be the initial stages of trying to make sense of the symptoms (coherence beliefs).

6.1.2   Coherence

> *"I didn't really - it didn't add up, but I just thought, well there's no reason for it, I can't explain it"*   Bob

During the course of the interviews as the symptoms and their implications were explored, some participants were pragmatic about their situation with the view that the symptoms were *"just another problem"* or part of *"old age".* However, some participants did try to analyse their own illness symptoms to make sense of their situation.

> *"It was over a weekend period anyway, and we were busy, we were visiting my parents, my sister was in rehab, you know, all this stuff, all tied up, stress tied up with it. So you begin to think. "OK is it in my head" Is it physical pain? Is it because of what - the emotional stuff, psychological stuff going on, is it transferring to physical? I don't know"*   Jenny

In some cases the coherence could be linked back to trigger factors, for example Nicola, who already struggled with life and work commitments from a young age, felt that her trigger factors contributed to her making sense of her symptoms.

> *"You know everything sort of came together. Which again I'm thinking, "Hmm OK you're getting too stressed here, obviously it's your body telling you to slow down"*   Nicola

Throughout the interviews there was a sense of participants preferring to wait for the medical consultation to hear from people who *"know what they're talking about"* before they made sense of what was happening. This may be because of fear of the unknown, the rationalisation that to speculate was futile (and therefore not speculating was a helpful coping mechanism), or a strong belief in the medical team, which was often the view from the retired participants. Not all participants tried to make sense of what was happening at this stage but there were 8 participants who did try to analyse their own illness and find reasons for what was happening to them.

> *"I was thinking what's the matter with me - sort of thing"*   Don

6.1.3   Consequence

Consequence beliefs were divided into beliefs about short-term future consequences, and longer-term consequences. Before diagnosis, only one person, Jacob, believed he would have a positive outcome even though he had been online to search for a diagnosis.

"But looking on the internet it indicates, if you catch it [arthritis] early enough the outcome can be quite good"   Jacob

Short term consequences were people's beliefs about the immediate future impact of their symptoms, their perception of the unpredictability of their illness (as demonstrated by Jane below) and its potential effect on their body and their day-to-day life, as evidenced by Cheryl's predictions.

"... I just want to know is it going to spread anywhere else, that's my biggest concern now, every ache and pain now I'm thinking oh no it's not coming there"   Jane

"And we walked half way up a mountain, just a slow amble and I said to him "Tomorrow I'm going to be exhausted" and I already knew that it would - this Sunday and Monday would be so bad"
                   Cheryl

People's beliefs about the longer-term consequences of their symptoms were pessimistic, using visual descriptions to paint a gloomy picture that in some cases demonstrated catastrophic thinking. These beliefs were intertwined with their beliefs about normality, their personal expectations and emotional responses. Both Nicola and Cheryl give examples of catastrophic beliefs regarding outcomes, which under current treatment regimens are relatively uncommon.

"It frightened me, I suppose, to think, Oh my goodness, you know, what's happening here? I'm going to be paralysed you know all this stuff goes through your head"   Nicola

"I guess I went through an hour of thinking, "Oh no I'm going to be in a wheelchair, I'm going to be this, I'm going to be that, I'm going to be useless"   Chery

Underpinning these pessimistic beliefs about longer term consequences was the perceived personal impact of symptoms and the disruption of future normality. These beliefs about loss and a feeling that life was over also linked back to an individual perception of low levels of control, which is discussed more fully under the personal control beliefs (section 6.1.4).

> "*This is my life. I could have like another 40 years hopefully. And I want to be able to - there's so much that I want to do and so much that I planned on doing*"   Jacob

> "*Em, I'd like to think the future's rosey, but being a realist I don't think it is. I think unless when I see the consultant next Wednesday he can pin point it and err...say well you've got a virus that's causing the problem and it will get better, em I can see a slippery road downhill but hopefully it's a long one, rather than getting worse quickly and it doesn't look rosy to be honest and that is a concern, because at the end of the day I'm only sixty*"   Terry

The fear of future consequences appeared to underpin people's actions to try and contain their illness (see control section 6.1.4) or an emotional response (section 6.1.6). Consequence beliefs were not demonstrated as stand-alone beliefs but intrinsic within other beliefs. Here, Nicola demonstrates the link between her consequence beliefs and her emotional response to these beliefs.

> "*I know that if you don't move, you won't move in the future. So I don't want to be like that, because I don't want to be a cripple*"
>   Nicola

6.1.4   Control: Personal

Personal control can be perceived as being either negative or low levels *"I've tried everything but nothing works"* (Jane) or positive or high levels of control *"I listen to my body then I rest"* (Jacob). The two areas that people seem to perceive that they had a high sense of *personal control* were exercise and pain relief. Exercise or "keeping active" was seen as a way of deterring the illness from progressing even before any medical intervention.

> "*I never fail to exercise when I can. Um because I don't want to be a cripple*"   Nicola

Exercise was also believed to be a way of controlling stiffness, enabling participants to continue to fulfil their daily routine and maintain some personal control.

> *"I do one or two moving exercises like that until I could limber myself up 'cos as the day went on they gradually eased off and got better with use. It's 'cos I've been lying in the night still that it more or less seized"*   Maggie

> *"I mean one of the things I have found that any aching in my fingers is eased considerably by doing the washing up."*   Don

Participants believed they could control symptoms by experimenting with combinations of exercise and medication to sustain normality in everyday life. Therefore even at this early stage there was an element of understanding the necessity to self-help.

> "*They're supposed to be two a day, and I sometimes try and just take one a day and I tried the other weekend not to take any and the pain I was in was unbearable*"   Sally

> *"Well I'm taking pain killers and I'm keeping as active as I can. I used to sit and my knees used to freeze into a position you know. When I got out I'd have to hobble for a while to try and warm them up again. And em... I tried Paracetamol and Ibuprofen to help"*
>   Bob

Personal control, whilst learning to live with the symptoms, was difficult but in order to maintain some normality a pragmatic approach was taken by several participants. For example Jacob's belief about personal control was that he should concentrate on managing one day at a time, rather than worry too far ahead.

> *"So, um I have to think in the short term rather than the long term, you know. Because I mean in the end of the day you know, you've got to live sort of day by day, I mean otherwise it's a long day"*
>   Jacob

Participant's cognitive appraisal of the illness fluctuated from needing control to understanding that their powers of control were limited, summed up by Tom.

"No there's not a lot I can do until I know well, what it definitely is that and see what they come back with".   Tom

This need for a diagnosis and treatment appeared paramount to achieving control.

"I need to know what's wrong so I can do something about it"

Ian

Other participants who also felt that the symptoms, which were new and unfamiliar, and trigger factors had left them feeling uncertain about their future reiterated this. The loss of control links back to coherence and without an understanding what was happening in terms of illness, perceived helplessness emerged.

"Because I'm a busy person, I'm a bit of a control person, you know with - with the things that I have to do during the day, and it just restricted me, and I couldn't do it"   Fiona

6.1.5   Control: Treatment

All participants were on medication for their symptoms at this pre-consultation interview, either self-prescribed or GP advised. Beliefs about the effect of medication were classified with the treatment control aspect of the framework. However, some participants did try and limit their medication, suggesting an element of personal control associated with treatment by medication. Participants believed, based on experience, that medication was effective in controlling symptoms, as Bob reports.

"I'm keeping on top of my anti -inflammatories today because they seem to help"   Bob

Beliefs about treatment control at the pre-consultation stage appeared to be based around the experiential success of steroids and anti-inflammatory medication; both these types of drugs are used in the early stages of inflammatory arthritis to control the symptoms and give pain relief. The majority of participants knew their medication by name and understood the reason for their medication and how to take them to gain maximum benefit. Whilst Cheryl described developing a belief that medication is good at controlling symptoms, Don described how the treatment

had not controlled his symptoms completely (but tried to dismiss his ongoing problems):

> *"I started the steroids and it - you know reduces the pain totally. When I was on the six it was brilliant I felt like a new woman…um… and then I went down to four and then I went down to two and I could feel the difference"*   Cheryl

> *"I saw the doctor he gave me the naproxen and they were the ones that did the trick…and he put me on some naproxen, which after a while did start to take some effect in that I could see the swelling going down … er although it didn't allow me to straighten out my fingers quite as much, I mean it doesn't matter because I don't do a lot that requires straight fingers…."*   Don

Participants recognised the need to take medication, as they debated risks versus benefits. Most of the participants were previously well, with no underlying medical problems before this illness, thus there was unfamiliarity with taking medication. Although participants believed that medication would bring treatment control and were desperate to have it, for some (such as Jane below) this felt like a loss of personal control, while for others (such as Terry), this was not a major issue.

> *"Just hate taking tablets – what choice do I have"*   Jane

> *"I said give me the strongest pain killers you can give without a prescription. And I don't know what they were but they worked"*
>   Terry

Participants understood that analgesics and anti-inflammatory medication could reduce symptoms such as pain. Not surprisingly, prior to diagnosis only one person mentioned that there might a need for a different type of medication.

> *"I understand it is really just that um an ibuprofen base, you know, is an anti-inflammatory but it doesn't actually combat the condition as I understand it"*   Sally

There were also beliefs about the expertise of the team and the belief that they had the answers as to how to control the illness and the symptoms.

> *"I just want to know what to do and that will happen when I see the consultant"*   Ian

> *"So I don't, I don't know. I just – I wish – I'm hoping that he'll be able to say to me on Friday, "This is what it is, and this is what we'll do,*   Sally

6.1.6   Emotional response

Emotional responses are a major contributing component to any illness. Participants described a constant battle with emotions especially relating to the impact of the illness. The theme of frustration often related to the restrictions the illness imposed on the management of everyday tasks, leading in some cases to anger.

> *"The hardest thing apart from the physical, you know side of it, is the frustration really of not being able to um just get on and do all the things I need to do."*   Ian

> *"I was angry, cross, angry because of the restrictions"*   Nicola

> *"I get really angry about that, that everyone else is still [small laugh] still living their normal lives and I'm - I'm not"*   Terry

Linked with frustration, and equally as prominent, was the emotion of *"feeling down"* or low mood, which participants attributed to the symptoms of the disease such as pain and fatigue and also to their ability to cope.

> *"When I feel exhausted with it you know and I feel really down."*
>   Fiona

> *"I would like to think quite well [coping] but someone else [wife] would probably say not... Well recently it's been getting me down since"*   Don

"I've had a lot going on so I've um I think I'm quite low at the moment and think I have been for a while, trying to cope with the pain, the discomfort "   Jenny

Several participants felt a sense of emotional fear of being trapped or isolated by their condition.

"I just felt so awful, I feel like I've lost complete control of my life I'm sort of stuck in limbo, I don't - I feel emotionally um it's been tough. I've felt really sort of isolated and um quite low"   Jane

"[Sarcasm] Yeah I'm loving this, absolutely loving it, not being able to work. You know these four walls have become like my - my prison almost."   Cheryl

The strong feelings portrayed by Jane and Cheryl above may be underpinned by a sense of fear for the future, and unspoken beliefs about consequences. These expressions of being trapped are similar to Nicola's use of the words 'paralysis' and 'cripple' in relation to her beliefs about consequences (section 6.1.3).

6.1.7   Identity

Several participants had beliefs about the identity of their symptoms and often this came from discussions with family members or friends, or from having seen other people with 'arthritis'.

"Just this one knee swells up on the side there… I thought em... Thinking about it and talking to people I thought probably rheumatoid arthritis"   Tom

"I suspected [it was arthritis] because both my parents suffer with arthritis...and my great-grandfather had rheumatoid arthritis, I suspected it could be something more than a tired knee, if you like"   Jane

The term arthritis was used to identify the joint problems, but often as a generic phrase rather than an understanding of a joint problem with an inflammatory component.

"To be honest I suspected it was arthritis, because mum had osteoarthritis and it just seemed to be at the back of my mind it could be"   Jacob

6.1.8   Timeline

In the context of illness beliefs timeline can represent beliefs about the short or long term duration of the illness (acute or chronic), or beliefs about the stable or fluctuating nature of the symptoms. There were no specific references by participants to this being a chronic condition, but by inference from their beliefs about future consequences, many probably did not think it would be acute. Several references were made to the fluctuating nature of the illness, based on experiences.

"I had a really bad week of it, then it went away for a couple of weeks, had another episode - in fact I'm on sort of the eighth day of the last week has been quite horrendous"   Jane

Some participants, such as Don, found this fluctuation difficult to make sense of, while others, such as Nicola had begun to hope during a quiet spell, that the duration might have been self-limiting (acute).

"Even now my fingers are throbbing you know and... but I this is strange because on a day to day basis it's different"   Don

"So I go through weeks of, like I say, I've had three weeks up to this last episode, of a week long and I felt relatively tired but I hadn't had so much joint pain, barely been there. Now, last week, it's been continually for nine days, well going into nine days, so and then I was thinking, you know, hadn't had it for about three and a half weeks, the actual joint pain, and I was thinking, "Oh I haven't got it," and it came back with a vengeance"   Nicola

The data presented so far demonstrate participants' beliefs prior to receiving a diagnosis. During the consultation that followed these pre-diagnosis interviews, nine of the 15 participants received a confirmed diagnosis of IA and started treatment; three were given a probable diagnosis of IA and information about starting treatment but were waiting for confirmation from x-rays and ultra sound investigations; and three participants had no definitive diagnosis at the consultation. Overall the consultation recordings show that participants were listened to, given a firm or provisional diagnosis, and positive messages about the future consequences

and control of their symptoms. Where relevant to the participant's responses or beliefs, the information from rheumatologist's consultation data are provided in order to show context. The consultation was an intervention, whatever the outcome. The following section therefore presents an analysis of the interviews held approximately 2 weeks post consultation and again at 26 and 52 weeks (using the same deductive framework) and describes the major changes over time.

6.2 Post Consultation

6.2.1   Coherence

Receiving a diagnosis helped participants have a greater sense of coherence of what was happening in terms of their joint problems. For example, for Nicola, the diagnosis made perfect sense.

> *"I had clinically proven rheumatoid arthritis, which came as a shock, but now it doesn't because adding it all up and seeing it, it just fits in with all the problems that I had."*   Nicola

In contrast, whilst the diagnosis also made coherent sense to Don, this was because he had misinterpreted the rheumatologist's diagnosis of RA. Despite the rheumatologist explaining the diagnosis was be confirmed by blood tests and x-rays, and different from the wear and tear arthritis in his knees, Don still believed this diagnosis to be part of the normal process of ageing that he need not worry about.

> *"I wasn't unduly perturbed about it, because it's the sort of thing that can happen to people as they get a little bit on in years. Er...some people get to escape these things, some people catch up with them"*
> Don

The 'official' diagnosis completed the picture and allayed fears and misconceptions about the label for several of the participants.

> *"I know that sounds really silly, but now I know what it is I'm not scared any more. I have an answer now, I know - I know what I'm dealing with"*   Cheryl

Participant's coherence beliefs were not always a positive construct at this stage when, as Jacob describes, they still did not know what the consequences were going to be.

> *"I mean I still have moments where I sit here and think, "I – I don't know really what this means for me."*   Jacob

6.2.2   Consequence

Most beliefs about consequences were still negative, even after diagnosis and information. They could be divided into external consequences, such as work issues or change in role, or internal consequences, which were symptom related. For example Cheryl was told by her rheumatologist that she had RA in an active form and that it could be controlled with medication, her belief was focused on the impact on her work situation.

> *"I was thinking, oh goodness gracious I can't give up work you know. I know I'm nearly 60, but I've got 2 more years before I'm 60, I had planned working till I was at least 62 and a half and I get the state pension"*   Cheryl

> *"And then, thinking about it I thought well if it is [IA] it's going to have a great impact on my daily life, my work, everything really, if that's what it is."*   James

Beliefs about future consequences were linked with the emotional response to the illness, with fears and worries for the future and the personal impact that the individual believed the symptoms would have on them.

> *"You know, am I going to be bed-ridden for the rest of my life because I couldn't get out of bed to get to the loo?"*   Terry

> *"I just thought, oh who's gonna look after me because I've got nobody"*   Fiona

> *"I think that one of my main concerns, or worries if you like is that I'm going to get that - the pain again, especially in my hands which again restricts what I can do"*   Ian

Even for those patients who had positive feelings (*"I'm sure it's nothing to worry about"* Tom) their beliefs about the diagnosis and the future still revealed underlying concerns regarding the successful treatment of the IA. For example Tom, whose reaction to the diagnosis was positive, was reflective about concerns.

> *"I still have a few worries about maybe the future, you know, whether or not it's all going to go to plan with the treatment. Whether it's going to be effective and whether or not I'm going to wake up one morning and you know not be able to get out of bed"*
>
> Tom

Despite beliefs about negative consequences there was a general understanding about the long term goals of the treatment mentioned in the consultation regarding the future of the illness. Don, who was told that his RA could be successfully treated by his rheumatologist reflected:

> *"The prognosis is quite good nowadays for it, much better than before"*   Don

6.2.3   Control

Beliefs about personal control focused on having a positive mental attitude. There was a shift in mental attitude from control (*"I have to stop"*) being a necessity, to a belief that control was a concept that could be used in a positive way to manage their expectations (*"If I rest now I'll be OK to take the dog out", Betty*, pre and post).

> *"But I think it's something that you …as much as you can control, you know, obviously with your own wellbeing and your own sort of positive attitude, you know."*   Fiona

> *"Right OK, now I know what I need to do, just get on with it now."*
>
> Cheryl

Positive beliefs about treatment control through medication were based on the experience of having had fast acting drugs such as steroids. Steroids, used regularly as first line treatments, instantly minimised the symptoms, producing the artificial effect of a return to normality.

"I obviously had the steroid injections and er. It's just I feel as though I'm back to normal"   Jacob

"So the steroid injection within a couple of hours I could feel vast improvement to what I was feeling… you know a lot of the pain was going and better movement straight … virtually straight away which was fantastic."   Terry

There was also depth of understanding of the second line medications, including their pharmacological effect on the body and acknowledgement of side effects.

"It reduces my immune system because it's my immune system attacking my body which is causing the arthritis so that suppresses my immune system to a more…. I'm guessing I'm more likely to catch colds and stuff like that."   Fiona

Specific details were given to the participants during their consultations, including the individual medications to aid treatment control, including name, dose and reasoning for prescribing the medication; but however complete the information, not all side effects were detailed until a reaction occurred.

"Naproxen - that was it. They were working alright but they didn't tell me that they thin the blood so much…And the side effects of them although not with everyone it tends to make you bleed, and I think it was the combined pair of those two that really got me you know. Because it was scary, I'm not kidding you"   Bob

Many participants' treatment control beliefs included not only control by medication, but also by the expertise of the rheumatology team:

"Obviously have faith in sort of - well medicine and er the experts really"   Don

6.2.4   Emotional response

Participants' emotional responses still included feelings about the restrictions, the symptoms and the diagnosis. These included fear and frustration.

"I mean I had days when I couldn't get out of bed and then I was very worried"   Cheryl

> *"Picking up stuff in me hands, then I drop it and then I get annoyed with myself"*   Betty

However, post-consultation there were now also positive emotional responses for some people, linked to improvement of symptoms including pain, fatigue and movement and therefore improvement in managing every day activities. These positive emotional responses included feelings of relief, and hope or becoming more positive about the future:

> *"I'm a lot happier now the pain's gone; I'm not so tired anymore"*
> Nicola

> *"I'm good, I'm positive because I'm feeling a lot better now"* Tom

> *"I mean I'm more positive about it now because like I said the difference between when I saw you last and the differences from when we came back from being abroad"*   Terry

These improved emotional responses were similar across most participants. An exception was one participant who at two weeks, despite aggressive symptoms, had not started her medication regime due to a delay in referral to the specialist nurses (who would have explained the medication and instigated therapy). Jane expressed feelings of hope, but these were overshadowed by anger at the delay in starting treatment:

> *"So when this medication start works and things are going to be easier then I may feel back to normal and I'm hoping for that, you know I'm really, really hoping for that. But at this stage I feel like I am so tired and I'm kind of angry at the system that from the moment I got this medication I cannot take it, three weeks. And I can understand that they are busy at the hospital because what can they do? That's how it is. I think I would be better off without seeing that [medication pack] on my table and being just angry like why cannot I start this and just have something happening, not looking at myself and taking off my wedding ring because my joint is swollen while waiting. And my knee starts and you know you feel like oh this damaged already, you don't want there because there's*

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something you want to reverse. So it just makes you feel angry a
bit."   Jane

Participants described an emotional response, which was both negative and positive as they began to come to terms with the new diagnosis, or began that journey. Cheryl was told that she had RA and felt relief. It was only at this point that she revealed she had thought she was going mad, implying that she had felt a need for validation through an official diagnosis.

"Now I know that I'm not going mad, um I'm a lot more – a lot more
positive, and my attitude's a lot more positive. It was a huge weight
just sort of lifted"   Cheryl

In contrast Fiona, who was told that she had RA by her rheumatologist, did not feel relieved but distressed, and wanted to withdraw from the world.

"It's horrible, it's horrible. You just - to be honest, you know you do
want to curl up really and just maybe have a sleep or just kind of -
you know - but I don't because I've got responsibilities"   Fiona

This negative emotional response may be because of a pre-conceived idea of the future as her mother has RA, therefore maybe linked with consequence belief. Equally it may be that Fiona is self-sufficient and reliant only on herself for finance therefore has a need to work, which links back to her first reaction to the diagnosis.

Information about the diagnosis did not change the fear of an unpredictable future and this was significant within the emotional response.

"So emotionally I think it can get tough, I think that one of my main
concerns, or worries if you like is that I'm going to get that - the pain
again, especially in my hands which again restricts what I can do"
                                                                            Betty

"My biggest worry is that I'm going back to thinking everything is OK
and then find I'm back to square one"   *Jacob*

"I was really like, "Why is this happening to me?"   *Fiona*

<u>6.2.5   Identity</u>

Beliefs about illness identity were linked with participants' emotional responses and beliefs about consequences. However, having a diagnostic label was important as a stand-alone aspect, as summed up below.

> *"So that's [getting a diagnosis] been a tremendous relief in that respect. Actually having a label to something like this and being like……..Well um, it's only a label isn't it you can do what you want with it"*   Cheryl

Cheryl had contradicted herself, as her pre-consultation beliefs were that she needed to be believed and felt that a diagnosis would help her friends and family understand the invisible symptoms.

<u>6.2.6   Timeline</u>

There was a realisation at this time point by several participants that the condition was long term, and that the idea it was simply one acute episode was no longer a possibility.

> *"I will still have rheumatoid arthritis for life,"*   Tom

> *"I'd probably given up any hope that it would be a passing condition, if you like."*   Bob

Participants' timeline beliefs about fluctuating symptoms meant that participants had to manage unpredictability; this often overlapped with emotional responses of hope for good days

> *"I'm hoping... I stay as I am now or get better because at the moment I'm quite mobile except my right ankle is a little bit painful but it's liveable up to what it was and so I'm hoping I either stay where I am or I get better"*   Jacob

> *"It's going to have its ups and downs, but I'm sort of erring more now towards, you know, more ups at the moment"*   Maggie

> *"I know that there's going to be some days where I'm just absolutely, you know, wrecked, and not going to be able to do*

anything, but there's going to be other days where I'm going to feel

OK, and I need to make the most of those days."   Nicola

6.3 Comparison of pre and post consultation findings

One participant believed his symptoms to be related to his reaction to an insect bite. Further exploration of this belief indicated that Terry had an underlying hope that if this was the causal factor then the condition could be "cured" or resolved quickly. This was dispelled at the consultation when a possible diagnosis of psoriatic arthritis was given. Post consultation, unlike the other participants he changed his belief about the cause of his symptoms from a spider bite to work. However, he still believed that the condition would resolve. This may be because of fear of the unknown, the rationalisation that to speculate was futile (and therefore not speculating was a helpful coping mechanism), or a strong belief in the medical team, (which was often the view from the retired participants).

Participants did not discuss causal beliefs for trigger factors in the post consultation interviews, possibly due to the closeness of the pre and post-consultation interviews, or lack of importance of cause, because the post-consultation interview focussed on the diagnosis and its consequences. Their beliefs about coherence changed from making no sense pre-consultation (*"there's no reason for it"*) to a sense of coherence post-consultation ("*adding it all up and seeing it, it just fits in with all the problems that I had").* Beliefs about consequences before the consultation were largely negative with vivid descriptions of the possible outcome of the disease, including a *"slippery road downhill"* and descriptions of becoming *"paralysed"* "*cripple" and "useless".* This continued post-consultation for many patients, with more concerns about personal roles and day-to-day consequences.

The emotional responses shifted following the medical consultation: the feelings of fear and isolation were replaced with more positive feelings, such as *"I'm good, I'm positive because I'm feeling a lot better now".* Improvements in disease control had a positive impact on living with the illness and a shift from *"anger"* about the unfairness to *"I'm a lot happier now the pain's gone; I'm not so tired anymore".*

There was a suggestion that participants were starting to reflect on coming to terms with a chronic illness, which was both positive and negative, in terms of diagnosis and the fluctuating nature of the disease. Timeline beliefs were different between the two sets of interviews. Prior to the consultations the data suggested the participants acknowledged the fluctuating nature of the illness, which shifted to recognising the long-term aspects of the disease during the second interview.

6.4   26-week interviews

The next section uses the framework to review the data from the 26-week interviews. As many illness beliefs were unchanged at 26 weeks, only brief summaries and any marked differences from the two earlier time points are described.

6.4.1   Causal Beliefs

Participants did not reflect on causal beliefs in these interviews apart from one participant who had changed his beliefs about the cause of his symptoms. Instead of attributing his joint problems to an insect bite as he had earlier on, Terry talked more specifically about individual painful joints and the belief that his symptoms were work related.

> *"Because I had – the joint in this thumb has been always – well not always been painful, but it's been painful for a number of years. Which was obviously probably the start of it. Or um I put it down to um, in the electrical trade, and of course many years ago there wasn't so many electrical and mechanical things around, and er you always cut your teeth on house wiring and (chopping the boxes). And the number of times you hit that with a hammer, and I put it down to that, or that was probably what gave me a problem with that thumb."*   Terry

Terry's causal beliefs had changed from a reason beyond his control (insect bite) to one that was his choice of lifestyle. There may be several reasons for this; the realisation of the chronic nature of symptoms may have made Terry look in hindsight for a more long term reason or that the illness belief around the insect bite was perceived by others (consultant and family) as irrational and therefore Terry felt he needed another reason for his illness.

6.4.2   Coherence

How participants made sense of the illness at 6 months varied between individuals. There were still participants who struggled to understand how this long-term condition occurred, linking coherence to causal beliefs and trying to make sense of the situation as a whole.

"No, it's – I mean I'm not one to particularly look at foods and things like that, but um nothing that way I can think. It's nothing sort of hormonal cycles or anything that would trigger it. No, nothing at all, it's just no rhyme or reason. Oh anything to try and make sense of it, but it's just no rhyme or reason whatsoever."   Sally

For other participants, coherence was trying to make sense of the illness within the context of their own life and how making sense of the situation needed reflection and acceptance.

"Now I know what it is I can make sense and do something about it"
                                                                                                    Ian

6.4.3   Personal control

At 6 months participants started to acknowledge that to take personal control meant that they had to adapt everyday tasks both physically in how they performed them, and also adjust to them psychologically in terms of how they viewed them. These beliefs about personal control arose from those experiences that successfully reduced the impact of symptoms.

"I think I've just had to adapt the way I do things very slightly with regards to the use of my hands to make sure that I don't if you like strain the fingers or whatever."   Don

"It's getting better. [Laughs] It's a struggle sometimes when I think, "Oh I've got to do this, I've got to do this, I want to do this, I want to get that done." Now I plan to do things over two days rather than try and do it in one. I'm just sort of dealing with the pain now, just living with it. Which is alright, you get used to it. And I know when not to push my body anymore."   Cheryl

Beliefs about personal control related to the need to listen to the body and recognise the symptoms and the fluctuation of the illness, which has been also discussed in the inductive analysis at the 26-week interview (see section 5.5).

> *"Um but when I'm feeling good, I try to move as much as I can. And when I'm feeling bad, I sit down and I don't do anything, I rest. I'm now treating it as um a bona fide um illness, that needs to be managed."*   Fiona

By adopting an element of control where possible, a positive change of attitude was noted in several participants, which illustrated the impact that illness beliefs have on each other. Cheryl described how her beliefs about personal control through resting are related to a change in attitude around the previous guilt she felt in resting, showing a shift in beliefs over 6 months:

> *"If I have bad days now, where I don't get out of my pyjamas and I just sort of lay on the sofa with the duvet, and I've got no energy, and just tired all day. But I allow for those days now, I don't sort of punish myself mentally where I'm thinking, you know, I should be doing something. I've just sort of changed my lifestyle, in a way. I try and accommodate um what's gone on with my body really."* Cheryl

The need to maintain positive control to promote positive emotional wellbeing was summed up by Jenny. After the diagnosis, like several participants, she acknowledged the need for change in the work place to reduce stress and therefore improve quality of life.

> *"And more – yeah, more positive about it, yeah, yeah. Because I mean I'm quite a controlled person anyway, you know, I need to control. And if things are out of control, then again that makes you feel emotional, an emotional wreck, I suppose yeah."*   Jenny

6.4.4 Treatment control

Beliefs about treatment control were based on experiences of treatment success over the previous 26-weeks. However, often on complex regimes, those participants with fluctuating disease and higher levels of disease severity struggled to come to terms with the medication they perceived as needed to control the disease.

"I found it [medication] extremely difficult at first, and I felt ill, I got bags under my eyes, people said I didn't look that well, and I must admit I struggled with it. But I persevered, and I took it every day. I haven't missed any day since I've been on it. When I saw consultant the other month I said to him I wanted to come off it, because I was a bit concerned and I didn't really – I still felt quite poorly from the medication and some pains from the joints, although I'd noticed swelling had gone down. So I'm beginning to notice benefits. It's taken a long time; I think I've been one of those that's taken like six months to get there. But it's happened. So I'm going to stick with the tablets, as he says, for the next couple of years. And if anything happens in the meantime then I'll face it as and when it happens. But it has made a difference to my quality of life."   Nicola

This captures the sentiments of several participants who continued to assess their beliefs about the potential benefits of the medication "*I'll do anything*" against their beliefs about the risks of side effects and the fear "*of overloading the system*".

"Diclofenac. I – I – I can't um – I've tried to go without them, but if I go – if I didn't have one yesterday, and I don't have one today, I'll be in – I will be in a lot of pain."   Terry

"But um I've been given various forms of er pain relief, which do control it, help it. Um I only take those when – when I get an episode. But rather than trying to just take them for the day I get it, I have to take them for a week or two to make sure that it's gone before coming off them again."   Sally

For some patients, when beliefs about treatment control belief were challenged by a poor outcome from medication, there was an effect on their emotional response:

"I suppose I'm terribly disappointed at having taken pills for six months and I'm not better."   Sally

6.4.5   Emotional response

Emotional response became less reactive and immediate, and more about the impact of a long-term condition.

> *"I just think, oh I know life's hard, and I know this is horrible, but surely there's a lot more that we – you know, we're not dying, it's not a terminal illness. It's a pain in the arse. And I – I do still crave my old life, and I would do anything, I literally would do anything to go back a year and be how it was. But I can't. So you've just got to get over it."*   Cheryl

> *"I'm just going to work (laughs) on the basis that everything's going to be the way it is now. You know, I'm not – I'm not really planning for the worst at all."*   Fiona

Overall there were fewer emotional responses demonstrated throughout the 26 week interviews, and those that did showed that the emotional response was not viewed in isolation but in the context of their pain or limitations.

> *"It's just a bit frustrating that you still get the pain and you still have to pace yourself."*   Jenny

> *"I get tearful, and I could cry when things happen or when I can't do something."*   Nicola

Post-consultation Jacob received an IM depomedrone injection; this had a dramatic effect on his symptoms. However, at the 26 weeks the effects had begun to wear off and this was shown in his emotional response.

> *"I – I – not depressed, depressed is the wrong word – but um I was a little bit disappointed when – when I found out what it was, because um I sort of – at the time it felt like it was going to be at that level or worse. Um I didn't think that I was going to have sort of another six months of just no symptoms at all. You know, um so, yeah, I had a bit of a – bit of a downer on that, you know, with regard to that."*   Jacob

6.4.6   Timeline – acute or chronic

Beliefs about IA as being long-term were becoming more evident at 26 weeks, and were linked to emotional responses as participants began to understand the concept of a long-term illness. The interpretation of the use of medication had a profound effect on Cheryl, who was under the impression that when she stopped the low dose steroid course (after two years) as directed by her consultant this would signify the end.

> *"Because I think one of the things, when you opened the book, it said, "It's a lifelong illness," didn't it? And I think that smacked you a little bit across the face. Because, yeah, when I went to the hospital the first time and spoke to the consultant, he sort of said to me, "Oh you'll probably be on this medication for like sort of two years." And I thought, "Oh yeah OK, in two years everything'll be fine."*   Cheryl

> *"But, you know, it's – it's like, you know, it's one of those things that's not going to get better, it's not going to go away, and I've got to learn to live with it, which I think I'm doing. But, you know, at the same time it is frustrating that you can't – you think, "I want to do that and I just – I can't."*   Maggie

6.4.7   Timeline - stable or fluctuating

Beliefs about fluctuating symptoms continued to be held by the participants but at this point several participants began to recognise warning signs, or an awareness of their body that preceded a flare of arthritis.

> *"And then, you know, then it's – I get it in my knees and my ankles and basically every joint. Um but, yeah, it's – it's not much warning, no, it's more a case of, you know, usually go to bed and think, "Oh that doesn't feel right," and by the morning* it's there."   Sally

For others the physical struggle with the fluctuating symptoms was linked with control beliefs, either personal or as Cheryl explains the continued trial and error around treatment control.

> *"Good days and bad days. The drugs still haven't stabilised. Um*
> *they keep upping my dosage, so they're not particularly happy with*
> *the way that that's progressing. Um I'm still not back at work."*
>
> Cheryl

The illness beliefs held by the participants at the 26-week interviews showed how their beliefs started to be part of the acceptance towards the diagnosis of having a long-term illness. The focus was particularly on coherence, consequences and timeline. However, within the interviews the illness beliefs became harder to distinguish as individual concepts but have become part of a complete schema and are interlinked. For example treatment and personal control beliefs were often linked with the emotional response. These blurring of boundaries will be explored in the discussion (chapter 8).

6.5   52-week interviews

At this point, all patients have had a diagnosis of IA, and multiple consultations with the rheumatology team. The main shifts in illness beliefs over the year are presented here.

6.5.1   Coherence and consequences

The framework divides the coherence and future consequences into separate beliefs as described in the literature (see chapter 4.8.2). Yet at 52 weeks the data suggest that as some participants started to understand the illness and made sense of their symptoms, the coherence and consequences beliefs were firmly interlinked. Fiona, one year after diagnosis, still doesn't have a sense of the future of her illness.

> *"I don't know where it's going and I don't … and I don't know what*
> *the outcome will be, really, and often it's good to have … to know,*
> *isn't it, you know, what's ahead, if you like, but I don't know what's*
> *ahead,"*
> Fiona

Beliefs about future consequences were specific, yet reflective, as participants re-evaluated their first year in order to reconsider their beliefs about the future. Tom talked about how his beliefs around the consequences of his IA had changed over the year, as his symptoms improved.

"When I first got diagnosed I thought that was the end, [laughs] um I wouldn't, you know, be able to walk the dogs, I'll be – in a year or two I'll be in a wheelchair or something you know, with a lot less capacity to do things. And now it's really good. I think I don't really think about it much anymore."   Tom

One year after diagnosis, many participants held positive consequence beliefs, with an emotional response of hope for the future.

"I'm hoping it stays as it is. There is light at the end of the tunnel. And don't let it get you down, because it will get better, it will improve."   Tom

"I'm hoping to go out into full-time work and start bringing some money back in, you know."   Jacob

6.5.2   Personal Control

Beliefs about personal control remained stable, balanced by the need to continue with everyday activity. There was evidence of beliefs about the need to plan in order to maintain control. These points are demonstrated by Fiona who as a single working mother was determined to fulfil her dual role, and believed that the efficacy of treatment control was down to her own decision making (personal control).

"Yesterday, I gotta admit, a couple of times I feel, "Oh shall I take some morphine?" But I've tried to steer away. It's a vicious circle. It's either um try and do – try and go through it. If I've got something to do, I've gotta go through it, yet I will work around things now. I will use the tablets to help me know, if I have a busy day then I will take extra pain medication"   Fiona

6.5.3   Emotional Response

Emotional responses were less fluctuating at 52 weeks than the previous time points, with variation between participants depending on the situation that they discussed and its individual importance. From a diagnosis perspective the emotional aspects of a long term condition indicated that there was a change as participants felt *"a lot happier"* and emotionally *"a great deal of difference"* from before, *with "I do feel a lot less angry"* shift towards positivity. Jacob demonstrated a shift from his earlier catastrophizing and depression:

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> *"Um at that time [around diagnosis] it was – it was um, well, I mean I must admit it was pretty dark thoughts going on, you know. Yeah, I thought, yeah, I couldn't live with this forever, you know. I didn't know how far it would go, but I didn't want – I – it was obviously mixed feelings, you know, I don't wanna be completely dependent on everybody, you know. I'm completely different now, yeah, yeah absolutely turned round, yeah. You know, as I say, I – I still um – I'm still aware that it can – it can actually come back.*   Jacob

Despite acknowledging the restrictions of the illness there was still an emotional improvement that had shifted to *"I'm not lying in a pit of despair anymore"* this was felt by all participants. The emotional responses had become more measured in their description. Jenny, who had previously described herself as '*can't stop crying*' (post consultation), demonstrates this.

> *"[It] does make me feel cross, rather than down. Annoyed, if you like, that there's certain things I might have to not do in the way that I want … want to do it. Yes, cross, I guess, more than anything, really."*   Jenny

6.5.4   Timeline

At one year, participants believed IA was chronic rather than acute: "*they said that it was lifetime. So I knew that there wasn't a cure.*" (Sally). The participants explored the timeline in terms of bringing *"some sort of quality of life"* by promoting positive changes to their everyday routine with a focus on thinking long term.

> *"And so everything that I do now since I've been diagnosed is focused on the best thing for me long-term. And not just short-term, it's got to be long-term."*   Maggie

Timeline – stable or fluctuating
Despite beliefs about successful treatment and personal control being stronger at one year than earlier, there were still frequent data regarding the fluctuating nature of the inflammatory arthritis. Even at one year, re-occurring flares challenged participants both physically and mentally. Sally revealed how a belief that her disease was not stable, was reinforced by a recurrence of her symptoms after some months.

"That was a – quite a bad – well I'd had lots of those sort of things [symptoms] previously, but because I hadn't had it for three or four months er, you know, it hit me hard."   Sally

The unpredictability of symptoms was still a problem. Even if participants understood the disease *"they were saying today that this is the nature of the beast"* (Jacob) and the value of medication *"had I not been on all this medication, these would have been much worse"* (Betty) the effect of a flare was profound.

"Pain is – it comes and goes more frequently, but it is more extreme when it does come. It's not chronic, it's stabbing, and it's a pain that makes you cry almost."   Fiona

"That's another thing, even you're very aware that it comes and goes, it's not always constant. And sometimes it comes with a vengeance and you're wiped out. And other times it's just chronic, but you can cope."   Nicola

From 26 weeks to 52 weeks, the data showed that as patients became accustomed to their illness their beliefs continued to alter according to their personal situation, and as the participants continued making psychological changes even at the end of the first year. The emotional responses had become more positive, fluctuating across the 52 weeks, encompassing all aspects from fear and distress (pre), relief (post), a mix of frustration and anxiety (26 weeks) to a positive mental shift at the last interview (52 weeks). The personal and treatment control beliefs became more evident, however they remained realistic within the fluctuating nature of the illness. People's beliefs about the longer-term consequences of their symptoms were pessimistic, painting a gloomy picture that in some cases demonstrated catastrophic thinking. These beliefs were intertwined with their beliefs about normality, their personal expectations and emotional responses.

6.6   Summary

The literature (section 3.6) suggests that illness beliefs are a profound influence within a person's journey towards "adaptation and adjustment". However the analysis of data shows within this group of newly diagnosed participants with IA, the illness beliefs are interdependent and are influenced by external aspects, such as social support and internal aspects such as hope or wishful thinking, which is outside the parameters of the illness beliefs. For example Jane, who

had clear coherence beliefs and a good understanding of controlled RA showed a strong emotional response as the treatment control turned out to be ineffective (page 168). Despite her hopes (page 179) she felt that her personal control was compromised due to the disease severity, particularly the profound impact of fatigue.

Don had a limited sense of coherence regarding his diagnosis, but high personal control (page 184) and thus made adaptations as necessary. Despite being hospitalised at one point due to severe side effects of the medication (page 178), he was accepting but as a retired gentleman his lifestyle demands were attainable within the constraints of his IA.

To better understand the journey toward adaptation and adjustment for individual participants, the possible links between patients' experiences and illness beliefs will be explored (Chapter 7). For example Terry's' belief regarding the timeline of the illness was different to the others, he believed in the illness being acute and curable longer than the other participants who accepted the long term (chronic) timeline earlier, thus his journey towards behavioural adaptation and psychological adjustment may be perceived as being different and influenced by his illness beliefs. The next chapter combines the inductive analysis of the participants experiences with the deductive analysis of their illness beliefs and sets these within the context of their quantitative self-reports of their symptoms, in order to understand individual journeys toward acceptance.

The overall findings will then be discussed fully in chapter 8, exploring the illness beliefs and their relationship with the findings from the inductive data and any influences on the acceptance of living with a long-term condition and impacts on adaptation and adjustments.

Chapter 7: The journeys

"Traveller, there is no path. You make the path as you walk"

Antonio Machado, *Border of a Dream*

(Cited by Fernanadez, Cortes and Tarragona, 2007)

7.1   Introduction

Chapters 5 and 6 reported an in-depth analysis of the patients' journey across the four time points – pre-consultation (0 weeks), post-consultation (2 weeks), at 26 weeks and 52 weeks. Both inductive and deductive methods were used to examine the experiences of the patients at each time point and any changes that occurred between the interviews.

Journeys, stories or descriptions often offer insight, understanding and new perspectives (Divinsky, 2007). These are metaphorical methods of description and can help people make sense of how they are coping (Doherty *et al.*, 2009). After developing symptoms (the start of the journey) people experience a road of changes to an endpoint (52 weeks). It is acknowledged that for the patients the journey will continue, however this is a metaphorical endpoint for the sake of this thesis. Often these journeys are considered a way of understanding the emotions that accompany the chronic illness (Greenhalgh and Hurtwitz, 1999). Influences on the journeys include prior experience of illness, family support or perceptions of support, life skills, coping strategies and expertise available (Doherty *et al.*, 2009), and also HCP support (Woods *et al.,* 2003).

This chapter explores the path or journey taken by each participant during the first year to determine if there are any possible common journeys that may be found within their accounts. These journeys may explore behavioural adaptation, psychological adjustment or acceptance or a combination of these. The following sections will explain how the journeys were analysed and developed and will describe the journeys found, giving examples of each journey and discussing the importance of these findings and their clinical implications.

7.2   Methods

A matrix, based on the quantitative data from the questionnaires (section 4.4.1) was used to start the initial process of mapping the journeys. In step one the data from the questionnaires were collated at each time point; changes over these time points were reviewed across each patient to evaluate any possible similarities or differences

between patient journeys (section 7.3.1). In step two, time points 0 (pre-consultation) and 52 weeks were compared as these showed the greatest change over time (section 7.3.2). In step three participants were then grouped together into potential journey types, based on any similarities in the quantitative data (section 7.3.3). In step four, the transcripts were then revisited and qualitative data examined to look for any commonalities that might explain the proposed common journey types (section 7.3.4). The results are described in detail below, following these analytical steps. However, there was overlap between the groups in some quantitative categories, for example with social support and other scores not being clearly demarcated between different proposed groups.

7.3 Results

7.3.1 Step one: Exploring the quantitative data across all time points

Examination of the patients' individual data across all four-time points (Appendix 18) showed there was a wide range of disease activity and helplessness. Patients' disease varied, with some remaining clinically stable and others fluctuating each time in pain, fatigue and global health. Perceived coping with disease generally and with fatigue in particular varied across 52 weeks, both within and between participants, irrespective of disease severity.

7.3.2 Step two: Reviewing the quantitative data at 0 and 52 weeks

In order to understand the beginning and end points of pre-diagnosis and one year, data at 0 and 52 weeks were examined for each patient (Appendix 18). This suggested that some patients exhibited an improvement in overall disease, and in levels of perceived control as shown by improved coping and reduced levels of perceived helplessness.

Some participants showed improvement in clinical status, which was sustained at 52 weeks (Bob, Don, James, Ian, Betty, Maggie); this group also had low levels of fatigue and fatigue impact. Social support varied across the participants: those who did not have a spouse or partner relied on friends, apart from Don who felt that his support was reliance on himself. Several participants showed a discrepancy between their actual versus ideal social support, for example Terry perceived that he needed a high level of positive social support at the onset of his symptoms, yet received an amount which he deemed to be too little. There was little difference across the illness beliefs as measured quantitatively. Some

participants showed a higher number of perceived reasons for developing their illness. There were also higher levels of emotional response for some patients.

7.3.3 Step three: Proposed grouping of journeys

Having reviewed the scores at the baseline and 52 week from the questionnaire data, participants were then grouped on broad similarities. Tables 7.1 –7.5 show the four proposed groupings and the mean scores for each group.

Table 7.1: Clinical scores for proposed grouping (mean)

	Group 1 (Bob, Maggie, James, Ian)				Group 2 (Jane, Fiona, Cheryl, Nicola)				Group 3 (Don, Sally, Betty, Tom, Jenny, Jacob)				Group 4 (Terry)			
Time points	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**
Pain	28.8	28.0	18.5	14.5	69.5	58.0	62.5	53.3	50.3	41.3	33.8	41.0	36.0	51.0	58.0	48.0
GHAS	21.0	21.0	16.5	11.8	56.3	53.0	50.7	46.7	56.2	52.0	33.3	34.2	54.0	55.0	56.0	37.0
Fatigue	01.8	01.8	02.5	02.5	07.0.	08.0	07.0	07.3	06.2	06.2	05.5	05.3	05.0	07.0	07.0	05.0
Fatigue effect	00.8	00.8	01.8	01.3	07.25	06.0	07.0	07.0	05.7	05.7	04.7	04.5	05.0	07.0	07.0	05.0
HAQ	00.1	00.1	00.1	00.1	01.3	01.8	01.6	01.8	01.1	01.0	00.9	00.8	01.0	01.0	01.0	01.0
RAQOL	01.1	01.0	02.0	02.0	25.3	24.0	26.5	227.	13.7	10.8	09.2	08.8	21.0	19.0	19.0	17.0

Pain and global health score (GHAS) range from 0-100 (high is bad)

Fatigue and fatigue-effect range is from 0-10 (high is bad)

HAQ score ranges from 0 (no disability) to 3 (severe disability)

RAQOL ranges from 0-30 with the lower the score the better the quality of life

Group 1 showed relatively low pain, fatigue, disability and high global health and quality of life, which remained stable over the year (Table 7.1). In contrast, group 2 showed very high pain, fatigue and disability, and low global health and quality of life, all of which improved a little over the year. Group 3 had moderate effects in all these areas. Group 4, which comprised a single patient, was different in that his pain increased as his quality of life decreased yet his perceived health status improved.

Three groups showed an improvement in clinical status with group 1 showing less disease severity and lower levels of fatigue from the outset. Group 4 showed moderate levels of pain and fatigue that varied with slight increase at the 52-week point, the fatigue and HAQ scores remained constant.

Table 7.2: Social support scores for proposed groups (mean)

n/a = participants do not have a partner or chose not to indicate a best friend.

	Group 1 (Bob, Maggie, James, Ian)				Group 2 (Jane, Fiona, Cheryl, Nicola)				Group 3 (Don, Sally, Betty, Tom, Jenny, Jacob)				Group 4 (Terry)			
Time point (weeks)	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**
Spouse/ partner																
Emotional	13.6	13.3	14.0	14.0	10.5	11.5	07.5	00.0	12.4	12.4	12.6	12.6	08.0	08.0	08.0	12.0
Ideal	13.3	13.3	14.0	14.0	08.0	13.0	12.0	12.0	13.0	13.0	12.8	12.8	13.0	13.0	14.0	13.0
Discrepancy	00.7	00.0	00.0	00.0	02.5	-01.5	-04.5	-12.0	-00.6	00.6	-00.2	-0.2	-05.0	-05.0	-05.0	-01.0
Best friend																
Emotional	n/a	n/a	n/a	n/a	09.3	11.0	10.3	11.3	12.0	12.0	12.0	12.0	11.0	11.0	11.0	12.0
Ideal	n/a	n/a	n/a	n/a	12.6	12.0	11.3	12.7	12.0	12.0	12.0	12.0	12.0	11.0	11.0	12.0
Discrepancy	n/a	n/a	n/a	n/a	-3.3	-1.0	01.0	-1.4	00.0	00.0	00.0	00.0	-1.0	00.0	00.0	00.0
Spouse/ partner																
Practical	12.6	12.6	14.0	14.0	12.5	11.5	08.0	03.0	13.2	13.2	12.8	12.8	8.0	7.0	10	10.0
Ideal	12.6	12.6	14.0	14.0	10.2	11.5	12.0	12.0	12.4	12.4	12.8	12.8	13.0	14.0	12.0	11.0
Discrepancy	00.0	00.0	00.0	00.0	02.5	00.0	-5.0	-09.0	00.8	00.8	00.0	00.0	-05.0	-07.0	-02.0	-01.0
Best friend																
Practical	n/a	n/a	n/a	n/a	12.0	10.3	13.0	13.3	10.0	10.0	10.0	10.0	14.0	12.0	14.0	13.0
Ideal	n/a	n/a	n/a	n/a	12.0	12.3	13.0	13.3	10.0	10.0	10.0	10.0	14.0	14.0	14.0	13.0
Discrepancy	n/a	n/a	n/a	n/a	0.00	-2.0	00.0	00.0	00.0	00.0	00.0	00.0	00.0	02.0	00.0	00.0

The social support questions ranged from 0-14, the higher the score the more support is perceived to be received or required

All social support scores (Table 7.2) ranged from 0-14; the discrepancy is calculated as the patients' perception of their ideal support minus the actual support received with a negative score indicating perceived insufficient support received. Not all participants completed all sections of this questionnaire; some participants for example did not rely solely on friends but other family members such as siblings or children. For clarity the results presented are those categories that the majority of participants completed: spouses/partners and best friend. Group 1 was the only group where the support was deemed appropriate and needed across all time points. Group 2 appeared to have larger discrepancies between actual and ideal emotional support. The patient in Group 4 had the largest discrepancy of all for actual versus ideal support from his spouse, both emotionally and practically.

Table 7.3: Illness beliefs for proposed groups (mean)

Time point (weeks)	Group 1 (Bob, Maggie, James, Ian)				Group 2 (Jane, Fiona, Cheryl, Nicola)				Group 3 (Don, Sally, Betty, Tom, Jenny, Jacob)				Group 4 (Terry)			
	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52
Identity	03.5	03.5	04.0	03.5	06.25	06.25	06.0	06.3	04.7	04.7	05.0	05.17	05.0	07.0	05.0	05.0
Timeline acute/chronic	20.5	22.8	25.5	26.3	26.5	24.5	25.0	26.7	21.0	24.6	25.8	25.7	24.0	23.0	23.0	24.0
Consequences	19.0	20.0	18.3	18.5	28.3	26.8	27.3	27.7	24.0	24.0	23.0	25.0	25.0	23.0	23.0	21.0
Personal Control	21.5	22.5	23.5	23.0	17.8	19.8	23	21.3	18.0	20.0	24.0	24.0	20.0	19.0	19.0	19.0
Treatment Control	18.5	19.5	19.8	21.3	19.3	19.0	17.8	18.7	16.0	19.0	20.5	20.5	15.0	16.0	13.0	13.0
Coherence	15.0	16.5	19.3	17.8	12.5	19.8	19.3	19.3	14.0	16.0	19.0	19.0	06.0	12.0	16.0	20.0
Timeline-fluctuating	13.8	13.8	13.5	14.8	16.0	16.8	17.0	17.0	17.0	17.8	16.0	17.0	20.0	16.0	16.0	16.0
Emotion	15.5	15.3	15.3	15.0	26.5	27.8	27.3	26.0	15.0	17.0	15.0	16.0	20.0	18.0	20.0	19.0

Identity is the sum of symptoms (e.g. including headache, dizziness) perceived to be rated to the illness

Timeline – 6 questions (score 6-30) High = chronic

Consequences – 5 questions (score 5-25) High = serious consequences

Personal control – 6 questions (score 6-30) High = personal control

Treatment control – 5 questions (score 5-25) High = treatment will control illness

Coherence – 5 questions (5-25) High = makes sense

Timeline (fluctuating) – 4 questions (4-20) High = fluctuating

Emotional representations – 6 questions (6-30) High = distressed

Illness beliefs are presented in Table 7.3. High scores on identity, timelines and consequences represent strongly held beliefs about the number of symptoms that are believed to be attributed to the illness, its long term and fluctuating nature, and the negative consequences. All four groups indicated their belief that this was going to be a long-term illness across the 52 weeks; with beliefs about fluctuating disease lowest in group 1. Groups 2 and 4 had the highest number of beliefs regarding the number of symptoms, with group 2 believing the greatest consequences of their illness. Emotional responses were stable in all groups but group 2 demonstrated the highest emotional responses (the higher the score, the greater the emotional impact). This remained stable across the year and did not show any signs of improvement.

High scores on the personal control, treatment control and coherence beliefs represent positive beliefs about the controllability of the illness, and personal understanding of the condition. Groups 1 and 3 showed the strongest beliefs in personal control at the pre-consultation point (0), and all groups apart from group 4 showed improvement in personal and treatment control beliefs over the year. However, group 2 showed the greatest improvement in coherence post-consultation, which was sustained across the 52 weeks.

Table 7.4: Proposed mean grouping for psychological status

	Group 1 (Bob, Maggie, James, Ian)				Group 2 (Jane, Fiona, Cheryl, Nicola)				Group 3 (Don, Sally, Betty, Tom, Jenny, Jacob)				Group 4 (Terry)			
Time point	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**
Anxiety 0-21	00.5	00.5	01.5	02.3	14.7	14.0	14.0	14.0	06.0	05.7	05.3	04.7	10.0	05.0	07.0	07.0
Depression 0-21	00.8	00.8	01.2	00.8	12.2	10.8	10.5	10.0	08.2	03.0	02.0	02.2	05.0	04.0	05.0	05.0
Helplessness 5-35	11.8	11.8	11.3	10.5	21.3	22.5	18.5	20.7	15.7	14.3	13.5	13.3	18.0	21.0	22.0	20.0
Fatigue coping 0-10	09.0	08.3	08.5	08.8	06.3	06.3	06.8	06.3	04.7	05.2	06.0	05.7	05.0	06.0	04.0	04.0

The higher the scores the greater the anxiety, depression or helplessness
Fatigue coping ranges from 0 (unable to cope) to 10 (coping well)

Table 7.5: Proposed mean grouping for coping and stages of change

Time point	Group 1 (Bob, Maggie, James, Ian)				Group 2 (Jane, Fiona, Cheryl, Nicola)				Group 3 (Don, Sally, Betty, Tom, Jenny, Jacob)				Group 4 (Terry)			
	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52
Confront	19.3	21.8	21.8	19.8	21.0	21.0	22.8	22.0	19.8	19.7	20.2	21.2	19.0	21.0	15.0	15.0
Acceptance	06.8	06.3	06.3	07.5	11.0	10.5	10.5	10.8	07.7	08.3	07.0	08.2	08.0	06.0	06.0	10.0
Avoidance	14.8	15.3	12.3	15	16.5	16.0	17.8	16.0	12.8	13.2	12.4	13.0	17.0	15.0	17.0	16.0
Stages of change																
Pre-contemplate	23.0	20.5	19.0	19.0	11.3	13.3	13.0	12.5	22.3	19.3	19.6	22.8	16.0	17.0	16.0	21.0
Contemplate	29.3	29.0	26.3	25.0	26.0	25.0	26.4	27.0	31	23.1	27.8	29.0	31.0	20.0	20.0	24.0
Action	29.3	29.0	26.0	27.5	25.0	26.0	25.4	27.0	28.4	27.6	28	29.0	31.0	31.0	31.0	28.0
Maintenance	27.0	24.0	17.3	25.3	24.0	26.0	24.3	25.4	26	27.4	28.4	28.0	29.0	28.0	28.0	22.0

Stages of change questionnaire:

Based on a five point system 1= strongly disagree to 5 = strongly agree.

The higher the score indicates how much the participant agrees with the 4 stages of change with regards to their own individual context.

Anxiety and depression (Table 7.4) in group 1 were minimal, with low levels of helplessness and high perceived coping with fatigue. Anxiety and depression improved over the year in groups 3 and 4, with group 3 showing the greater improvement. The group with the highest distress scores was group 2, which linked with clinically significant high helplessness scores and moderate fatigue coping scores. Group 1 was the only group where helplessness was minimal, group 2 showed the highest levels of helplessness across the time points with little improvement. Both groups 3 and 4 showed improvements, although the scores in group 4 remained high from a clinical perspective.

There was very little difference in the stages of change within the four groups (Table 7.5). There was little fluctuation across the 52 weeks, with group 2 scoring the highest when looking at the three categories across the 52 weeks. However, group 2 seemed to stay in the contemplation phase longer, and their use of action strategies was lower. Group 4 had lower acceptance scores and slightly higher avoidance.

Stages of change were comparable in groups 1 and 3. Group 4 spent longer in the action stage and less in maintenance stage, group 3 in the contemplation and action stage before improvement in the maintenance stage.

In summary, taking all the data together, group 1 demonstrated stable disease, with minimal disability, as measured by the HAQ. Fatigue was not classified as a major problem and they perceived that they could cope well with the level of the fatigue they were experiencing. They had adequate social support that met their emotional and practical needs with no discrepancy.

Group 2 demonstrated fluctuating disease severity across the 52 weeks, with high levels of perceived impact on their overall health and high levels of fatigue. The questionnaires showed high levels of helplessness and low quality of life. They perceived that they had received overwhelming social support indicated by a negative discrepancy between their own perceived need and high amount received, thus indicating they felt the support was over and above their requirements.

Group 3 demonstrated fluctuating disease severity across the 52 weeks, with moderate levels of perceived impact on their overall health and high levels of fatigue. The questionnaires showed high levels of helplessness and low quality of life at the first two points, which improved considerably over the 52 weeks. They had adequate social support that met their emotional and practical needs with minimal discrepancy.

Group 4, a single participant Terry, appeared to have a journey not mirrored by others. He had only moderate disease across all symptoms, yet poor perceived coping, and an indication of avoidance. His disease was recorded as constant throughout the 52 weeks with no improvement in symptoms or HAQ score. The initial measurement showed low social support was received from his spouse for both emotional and practical support, and measured high levels of discrepancy between what he wanted (ideal) and what he received (actual).

The similarities at this point in the analysis therefore appeared to be disease severity and coping scores and appeared to identify four potential journey groupings. The decision about cut-off points for range of symptoms or coping strategies that differentiated the groups were not clear cut for any single variable or patient; groupings were based on the profile of all the data for each patient. Next, to add depth and understanding, the qualitative data were explored and integrated into the proposed groupings.

7.3.4   Step four: Integrating the qualitative data

The transcripts were examined across the year for each participant, by proposed group, to review any similarities in coping strategies and experiences as described by the participants. Coping was a distinguishing feature between groups, the end point appeared the same, acceptance (figure 5.4) but the journeys were different. These findings underpinned the proposed labels for the four journey types. Importantly, these journeys appeared to be largely defined not by the journey end, but by the journey processes of coping (Table 7.6). The findings are now presented, illustrated by the qualitative data.

Table 7.6 Labels identified for the groups

	Group 1 (Bob, Maggie, James, Ian)	Group 2 (Jane, Fiona, Cheryl, Nicola)	Group 3 (Don, Sally, Betty, Tom, Jenny, Jacob)	Group 4 (Terry)
Journey descriptor	Pragmatist (flexible coping)	Emotion-focused coping	Problem-focused coping	Minimising

These journeys were separated by the patient's approach to dealing with their IA – through *pragmatism* (flexible coping), *emotion-focused coping*, *problem-focused coping* and in one case, *minimising*. It should be noted that not all journeys could be completely separated. This was particularly evident with two females in the problem-focused group (Maggie and Sally), who displayed elements of emotion-focused coping in the qualitative data by the use of support groups, indicating some elements of flexible coping. However, their motivation was to improve quality of life in practical ways, and therefore they have been placed within the problem-focused group, as that seemed more appropriate to their coping strategies. In some instances within the emotion-focused participants there were examples of problem-solving using a flexible approach, however this was prompted by the impact of their illness rather than instigated by the participants themselves.

The matrix analysis showed that there were four possible journeys, and the next section (7.4) gives a brief outline of each journey. The narratives (section 7.5) are written based on a technique by Riessman (1990) and detailed as the story of an exemplar patient for each journey. The narratives are written close to the patients' data, to keep the story poignant and in their own words. Finally the differences and similarities of the journeys are considered (section 7.6). This section looks at all four journeys validated with patient data from the transcripts and with reference to the findings of any potential influences that are common across the journeys.

7.4   Overview of the journeys

The next section presents an overview of the journeys using a thumbnail sketch of 11 participants. Section 7.5 then presents a detailed narrative for the remaining participants – who each represent a journey (Bob, Cheryl, Jacob and Terry).

7.4.1   Pragmatist (flexible coping): "Doesn't stop me from doing anything I want to do"

Pragmatists appeared to use flexible coping in order to get on with their lives as normal, and push their IA into the background. The pragmatists felt that they had appropriate social support (from their spouse) from the outset (all were married). They had rated their actual support as 13.7 out of 14 (mean) and their ideal was this

support as 13.6 out of 14. Their disease presented as moderate and all but one started on disease modifying medication at the first consultation (methotrexate). Prior to the consultation there was a need for a diagnosis and treatment but more importantly was the need to understand what was happening, and then to move on and get on with life.

Maggie

Maggie was in her late 60s. She lived alone in a large 3 bedroom detached house at the top of a very steep hill, which is significant as she felt isolated when she had a flare and a fear that she would not be able to manage the journey home if she went out. She was a retired chemistry teacher with a passion for photography, she was chair of the local photographic society and her front room table was often scattered with photos in preparation for the next exhibition. Maggie used a mix of problem-solving and emotion-focused coping, asking for help when needed. Her two sons lived away but they were in regular contact by phone, and when Maggie needed help for example to clear the loft, they would come home. She attended a physiotherapy group at her request to strength help strengthen her knees, she used the techniques learnt, including exercises and heat therapy regularly to help maintain stability and reduce pain as needed. Her other enjoyment in life was her badminton group, comprising retired people who would meet weekly to play and then have lunch. She had not been to the group since problems with her hands started, however as the year progressed and the IA become under more control she returned and felt her life, although slower, was back to her own defined normality.

James

James was 49, lived with his wife and very young children (3 and 18 months) on a large canal boat. The interviews were conducted often with one child in a push chair, and always on neutral territory away from his home. His wife worked part time and they managed child care between them. Although a carpenter by trade his main craft involved boat building and taking people on sailing trips. His initial fear was both for his business and for the fact that he would not be physically able to maintain a relationship with his children, for example take them to the park or swimming. His IA was controlled by medication and throughout the 12 months it had little impact on his life-style. He asked for help when needed from his boat yard colleagues to maintain his business using problem-solving techniques. At the 6 month point he had just returned to this country from collecting a Danish boat that he was going to renovate, he had put this on hold until his IA was controlled and although the impact of IA was

minimal at this point he had changed his plan for renovation to incorporate help from others and an increased time line.

<u>Ian</u>

Ian lived alone in a modern house in a small town. He was divorced with two daughters, both of whom had completed degrees and were working and self-sufficient. He had a girlfriend who was supportive but anxious so he kept many of his symptoms from her. He was 52 and worked as an IT consultant for schools. He was away for the majority of the week working long hours but his main passion was deep-water diving, which he continued to do assisted by the medication when he felt it was required. He asked for support from his partner occasionally but felt that the IA had little impact on his life and continued to live without interruptions and few allowances made for his IA.

7.4.2   Emotion-focused coping: "I feel like I've lost complete control of my life"

Emotion-focused fighters tended to use emotional coping strategies in learning to live with their illness. These patients had moderate fluctuating disease and fought to be believed. They received high levels of family support at the outset, which they perceived as being above their ideal; this was then withdrawn post-consultation to below the level that was felt to be needed. The participants felt that this was because there was a perception from family and friends that now a diagnosis was made social support was no longer needed, and that the diagnosis itself should in some way enhance personal coping skills. This group used a range of emotionally-focused coping mechanisms including accepting support from the medical team, emotional disclosure and disengagement. Their moods showed signs of initial anxiety (mean scores 14.7), which continued throughout the 52 weeks, (mean scores 14) and moderate levels of depression during the first 26 weeks (mean scores 11.5). The helplessness scores remained high across the 52 weeks from 21.3 pre-consultation to 20.7 at 52-week interviews. The changes in the 52 weeks appeared to be an emotional shift as the patients continue to cognitively reappraise their illness.

<u>Jane</u>

Jane was a very articulate 34 year old. She was of mixed descent and had travelled extensively before settling in the UK with her husband, whom she met while she was travelling. Jane could speak four languages and her small lounge was floor to ceiling with books, mainly factual and several in different languages. She lived in a

maisonette in an old tenement building with her two year old daughter. She had a supportive friend network who she had met through parenting classes and often used them to help her emotionally and well as practically. Jane worked almost full-time in an export agency, she was always supported by her boss in terms of time off from work for appointments. She was in regular telephone contact with her parents although admitted that these calls were often difficult as she felt they did not give her any emotional support or very much empathy. Her husband lived away for great lengths of the time away as he was doing his PhD and they did not have the financial resources for him to return home often. Jane felt that the quicker he could achieve this the better for them as a family. She was often in tears with the lack of support and justified that she could not tell him about her emotions as it was unfair as he was away. In fact Jane moved up to be with him before the end of the study. She relied on the team for emotional support and found the situation hard to come to terms with. Her problem solving techniques were minimal, often forced on her due to symptoms rather than by active choice.

Fiona

Fiona lived in a three bedroomed council house, with steep steps leading down to the front door. Fiona was currently on sick leave and had been for a while, this was due to other neurological conditions. Fiona was divorced and not in contact with her ex-husband. She had two children, a boy who was 10 and a girl who was 18. Fiona enjoyed her time helping others and often talked about her role as a carer to other neighbours. During the 12 months of this study, Fiona had a lot of physical changes in her life. Her neurological condition worsened and she no longer did any informal caring herself, she underwent a hip replacement and a hernia repair, her daughter gave birth to a baby girl, gave up her job and moved back home, and her son came under the radar of social services. Her moods and ability fluctuated during each visit. She was thrilled to become a grandparent and became involved in the care of the baby. She continually accessed support from the GP and social team and also needed support from the nursing team regularly, however did not always respond to their suggestions. She relied on her daughter for emotional support and was very open with her emotions particularly expressing anger and despair. Fiona tried the educational programme and also attended an individual session on coping, she rejected the problem solving techniques offered in favour of reducing her activities.

Nicola

Nicola was a 58 year old woman, who was working as a secretary. She lived alone having been divorced some years earlier. Nicola had two sons who both lived within an hour's drive of her home. Her relationship with them appeared mixed. Her youngest son was supportive and where able he would help out both practically and emotionally by talking. The eldest, who was married and had young children very rarely visited his mother, but would expect her to visit them on a regular basis and babysit. Nicola felt he had no insight into the fact that she was ill and felt that she should have more emotional support from her sons. Nicola worked full-time, leaving home by bus at 7 in the morning and returning home 12 hours later. She was concerned about the future and anxious to continue working full time until she could retire and her anxiety was constant throughout the 12 months. Although she started to change certain aspects around her working hours, her response was to seek out others for social and emotional support. She became a regular attender of the local RA group, attended the OT sessions in her local hospital and became reliant on the contact of the regular rheumatology follow-up appointments.

7.4.3   Problem-focused coping: "I have to pace myself, I don't like it but…."

Problem-focused fighters and their families appeared to use problem-solving coping strategies, for example using medication appropriately and seeking out information. The participants' aims at the initial consultation were to seek answers and appropriate treatment in order to re-adopt their normal lifestyle, in particular their work. They struggled with role changes but as the journey progressed took charge and became more positive about life generally.

Don

Don was in his late 60s and lived alone in a terraced house in a block of houses previously owned by the council. He was a retired mechanic who had pursued this as a hobby, renovating old classic cars, only recently being stopped by the pain in his knees. He owned two classic cars which he would still take to shows. He was divorced and talked about his ex-wife, they were still in contact but not reliant on each other for care or support. His second wife had died. His family support came from his nieces (aged 11 to 30s), who all lived locally. His youngest niece was diagnosed with juvenile chronic arthritis when she was 10 and he always appreciated how lucky he was in health because of this. He spoke often of the children and his walls and shelves were covered with photographs. He became pro-active in his management of

his arthritis, and by the second visit an exercise bike had become ensconced in his lounge to promote activity to help strengthen his muscles so that he could return to his car maintenance. He also changed the layout of his garage to enable him to continue with his hobby, however he recognised the need for manual assistance when moving engines.

Betty

Betty was 70 when she was diagnosed. She was an ex-nurse and had experience of the NHS both as a professional and as a service user having recently lost her son to leukemia. She lived at home with her elderly husband and their dog. She had three other children and several grandchildren in close proximity to her country bungalow. She had made some specific alterations to her life to help reduce pain. For example, her husband would take the dog out in the morning when she felt stiff and she would do the afternoon walks. Betty also felt that driving had become a hazard so she would now make other arrangements, for example asking one of the grand-children or taking a taxi.

Sally

Sally lived with her husband and 3 year old son in a modern 3-bedroom house, which on the first visit was in the process of having major re-work on the external features. She had already taken sick-leave from her job as a maître d' at a local Italian restaurant. This appeared to be due to the fatigue caused by her IA. She was well supported by her husband and his family, who lived locally, and her son had just started pre-school which had helped in daily life. Her son was born after many years of difficulty in conceiving so Sally throughout the 12 months made very practical changes to accommodate her symptoms but put her son first. She resigned from the restaurant and when her son was at pre-school started work on her internet based business. Throughout the 12 months she constantly listened to her body and used problem solving techniques to maintain a lifestyle that she felt was conducive to maintaining a good quality of life.

Tom

Tom was a 40-year old man who lived with his wife, teenage daughter and several animals, including 3 dogs, chickens and a cat. During the year he also spoke of another daughter who lived away from home with a baby, who was going through a court case with regards to custody, which often added to Tom and his wife's' angst and stress. Tom lived in an end of terrace house on the edge of a small town. He was

keen on renovating and always had a "project" ongoing at each home visit. He was determined and independent although acknowledged that sometimes things would take him longer than before. He worked as an engineer. His work colleagues were supportive but he received mixed messages from management. Although he did not change his job, he changed his work role to reduce the amount of driving. This reduced some of the enjoyment of the job, but Tom felt that this change enabled him to continue working full-time.

<u>Jenny</u>

Jenny was a 52 year old school liaison officer. She lived in a 3-bedroom semi-detached on a small estate with her husband and two sons. Jenny worked full-time however, did reduce her hours of work throughout the twelve months to a more manageable level, although she acknowledged that for her this meant just working the hours she was paid for. External stressors for Jenny came from her extended family: her sister was an alcoholic and this often put pressure on Jenny in terms of supporting her mother and her sister. Jenny and her family made practical changes. Her son would go shopping with her as he was learning to drive so it became a solution that benefited both of them without disrupting their routine. The family changed their diet to support Jenny with losing weight and one or both sons would go swimming with her on a regular basis. All members seemed to turn something potentially negative into something positive.

7.4.4   Minimising: "I'm fine thanks"

This was a single participant, Terry, whose detailed journey is presented as an exemplar (7.5). In summary his coping strategy was to minimise the impact of IA. Social support was not forthcoming in the initial 26 weeks. Frustration due to physical restrictions caused moderate levels of anxiety and helplessness. Major lifestyle changes were evident and the personal focus was around normality. Throughout all the interviews continual downward comparisons were made with people he perceived as worse off than himself; (i.e. he minimized his own problems). Acceptance of the condition was spoken about in rationalising the decision not to start second line treatment, although appropriate use of anti-inflammatory medication was seen as acceptable. By the end of the twelve months the patient had been lost to clinical follow-up and had disengaged with the medical team.

7.5   Exemplars

On analysis the clusters of the participants into four possible journeys, using quantitative and qualitative data, appeared to be defined by coping style. The next section uses four individual patient journeys to explain how these trajectories can be clarified by the explanation that the participants gave at the time of their interviews. The words and phrases used in writing these narratives have been kept as close as possible to participants' interview data, but these are not reported verbatim.

7.5.1   Journey 1 - Pragmatist exemplar: "Doesn't stop me from doing anything I want to do"

The pragmatist's journey is one of flexible coping, in order to get on with their lives as normal. The exemplar journey chosen is Bob.

Bob's background:

Bob lived with his wife in a comfortable one-bedroom apartment in a purpose built retirement complex, which they had moved to prior to Bob having any symptoms. He had taken early retirement from the forces some years before first noticing his symptoms. He had two grown up daughters, both settled and living away from the area. The initial phone call with the researcher was curt and short; however on meeting both he and his wife were welcoming. His wife was present throughout the interviews, although did not contribute.

Bob's journey:

Bob's journey started with swelling in his right hand that seemed to come on fairly quickly over the space of a couple of days and he soon realised that he was unable to straighten out his fingers. He was quick to seek out a medical consultation and saw a locum GP at his practice who prescribed an anti-inflammatory medication, which initially helped with the swelling, but the straightening of the fingers remained a problem. He found that warm water helped his hands and washing the dishes in the mornings became a new daily routine.

At the end of the course of treatment he revisited the GP practice and saw his own GP who felt that a second opinion was needed. He was referred to a musculoskeletal specialist in the community who after taking some x-rays referred him on again to the hospital consultant. By this time both hands and wrists were affected with pain, swelling and morning stiffness. Bob had no idea what could be wrong with him prior to his hospital appointment.

He saw a registrar at the hospital, who explained the diagnosis of rheumatoid arthritis to him. He was given a steroid injection by the nurse and started on Methotrexate. Bob described the reason for using Methotrexate was to ease the symptoms and understood that the monthly blood tests required were to monitor

the red corpuscles and liver. He was also given some written information on Methotrexate and Sulphasalazine (just in case the first medication failed), although he was unsure where he had placed them at the time of the interview.

The diagnosis was just a name; he felt that these things just happen to people in later life and was not unduly perturbed. He was confident that the medication would allow him to lead a normal life, although he hoped that the medication would work first time and he would not get any worse. He saw the physiotherapist, who gave him a list of exercises to do at home: the grip exercises he continued with as he saw the benefit, and the upper arm exercises he tended to ignore. Even in these early stages he made changes, including a bigger car to enable him to get in and out with greater ease as the doors opened wider and devices to open jar lids. He also saw the occupational therapist who showed him exercises to keep his hands flexible.

The sixth month stage of the journey showed an improvement in the control of symptoms, and in fact Bob had been given an extended out-patient appointment for 26 weeks, with the understanding that he could ask for an earlier appointment if he felt his symptoms were beginning to deteriorate, and he was happy to ask for help if he felt he needed it. Bob felt at this stage that although he had accepted the fact that he had to live with IA, he was not going to let it stop him from doing anything and had booked a holiday. He spoke about being happy to cope with it and could not see any reason why he should avoid anything.

The following six months showed little change in his physical condition and no changes in his medication. He was still using his play-dough to keep his fingers flexible, and continued to wash-up in the mornings to ease the stiffness. He asked for help if he felt he needed it and felt supported appropriately. Bob described himself as being comfortable with both his illness and his situation, with no swelling and no pain, just stiffness in the hands. He felt that he had changed small things to make life easier and sometimes had to consciously stop and think about how to do things, such as opening jars or bottles, but overall he was back to normal with little impact on his life.

<u>7.5.2   Journey 2 – Emotion-focused coping: "I feel like I've lost complete control of my life"</u>

The emotion-focused fighter's journey is one of emotion-focused problem solving. The exemplar journey chosen was Cheryl.

Cheryl's background:

Cheryl was an outgoing 40 year-old, who lived with her two teenage children in a terraced house on a new housing estate. She had been divorced for a couple of years, and although the divorce was initially acrimonious, she was now on good terms with her ex-husband and in-laws. She had a new partner and prior to the symptoms felt good about herself. She had worked on a delicatessen counter at a local supermarket, which prior to her symptoms she would walk to and from, as she had no transport of her own. She had since signed herself off work.

Cheryl's journey:

Cheryl's first symptoms began in her feet; she made excuses for the pain, blaming herself (weight) and her shoes. It was not until the pain affected her wrists, with a sharp stabbing feeling that prevented her from doing her job properly, that she sought medical advice. Her GP misdiagnosed her as having carpal tunnel syndrome, gave her painkillers and signed her off sick for two weeks. The pain did not get easier despite the use of anti-inflammatory gels so she returned to the GP. The pain was overtaken by sheer exhaustion. After being told that her pains were psychosomatic and after a several further visits to the GP Cheryl was finally referred for blood tests. Although she was unsure of the results she was called by the GP to say her markers were raised and that she needed to be seen that day. This return visit to the GP (a different GP to the one that phoned) resulted in no changes; in fact she was told that she was coping well with just painkillers.

This was the start of Cheryl's fight to be believed. Even leading up to the rheumatology consultation her thoughts were that she needed to be believed, for someone to tell her that she had something wrong with her. Her friends could not

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understand why Cheryl, whom they considered the life and soul of their social life, was unable to get dressed in the mornings. The physical aspects of her new illness, such as getting her legs into her knickers were obviously a problem, yet it was not just the physical aspects that were an issue but also the psychosocial effects of the illness. Cheryl felt it was like being stuck in limbo, the not knowing and not being able to understand the emotional impact of the IA. This gave her the feeling of complete loss of control that also profoundly affected her. Her new partner became her carer and her friends distanced themselves.

Post-consultation, the diagnosis came with a mix of emotions. The positive was that she was believed, that her illness had been validated. However, this was coupled with frustration because now that she had a diagnosis, her friends and partner felt she should be able to cope. There was also anger at having a long-term condition, a resentment of "Why me"? The perception of the lack of understanding from work, family and friends led to an emotionally confusing and frustrating time for Cheryl. Having received a diagnosis the partner felt that Cheryl should cope in a certain way, the relationship disintegrated and ended before the 26 weeks interview.

The good days and bad days continued, and with the dosage of methotrexate increased to try and control the disease there were more good days. The chores were divided between Cheryl and her children, although Cheryl admitted to not doing much compared with before; she remained on sick leave and had mentally changed to reprioritising her day. She still needed regular clinic follow-ups and admitted to feeling lost without them for support. For Cheryl the contact with the rheumatology team reaffirmed her illness, and fulfilled her need to be believed. She described the change in saying goodbye to the old Cheryl and coming to terms with the new one, and found the emotional adjustment harder to accept than the physical side. Cheryl felt repeatedly as though she had given so much that there was no more to give, she was exhausted, physically wiped out, but her mind continued to race, to over think, the emotional symptoms and the mental challenges were harder to accept than the physical symptoms. At 52 weeks and on combination therapy Cheryl felt in a better place. The biggest change was that she

just concentrated mentally on the things worth caring about, refusing to become stressed about the changes in her life. Her employers had dismissed her on medical grounds and the relief Cheryl described was immediate, the decision had been made for her. Cheryl felt more normal than before, with the fear of being isolated and dependent lessening as time went on. The feelings of guilt and helplessness and her feeling that life had stopped had been replaced with living for today and tomorrow.

7.5.3   Journey 3 - Problem-focused coping: "I have to pace myself, I don't like it but…"

The problem-solving coping is one of problem-solving, in order to get on with their lives as normal. The exemplar journey chosen is Jacob.

Jacob's background:

Jacob was a quietly spoken 40-year-old man; he lived with his wife, and a daughter who attended the local primary school. They lived in an old suburban terraced house. He had always worked as a carpenter and was presently taking time off as he found it impossible to hold his tools in a safe manner. His wife was supportive and practical, and had already at the first meeting changed their diet to try and resolve some of his joint problems. He and his family had recently made plans to emigrate to Australia.

Jacob's journey:

Jacob's problems began with his feet, an achy nagging feeling which he attributed to having been working on a job which involved laying floorboards and therefore he was crouching and tiptoeing all day. This was accompanied at a later time with discomfort in the wrists followed by the shoulders, never painful enough to seek medical help, and as Jacob was self-employed he had the flexibility of finishing work early or taking the odd day off. The pain increased and Jacob sought the use of anti-inflammatory tablets, this was swiftly accompanied by an episode of fever and general malaise. Determined not to cancel his holiday to Australia he persevered with tablets and went on his holiday. While he was away he describes having problems with his knees and feet (pain and swelling); this time Jacob could not think of any reasons for the joints to have become a problem.

On return to the UK he made an appointment with his GP who referred him to a podiatrist, took blood and when he enquired he was told that there was no connection between his feet and his hands. When the blood results came back

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Jacob was prescribed an anti-inflammatory and was referred to a rheumatologist. Before his referral he had already typed his symptoms into the Internet yet the results of this search and the finding of a potential (correct) diagnosis did not demoralise him as much as the impact of the illness. Struggling to walk and the lack of work had an impact on Jacob's perception of the change of his role within the home, as he perceived himself as the main wage earner. The pain and sleepless nights became entwined and even in these early stages Jacob had started using his medication appropriately to try and manage the pain and sleeplessness. This impact went hand in hand with the emotional frustration of not being able to get on with things and the guilt that his wife had to take on different roles and responsibilities. His wife was supportive and had already started being proactive in trying to remedy the situation by changing his diet based on a book she had bought about curing arthritis. Jacob's expectations of the consultation were that he wanted to find out as much as he could, and although he had a hope that he would be told it would burn itself out, he balanced this belief with a perception that he would need to start medication.

The consultant gave Jacob a definitive diagnosis, which he expected, removed fluid from his knees and injected steroid. Overall Jacob felt it was a positive outcome, given that the doctor was so reassuring and that he felt so much better. His pain had reduced, his hands had settled, his walking improved; all he had at this time was a little immobility in his fingers. He had also developed a routine that enabled him to manage the arthritis: after taking an anti-inflammatory he would get up and take his daughter to school, have the day for jobs and then return to collect his daughter. He worked within his physical abilities and became the main carer for his daughter, this he felt would continue into the summer holidays.

The weeks following the diagnosis showed that Jacob developed problem-solving skills, pacing and planning to suit his needs at the time. His mother died so he spent time renovating her house. He felt lucky that his wife continued in her job and was supportive and optimistic about the future, and although his plans to emigrate were on hold they remained firmly rooted in the back of his mind as a future possibility. He saw positives in the fact that he could spend more time with

his daughter, although financially he felt at a disadvantage. Eager to demonstrate improvement in his grip Jacob had painted a portrait of his parents. He continued on his Methotrexate, and used his anti-inflammatory as he needed; he had used the helpline telephone number once to discuss some tingling in his hands. He discussed his flares and fluctuating disease and his methods of problem solving, occasionally launching into a "gung-ho approach" for some things but then becoming aware of his body. His wife remained on his side throughout occasionally prompting him not to overdo things, but as Jacob succinctly put it "I know me own body".

7.5.4 Journey 4 – Minimising: "I'm fine thanks"

The minimiser's journey is one of reducing the impact of his symptoms and rationalising disease by minimising the symptoms and declining medication. The exemplar journey is Terry.

Terry's background:

Terry was a gentleman who was approaching his sixties. At his first interview he was living with his in-laws as he and his wife had just returned from living abroad. He had one son who at this time was away at university but returned at various times during the 12 months. They moved into their own home just before the 26 weeks interview. He was currently not working; his trade was as an electrician. His wife appeared briefly during the first interview and seemed from her comments to Terry not to understand the impact of the symptoms as she made reference to his change in moods and lack of desire and inability to work as before.

Terry's journey:

Terry was living abroad when the first symptoms started; the symptoms were severe causing a huge disturbance and impact on his life, such as getting out of bed in the mornings and getting on and off the toilet. He blamed his symptoms initially on a spider bite but this changed along the year. His hands and knees swelled without warning and despite being in pain it was two weeks before he visited a doctor, when he had reached the point of not being able to do anything, not even get out of bed. He was anxious to pinpoint the reason behind his symptoms and was hopeful that the consultation would lead to a cure or control so that he could return to work.

Emotionally he struggled; weekends away with friends became an unbearable situation as he grappled with not feeling normal. His wife interrupted his initial interview. Her comments appeared to suggest a lack of understanding and lack of communication, with frustration on both sides and her embarrassment

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about his condition. Terry had good expressive phrases to describe his symptoms and his frustration came from the lack of awareness of others and his desperation to maintain normality. His outlook initially was contradictory, with hope for a cure yet pessimism about the rocky road ahead.

After the initial consultation he was still waiting for a confirmed diagnosis as more information was needed from the ultrasound scan, but arthritis was mentioned as was the word psoriasis, and the consultant was certain the two symptoms were linked. No medication was started initially but Terry confidently alluded to the fact that he felt better both in his mood and in his joints. There were continued contradictions during the interviews with Terry feeling frustrated at the role changes, lack of physical ability and worry about the future; but at the same time "feeling better" and hoping for a cure, frequently comparing his situation to those he felt were worse off, saying "at least it's not cancer".

By the sixth month Terry had received two steroid injections, one locally into his shoulder and the other intramuscularly (systemic treatment). He described the result as "dramatic"; he was able to get up and do more, was thinking more positively about the future, even considering going back to work both for the financial side and also the social interaction. He was eager to show his hands, the improvement in his grip and reduction in swelling. He referred to being normal again in all contexts, from having a bath to walking up and down stairs. Yet talking further about the impact it was evident that things were not back to the complete sense of normality that he would have liked. Terry believed he was pacing himself, but this was actually enforced rest from the symptoms rather than from choice, his body had become a constant reminder of what he was unable to do.

Terry was by now taking painkillers and anti-inflammatory medication when the pain became severe and had been given a choice of second line therapy. He spoke about the need and reasoning behind the use of these medications in a clear rational way. Yet Terry had made up his mind that the potential side effects outweighed the benefits of taking any additional medication. He even commented on the possible disapproval from the consultant concerning his decision to decline disease modifying treatment. He talked about living with the fear of the future

getting worse, losing further normality, yet continued to rationalise his choices by repeatedly saying that he was fine.

By 52 weeks Terry was making enforced changes to accommodate his symptoms, although often these changes were almost unconsciously done without the awareness of having changed, such as using handrails on stairs or walking slower. His main concern was the way others looked at him, as if his normal appearance belied how he really felt; he was unable to find anything positive about the arthritis but was overall lighter in mood, more even and less low in himself and was talking about future plans, including a house move and ballroom dancing. He moved house between the 26 & 52 week follow up and appeared to have no further outpatient appointment. He was disinclined to chase this.

His wife appeared at the last interview and there was a companionship and comfortable feeling not seen in previous interviews. Terry had acknowledged this throughout the final interview that although the frustration was still there from both him and his wife they were able to plan for the future.

7.6   Possible influences on the journeys

The presentation of the journeys is based on qualitative data, supported by quantitative data. The inductive data were used to review similarities within the groups then comparing the quantitative data in these groups. The possible influences were identified by examination of primarily the qualitative data and do not seek to establish cause and effect. Five key themes were identified as possibly influencing the patients' journey: W*hat do I need from the consultation? Support from the team, varying social support, coping in real life*, and *changing the old me for a new one*. The key findings that follow are supported by qualitative data taken from the transcripts of the four previous exemplars. Although the following section is not a traditional way of presenting findings and then discussions, due to its complexity it was felt more appropriate to immediately comment, with data and discussion integrated.

7.6.1   What do I need from the consultation?

At the first interview the participants were asked what they thought was going to happen at the forthcoming rheumatology consultation and also what they expected from their visit. Some expectations of the consultation were common, with all patients expecting a full examination and discussion of symptoms. The difference between the four journeys was the expected outcome: i.e. what the patients needed from the consultation. Bob (pragmatist) just felt it was reasonable to get advice with or without a diagnosis and to get on with life. For the others they were more specific. Cheryl's needs related to the validation of symptoms and the struggle of being believed (emotion-focused group).

> *"My biggest fear is leaving there Friday [the consultation] feeling as exactly as I do now, completely none the wiser… I just want someone to say, "this is what we think it is". I just don't want to be fobbed off."*   Cheryl (emotion-focused)

Contrary to this Jacob (problem-focused) wanted information about how to manage his symptoms and something to help him on a day-to-day basis.

> *"I'm hoping really that they can give me something that's going to help, you know, just help get my strength back….I'd like to find out*

as much as I can from the consultant, what you can get- well as many positive things I can get from them really."

Jacob (problem-focused)

Terry (minimiser) was the only participant who mentioned hoping for a cure; this may be linked back to his original causal belief and hope that the IA was related to a spider bite (section 6.1.1) and therefore temporary.

I would like to know em...and hopefully they can find something to either cure it or make it more bearable so I can return to work and do things."

Terry (minimiser)

There is very little in the literature that relates specifically to patients' needs and expectations prior to the consultation, especially in the musculoskeletal literature; studies relate to communication issues more than expectations. Those that relate to expectations are based in primary care (Little *et al.*, 2001, Britten *et al.*, 2004) and are often about the lack of time given for discussion, or communication issues (Johansson *et al.*, 1996). However, the majority of studies are outdated and both communication skills and patient decision making has changed. Main *et al.* (2010) suggested that addressing patients' beliefs and expectations in the consultation would improve adherence and are at the "heart" of all clinical interventions; this was based on anecdotal and clinical evidence. Lærum, Indahl, and Skouen (2006) identified five key features of a successful consultation. This was based on a hybrid analysis (qualitative study including observation of consultations and a subsequent patient interview, and quantitative data from consultant notes) of 35 patients with lower back pain.

Table 7.7 Features of the "Good back-consultation" (Lærum, Indahl, and Skouen, 2006)

1	To be taken seriously (seen, heard and believed)
2	To be given an understandable explanation of what is wrong
3	To have patient centred communication (i.e. seeking patients' perspectives)
4	To be reassured, and if possible be given a favourable outcome
5	To be told what could be done

If health professionals understand people's expectations from the start, a more focused individual approach could be adopted in consultations. Thus the fact that Terry was focused on normality and hopeful for a cure may have needed a different approach from a more emotive Cheryl who needed validation of her symptoms.

> *" Then I do feel, yeah, like you – yeah probably more confident actually, that I'm not just a malingering old cow, as my son calls me."*   Cheryl (emotion-focused)

Kralik, Brown and Koch, 2001) found that women receiving a diagnosis of a long-term illness (including diabetes, breast cancer and psoriasis) found that this was a memorable event in their lives. They suggest that healthcare professionals should not underestimate the value or importance of the diagnostic label, however for these women it was about feeling validated, about being believed and having an illness identity, which fits with Cheryl's needs. Cheryl's initial euphoria is replaced by an overwhelming sense of change and as in Kralik, Brown, and Koch (2001) a sense of intrusion with feelings of helplessness and overall emotional distress. A study in India, analysing 100 randomly selected patients with established diabetes, showed a link between patients' positive attitude at the time of diagnosis with a significantly higher adherence to exercise (Kaur, 2010). This adherence could be related to the reinforcement of this positive attitude by the consultant at the initial consultation. The acknowledgement of the emotional needs of the patients by HCPs therefore has significance for future successful implementation of self-management techniques.

Although this study was in diabetes, this may explain why Bob (pragmatist) had such a favourable outcome from the start. His positive outlook with both his symptoms and his medical care "*the medical care is so much better here than where we last lived"* and the positive consultation led him to believe from the outset that his arthritis would not impact on his life. This led to a high level of adherence and a desirable journey encompassing behavioural adaptation and psychological adjustment.

> *"[He] did explain that there are treatments available now which will help alleviate the symptoms considerably and leave you more or less free to live a normal life so there's nothing unduly to worry about it these days."*   Bob (pragmatist)

Bob, Cheryl and Jacob received a diagnosis on their first consultation. Terry's journey (minimising) was different. Terry's 'need to know' what not fulfilled at the consultation because there was a delay in receiving the diagnosis as he waited for ultrasound and blood results. Terry therefore stayed on NSAIDS until three months when he was offered methotrexate. He could rationalise the use of the medication, the purpose of the treatment, the potential side effects and the benefits, he understood the long-term effects both of having and declining the medication. He declined. His relationship with the medical team was different from that of the other groups and he later disengaged completely.

Although no obvious differences were seen in the Illness beliefs across the time, within the pre-consultation interview the qualitative data supported by the quantitative data suggest that there is a link and these underpinning concerns here arising from illness beliefs appear inherent within people's 'what I need from the consultation'. This was discussed within the deductive chapter (section 6.1.7) and will be revisited in the discussion summary (section 8.2).

7.6.2   Support from the team

The diagnosis is only the beginning of the journey where the patient is an integral part of a successful relationship. Relationships with the teams in these journeys were based on individual needs and changed for some participants over the 52 weeks. Participants in all four journeys commented on the clarity of the explanation and information received at the first consultation. However, the relationships between the participants and the rheumatology teams varied as time continued and as the patient became aware of their own needs.

Cheryl (emotion-focused) disengaged with the physiotherapists as she felt that they did not understand or take into account her levels of varying pain. In contrast, she felt understood by the OT who at first meeting discussed her emotional needs in a personal way.

> *"When I went to see Occupational Health [Therapist], I thought she was gonna give me a walking stick and some bits for the kitchen. But she didn't, she gave me a box of tissues and said, "Right, tell me how this has now affected your life." And I was like, "Oh," because it was just going to see a counsellor almost. And I think*

that's – that was – that was – and it really threw me. Because I
didn't expect her to be um – what was the word? – Sort of dealing
with my emotional wellbeing."   Cheryl (emotion-focused)

Her reliance on the team was different compared to the other journeys, for instance Jacob and Bob saw it positively if the time to their next appointment was extended, whereas Cheryl needed regular contact.

"He is very pleased with the progress, to the extent that he's turned
round and said he doesn't want to see me for nine months, so I go
back next April, that's fine by me."   *Bob* (pragmatist)

"I think if I didn't have regular hospital appointments I'd feel lost. Um
yeah, no I – I (small laugh) I quite enjoy them (laughs) in a strange
sort of way. Makes me sound really odd, but they – they keep me
sort of, yeah, I know what I'm doing, and I know they give me sort of
the information that I need."   Cheryl (emotion-focused)

A poignant factor was the change in Cheryl's relationship with the consultant after the initial diagnosis as she sought emotional support.

"No and I think – I don't think – I don't think doctors are the most
helpful um people either. Because doctors are very um – they're
very stoic, aren't they, and they're very – they've got all the facts
and they – you know, "This is what's happening to you, this is
what – what your body's doing, this is what – you know, now here
you are, here's your drugs, go away and deal with it". The nurse, the
only person that I've felt completely comfortable with and confident
with is the nurse, the rheumy nurses."   Cheryl (emotion-focused)

This reinforces the findings from a qualitative study by Radford *et al.* (2008) who found that emotional support is needed at the point of diagnosis of RA, but this should be based on patients' individual needs. The provision of emotional support that patients in the study reported was essential at the time of diagnosis, and included being listened to by health care professionals, in a safe environment. Hill *et al.* (1994) demonstrated that a rheumatology nurse was as effective as a consultant rheumatologist in managing disease activity, but was more successful in managing

patients' symptoms, and improving psychological status. These three concepts; need for emotional support, a safe environment in which to be listened to, and support from the rheumatology nurse, fit Cheryl's journey well. The relationship with the team begins from the first point of contact and is long-term.

7.6.3   Varying social support

One common theme in a study of MS patients (Solari *et al.*, 2007) was the aspects of social isolation that emerge post diagnosis, represented by lack of understanding of family and friends, leading to a feeling of having to cope alone, thus indicating the importance of social support.

Social support is one factor that can provide a person with an effective coping strategy or can facilitate the adoption of more appropriate strategies (Cohen, 2004). Social support can be viewed in theory as emotional support or tangible (practical) support (Schaefer, Coyne and Lazarus, 1981). Patients in this study viewed support in several ways, often with discrepancy between what the patient felt they wanted and what they felt they received. Some family members became over protective, such as Cheryl's partner who went from being her partner to "*her carer*" in a matter of weeks leading up to the consultation. In this situation Cheryl lost control and when post-diagnosis she tried to regain it, this relationship failed as her partner withdrew, as did her children and friends.

> *"But he can't – I don't think he can deal with that [diagnosis]. He's – it's all been so sort of intense that he's quite happy to keep living in that role, and I'm – I'm not. Um but we'll see. "And I don't want to be um – um I don't want to be a burden to anybody. But I don't – I don't – I don't think I need a carer."*   Cheryl (emotion-focused)

The friends took time to re-evaluate and understand and it was not until the 12-month interview that the friends and family had accepted the changes.

> *"She's [daughter] still very protective of me, still very um, "Are you taking your medication?" She gets angry if people push me on stairs and things, 'cause I can't – yeah, I can't get up and down steps as fast as I used to. And she does lose her temper a bit, and she says to me, if we're going into town*,*" Mum, take your stick, just*

so, you know, you look – people can see that you're not walking as fast because you have a stick. It's not because you're just being difficult or anything." I think she worries more about things like that than I do."   Cheryl (emotion-focused)

Ryan *et al.* (2003) found that social support influenced control perceptions in people with RA. Cheryl developed her own independence over the 12 months by reinventing herself and developing new coping skills, and whereas she was once an outgoing sociable person she changed, becoming less dependent on her social life.

"What were you scared about?" [Interviewer]
"Being dependent on other people, being reliant and isolated. And – and that doesn't – that doesn't scare me anymore. I quite, like I said, I crave that, I crave being on my own."
                            Cheryl (emotion-focused)

For pragmatist Bob, his wife supported him, working together as a team and he found he could ask for help *"whenever I need it".* Jacob (problem-focused) was overwhelmed by the support from his wife who from the beginning of the journey accepted the role change, and looked for assistance or remedies, the diet for example, grasping at anything that may help, and being proactive. However, her support, which was initially overwhelming, was channeled into a problem solving approach by 26-weeks and therefore became acceptable to Jacob.

"You know, it gives her some satisfaction to see that she's – she's helped morally err, you know, and um – and with the things she does as well, you know. So – because she's had a lot, obviously a lot to get on with as well. She's pretty much running the house, you know, paying the bills, and she's doing the overtime. And so yeah, I think it gives her a bit of err – of hope as well. But I think she's come to – to terms now that – you know, obviously she was the one that really err instigated using the sort of natural remedy, if you like. But I think she's come to terms, you know, now that that's probably too much, you know, to ask for really."
                            Jacob (problem-focused)

Terry (minimiser) appeared to struggle with his social support. He openly discussed his wife's emotive reaction to his symptoms and the impact that the symptoms had on their lives as a couple. His wife did not appear to understand his IA, and he did not perceive her to be supportive in the early stages; her attitude appeared to give him something else to worry about.

> *"Look at my hands, I can't even bend my fingers let alone do any work, I can't work, which means we don't have the money we're used to and she just doesn't get it."*   Terry (minimiser)

> *"She does… I mean she gets frustrated with me because we're not old people really in today's … I mean yes forty years ago people who were sixty were quite old weren't they but I don't feel we're like that today you know and you know it is restricting what I can do and what I can't do"*   Terry (minimiser)

> *"You know, I think she gets annoyed and frustrated with me at times, and doesn't realise quite how I'm feeling."*   Terry (minimiser)

Terry relied on his wife for support, yet initially this was not forthcoming. As Terry adapted in his own way there was a definite shift in the attitude of his wife.

> *"I potter, we're looking to move. My wife is much happier I think she has accepted that I can't do everything I used to, but I'm managing fine thanks."*   Terry (minimiser)

Social support can influence a person's journey both from a positive and negative perceptive (section 1.6); it can influence their perception of control and emotional support and can boost self-esteem. In this study there was a clear divide in the emotional social support needed by the emotion-focused participants and the instrumental or tangible social support needed by the problem-focused participants and pragmatists. The effectiveness of social support is reliant on the patients' perception of their own needs. If emotional support is reduced in the social setting then these data have shown the individual may find it difficult to cope with the

impact and distress, resulting in lower levels of general well-being and higher levels of anxiety and depression.

> "*Initially she changed everything – I mean watched everything I ate, bought me books on how to control the arthritis, was against meds, too much really but well…*Hmm um *I think probably the most positive thing I can take from it is that I've um – I mean I'm lucky that I've got support from – from my wife, you know, and um obviously she's the one that's – you know, everything falls on her, i.e. the mortgage and the bills and what have you and um, you know, I couldn't do without her, you know, she's been very understanding.*"
>
> Jacob (problem-focused)

This study has shown that interactions with close family members and friends have consequences for the emotional and physical well-being of individuals who are starting to come to terms with IA. Therefore a logical concept is to use family and social interventions and there is emerging evidence of varying degrees of their effectiveness. Research suggests that family support leads to improved self-management behaviour through improved self-efficacy, mental health and adjustment to illness (Rosland and Piette, 2010). However, there are limited studies in IA to recommend which intervention is effective in each situation. Group education programmes with spousal input have been shown to have a positive effect in RA (Riemsma, Taal and Rasker, 2003). Research into future interventions could explore content aimed at specific family members in how to support patients' needs to make their own choices. Further research is needed to assess family intervention and also specifically targeted programmes. The data from this thesis suggest it is possible that each journey requires different types and levels of support, and being aware of how people assimilate information may assist in long-term self-management care strategies.

7.6.4   Coping in real life – making choices

The patients often employed coping strategies without having had specific health professional education or group self-management programmes. However, Cheryl (emotion-focused) relied on health care professionals, especially the nurses for emotional support. Bob and Jacob (pragmatist and problem-focused) both

acknowledged the role of the team and used the information gained (for example exercise regimen) to inform their coping but declined any programmes or group support.

> *"So once I start to exercise them again that's when I start to get the flexibility back. As the same applies to my shoulders, they stiffen up overnight and within half an hour perhaps of getting up and getting dressed the pain in the shoulders if you like tends to disappear and the flexibility in my shoulders come back to what I term as normal"*
>
> Bob (pragmatist)

Both Bob and Jacob were active in demonstrating coping strategies that included cognitive reframing (changing the way they viewed things). This may be related to the perceived effectiveness of problem-focused coping in contrast to emotion-focused coping (such as emotional expression), which has been shown to be related to helplessness (Englebrecht *et al.,* 2012).

> *"I have to pace myself, I don't like it but…look I'm so much better, I just hope I can stay this way with the medication"*
>
> Bob (pragmatist)

> *"One of my biggest challenges, is to try and get - you know, to be able to do my job I'm going to need to be able to get over that, or do something a little bit – you know, some lighter work, probably not so – so physically demanding. But err I certainly want to stay in the kind of – in my line, you know, the kind of work I do. And there are a few pathways, you know, I can – I can do that."*
>
> Jacob (problem-focused)

Patients with IA who use active problem-solving as a coping strategy tend to adapt and adjust positively to their disease, putting its impact into perspective, which allows them to manage their IA more successfully (Englebrecht *et al.,* 2013). The patient driven request for information should be recognised, as it is different from a person passively receiving information. For example, Shaw, Wilson and O'Brien (1994) found in patients undergoing breast biopsy and their partners, seeking information was one of the principle modes of coping and information, given appropriately reduced distress about uncertainty. Although limited in its sampling

Shaw's study does show the importance highlighted in the journeys described in this study regarding appropriate information and education being tailored to the needs of the individual.

Cheryl used emotion-focused strategies, including emotional disclosure and one to one psychological support from the team, which focused on issues around her individual needs. This enabled her to make a psychological shift over the 12 months of her journey and although there were examples of problem-solving, Cheryl's main achievement was coming to terms with a long-term illness.

"Emotionally I feel in a better place as well. That was the – that was the worst thing for me: I just couldn't get my whole head around what it had done to me. Not – not the physical sort of implications more so, but the mental and emotional, you know, what it had robbed off me"

"I'm not feeling quite so angry anymore. I'm not looking at this as a burden anymore, it's just something that's part of me"

Cheryl (emotion-focused)

It is suggested that longer disease duration is associated with more effective coping, which implies that patients adapt over time (Englebrecht *et al.,* 2012). Yet the qualitative data in this thesis clearly show that in early IA the participants showed a range of effective coping skills. The importance about the journey of Terry (minimiser) is the element of patient choice. The definition of adherence describes persistence in practice or maintenance and is used to capture the routine that patients with IA ideally engage in when taking their medication (Treharne *et al.,* 2004). The primary reasons for prescribing disease-modifying medication in IA are to control symptoms and improve function and quality of life over time (Smolen *et al.,* 2010), therefore non-adherence may have a personal health impact and health-economic consequences (Elliott *et al.,* 2005). Berry, Bradlow, and Bersellini, (2004). found that in rheumatology clinics non-adherence to medication was more common in newly diagnosed patients (28%) than follow-up patients (1%). However this was based on NSAIDs rather than DMARDs. Adherence estimates in patients with RA for prescribed DMARDs vary from 83% (methotrexate) at 6 months to 59% at three years (Viller *et al.,* 1999), although these studies are not adjusted for disease activity and therefore may not be comparable. Beliefs about medication appear to be a

contributing factor to adherence (van den Bemt, Zwikker, and van den Ende, 2012). Those patients with RA who believe their medication to be necessary have greater adherence, with an association between medication adherence and positive self-efficacy (Hill, Bird and Johnson, 2001).

Therefore the clinical perspective may be that Terry (minimiser) is in denial, yet his refusal to take medication and attend follow-up may be his coping strategies based on his beliefs. For example he has rationalised his need for medication by considering all the options and risks of side effects against the benefits of medications. In this case he may feel intervention is inappropriate as he feels he and his wife can cope and have adjusted and feel that medical input is not needed.

If the beliefs of Terry had been recognised the clinician could have explored his illness beliefs relating to long term consequence of untreated IA. Although his understanding of the mechanism of the medication was demonstrated he may not understand the 'side-effects' of untreated IA.

7.6.5   Changing the old me for a new me

Across all journeys there was a sense of normality being disrupted, although the impact of this disruption varied, being less profound for Bob than for Terry. The concept of biographical disruption was described over 30 years ago (Bury, 1982), based on the experience of people with RA. This theory purported that a chronic illness would disrupt a person's assumptions about their lives and who they are, and how they normally behave (e.g. I am not normally someone who asks for help). All participants in this current study experienced some biographical disruption as they all struggled with their symptoms to try and maintain their normal lives. They had disruptions in their explanatory framework and had to accommodate changes in their physical self.

However, after the diagnosis patients took different directions to maintain their normality. After the initial diagnosis Bob (pragmatist) quickly re-established a sense of normality, this may be because his arthritis was stabilised quickly and flares were minimal. His routine included washing up to ease the stiffness of the hands in the morning and doing finger exercises suggested by the OT; but life continued with the new regimen resulting in minimum impact.

"But I mean I haven't really had to seriously think, "Well can I do that or can't I?" I haven't got down to that level yet. I mean you'd probably say the same about the trip we're doing, starting Monday. I haven't consciously changed anything that we're going to do on that to adjust for – I haven't felt the necessity to." Bob (pragmatist)

Being able to continue with minimal disruption was not possible for Cheryl (emotion-focused) or Jacob (problem-focused). Their disease was more fluctuating in nature with changes throughout the 12 months of medication; this fluctuating nature of their illness had a greater impact forcing both to give up their jobs as they were unable to meet the demands of their professions. There was an element of frustration and despair of the changes or disruptions to their normal routines and this continued throughout the first 26 weeks.

"I get really angry everybody else is still living their normal lives, I'm not."   Cheryl (emotion-focused)

"It's the guilt that I struggle with, that me wife has to do so much, that's not normal."   Jacob (problem-focused)

Both narratives showed elements of the chaos story (a life that will never get better) and the quest story (transformation into a newer and stronger self) (Frank *et al.,* 1998), with the latter becoming more prominent as they struggled to re-invent a new normal that would encompass their lives.

"Well everything's constantly adapting and evolving and life constantly changes. But it's just having confidence and knowing that, things may change, but fundamentally they don't change who you are or what you think's important. And, you know, my values and my standards and my – my morals are all still the same. If anything, I think I've become a – a better person. Um I'm a lot – I have a lot more sort of empathy with people and I'm not so judgemental and a lot more tolerant, I think. And that's not a bad thing, is it? I just think if – I think everybody should go through a chronic illness, and it just puts things in priority, just makes things – whatever is important to you. Like I said, I wouldn't go back to being

the Cheryl that I was 18 months ago, not for all the tea in China.
'Cos I think, even though I was content, I don't think I was happy
with who I was."   Cheryl (emotion-focused)

This powerful description of change resonates with Locock, Ziebland, and Dumelow, (2009) and their theory of biographical repair where a sense of normality is restored by learning to live with altered circumstances and by redefining

importance in a response shift (Schwartz *et al.*, 2006). However Cheryl's disrupted normality does not alter her core concept of self. These conceptions of normality were changed through both emotional coping (Cheryl) and practical problem solving (Jacob), and were linked to confidence and expertise in managing their condition.

"I feel more normal than I did. I don't feel like I've got this
massive chip on my shoulder anymore. I don't feel like I sort of sit
there and go, "Woe is me," and I feel like I'm probably, yeah, I'm not
the same Cheryl that I was 18 months ago, but I'm definitely not
the same Cheryl that I was 12 months ago."

Cheryl (emotion-focused)

"You know, I think probably I'm find – I'm finding that um while I can
still do things, albeit I can't do them maybe as effectively or as
quickly as I – as I used to, I'll still find the way to do it,
I don't – I don't think I've err met anything yet that I, you know, can't
sort of achieve if – you know, but I haven't really – as I say, I'm still
only sort of on a – a bit of a learning curve really back, you know, to
what I used to do. I think – I don't think I would be able to go out and
– although I say I've regained strength, I don't think I would have – I
still haven't got the strength I – I would need to do what I used to
do."   Jacob (problem-focused)

Terry, the minimiser, has a chaotic story that is more profound than for the others as he travelled along his individual path, with his lack of perceived social support, (although this changed towards the last month), the decision to disengage from the medical team and his loss of self were significant in his descriptions of the

journey. His disease was moderate and restricting with swelling in his hands and the pain evident from the grimacing facial expressions.

"You feel like a stupid old man I suppose."　　　Terry (minimiser)

There was a continual disillusionment with the impact of the illness, disrupting his sense of normality.

"I'm not even 60 – I just want to be normal not an old man"

Terry (minimiser)

Although not the only person to make downward comparisons he was the only participant where it became a recurrent theme alongside normality as he struggled with the illness in his everyday life.

"Don't get me wrong there's people that are far worse off than me, all those poor soldiers are coming back with legs missing and you know whatever but I suppose you have to think of what your own situation is to a degree but I'm just…. Well I'm more positive about it hopefully she's not got some miracle but got some cure that will make it a lot easier because at 60 you know you should have at least 10 active years after that………. And you see old people around in parks and pubs or wherever you go that are frankly in some cases is in better shape than I am"　　　Terry (minimiser)

His "miracle cure" came in the form of two steroid injections between the post-consultation interview and the one at 26 weeks, with a "dramatic response", which enabled Terry to grip and function "as normal"

"But they did say three to four months, I think. But um I certainly haven't gone downhill, not like I was when you saw me first, and prior to that. [ ] I can do most things now, although I am slow"

Terry (minimiser)

His desire for a cure and concerns regarding taking any medication other than painkillers and the occasional anti-inflammatory tablets may have hindered his acceptance of the long-term illness. Terry struggled with the frustration of the illness despite a daily impact on his life.

"But um I mean we walked into town the other day and um sometimes it's worse than – my left leg is giving me a bit of trouble and I was limping. And my wife said, "Well why don't you get the bus back?" I said, "No, because I've got to walk through it, and carry on. If I don't use it I'll lose it. And so I'd rather put up with a bit of pain and limping. (Laughs) She says, "Well you're walking like an old man." I said, "Well (laughs) just look in the mirror," you know. But, you know, you've got to – well I just think you've (just got to)."

Terry (minimiser)

Accepting the situation was difficult for both Terry and his wife, and there was a disparity between Terry's support needs and the social support that he actually received. This may be due to lack of awareness or communication from Terry about the symptoms, or lack of understanding from his wife, because he looked well, giving her no rationale as to why his life was so disrupted.

"I don't think she understands sometimes. And no one does. I mean 'cause to look at me, I look fine. I know I do, I look, you know, good, pretty good for my age. And um – and it's – and I know if someone says, "Oh I don't feel well, I've got a headache," or, "I don't feel" – you can't see that pain. You'll only see it if they've got a broken arm or there's blood pouring out of a part of the body, you know, then you know. Or if they're err – got a really bad fever or – or sort of desperately ill with something like cancer, with hollow face and grey and at death's door. But a lot of people that have got pain in their joints and arms and legs, unless it's the visual type of arthritis with the big swollen, you know, fingers turning one way and the other, you can't – you can't see it."   Terry (minimiser)

Terry struggled with the loss of normality and his search for an improved quality of life continued as he came to terms with his illness and loss of identity. Terry's journey through the processes of adaptation and adjustment started at the end of the 12 months with a re-evaluation of his role and an ability to perceive his

life within his new normal; he had started to become more accepting as had his wife. He had begun to accept that he may never return to his previous normality and the initial perceived biographical disruption to his self-worth and personal identity as a high wage earner, were starting to be challenged as he and his wife started cognitive reframing on their journey towards acceptance.

> *"And I – and it's – that's – I mean it's frustrating and I like have to accept it. I mean but I know, I mean maybe I could look at some other – maybe driving. But I don't know, I don't know, you know, I've – I've sort of got used to this now. And we manage OK. Not – not – I mean the money's not there anymore but – but fortunately we're mortgage-free, so, you know, a lot of people are not in our position. I mean it's not – we're not – can't afford this and can't afford that sometimes, but you have to live with it."*

> Terry (minimiser)

Whilst the reality of loss and disruption result in changes in self-perception and loss of normality (DeVellis *et al.,* 1990), these data suggest the possibility for acceptance of adverse situations through personal transformation, and positive responses to illness challenges, as suggested by Neill (2002).

7.7   Adaptation and adjustment

Chapter 3 reviewed the literature and discussed the lack of an agreed definition for adaptation and adjustment within IA and whether they were processes or outcomes. The clinical implication of this uncertainty is that HCPs and patients may have different understandings of the aims of the treatment and therefore different definitive end points. As this thesis reviews adaptation and adjustment it was felt important to ascertain each participant's understanding of these phrases to see if they match those decided by the researcher (section 2.6):

Adaptation is the practical or behavioural changes that the person has to make in order to make their life successful in terms of the activities of daily living.

Adjustment is the psychological change the person has to make in order to maintain a quality of life that they perceive to be satisfying.

In order to understand the patient perspective at each interview, each participant was asked to define adaptation and adjustment. There was little change in the responses between pre and post-consultation, so the results shown will focus on the answers recorded pre-consultation and at 52 weeks. The researcher varied the order in which the definitions were asked; sometimes a definition of adaptation was asked first followed by adjustment and other times vice versa. Examples of the patients' definitions are found in table 7.8. To simplify the analysis each definition is labelled with the patients' name.

Table 7.8 Patient perspective - What do adaptation and adjustment mean? – Example of definitions from the transcripts

Patient name	Adaptation (pre-consult)	Adaptation (wk. 52)	Adjustment (pre-consult)	Adjustment (wk. 52)
Nicola	*"Adapt things to suit my abilities"*	*"I wouldn't really say I could define it. But you just have to get on with it"*	*"some form of lifestyle of how I do things or approach things perhaps"*	*"it's adjusting to how you do things or um […] it's like cutting your cloth isn't it?"*
Bob	*"well it means I would have to ….I was doing things slower or in a different way"*	*"I suppose I've had to adapt certain things to a slight change of lifestyle. Well you just consciously stop to think what you're going to do"*	*"you might have to vary your lifestyle from something that you were doing before because you can't achieve it currently so you're adjusting your lifestyle to suit your new circumstances"*	*"I suppose you adjust your lifestyle to cope with the problems you may have. You probably adjust your whole lifestyle slightly to cover any infirmity"*
Betty	*" adapting I think is more or less for life like I've got things to help screw off tops, it's more of a lifestyle"*	*"adapt is to change, I think adapting is how you feel as well as using tools to adapt, to make life easier for you"*	*"It's about how you feel" "It's something you do when the pain is probably there and which you have to do something temporarily"*	*"A day to day thing that you can do to alleviate what's going on in your life at that time"*
Ian	*"adapt would be to adjust to external conditions or conditions that are making you – yeah, it would be externally dictated by something else, how you would arrive at the same point that you did previously."*	*"Almost adapting to circumstances, maybe adapting would be physical"*	*"You – you adjust things, and I think you adapt through knowledge but you adjust, without taking on-board the external factors. To adapt, you'd have to consider the external factors. Whereas adjust, you might do that without knowing."*	*"Adjustment would be changing something, would probably be something more mental"*

The definitions were clustered into groups of similar meaning for adaptation pre-consultation and adaptation at 52 weeks, these were then compared. One of the patient partners then repeated the exercise independently to compare findings with the researcher to ensure the findings were valid.

The findings from the adaptation definitions changed very little across the 12 months. They were divided into two groups: the physical (bodily changes) element of the IA which caused patients to change their behaviour day to day, and the lifestyle changes which were determined by the patients as more permanent. The latter included where aids were used and patients became adept at listening to their bodies, beginning to plan and pace. A year on there is assimilation of adaptation into a new normal, with physical and lifestyle changes that are evolving, requiring a change of attitude, long-term.

Patients were divided in how they defined adjustment, particularly between psychological and physical changes. The consensus of opinion when defining adjustment was that it was often an unfamiliar term and patients often asked whether the two terms are synonymous. One interesting concept that arose was the change in those who turned from adjustment as a lifestyle concept to a psychological understanding. Those who demonstrated emotional- focused coping throughout the 12 months changed their definition of adjustment alongside their coping, from a lifestyle issue to a more cognitive understanding.

The definitions of participants were not consistent with the HCP's definitions. In addition, these current data found no consensus between patients, with individuals having their own unique definitions. It could be argued that this is due to the patients being at the start of their journey and therefore not having completed their own adaptation or adjustment. Equally it may be that the terms adaptation and adjustments are used differently by health care professionals and are interpreted differently by the patients.

The point is that the patients are not asked, yet these terms represent the end points in studies or are used as a way of measuring success in education programmes (2.6). Therefore it may be clinically significant when planning care to establish that health care professionals and their patients have the same understanding when deciding on treatment and care pathways. The importance of this is that health care professionals need to be aware that the terms used in clinic may have different implications to the patients than they have to them.

7.8   Summary

The individual journeys show different coping mechanisms in early IA with a clinical implication that in the early years tailored support is needed for self-management and appropriate emotional support. Therefore, in order to individualise care, identifying and understanding the individual needs are paramount in promoting effective treatment and positive outcome. Each of these four journeys evolved; sometimes they overlapped with their decision-making, and other times they maintained very separate paths. Patients all made choices that they rationalised within their individual context. Rationalising can be defined as the process by which someone attributes their understanding and reasoning for their chronic illness in order to provide plausible reasons for their reaction and behaviour (Gillibrand and Flynn, 2001). There may be an element of reality avoidance, or as Levine *et al.* (1986) suggested, in a population of patients with diabetes, denial of future difficulty in adhering to regimens would be an influencing factor on adherence to the present situations.

Having looked at the findings at the four time points and across the 12 months the next chapter will discuss the implications of this research with regard to current knowledge, clinical implications and further research.

Chapter 8 – Discussion of the research findings, and the implications for research and clinical practice

Chapters 5, 6 and 7 presented the results and summarised the findings from an inductive, deductive and longitudinal perspective. This chapter discusses the combined results from these chapters and considers the implications that these have for clinical practice and future research. Where helpful quotations presented earlier in the thesis are represented to highlight key points.

8.1 Thesis aims

The aims of this thesis were:

1) To explore participants' beliefs and emotions prior to having a confirmed diagnosis of IA.

2) To explore and understand the experience of having a diagnosis of IA.

3) To investigate how beliefs and emotions change over the first year, and which factors influence adaptation and adjustment to IA.

4) To understand the role of illness beliefs in newly diagnosed patients and whether these beliefs influence adaptation and adjustment to IA.

5) To assess and examine quantitatively changes in illness perceptions and adaptation during the first year of living with IA.

8.2 Novel findings

This study has identified that patients make individual journeys during their first year of inflammatory arthritis, and that these may be defined by four different coping mechanisms. These novel findings are based for the first time on prospective, longitudinal data starting before diagnosis. They indicate that some degree of acceptance is achieved within the first year; however the journey towards acceptance and the nature of the acceptance is individual to the person. Linked with this, is the novel finding that the definitions of adjustment and adaptation from the patient perspective differ from the professional perspective, and from each other, yet the process to adapt and adjust they go through is similar, with the outcome being a degree of acceptance. Furthermore, new information that defines acceptance in this population is generated.

The literature suggests that illness beliefs influence the process of adjustment and adaptation towards acceptance. However, this study has found that based on qualitative data, illness beliefs are interdependent and influenced by external factors. This suggests that illness beliefs need to be understood in the context of their importance within the person's life, and not as stand-alone beliefs if clinicians are to understand their influence within the first year.

The data collection and hybrid analysis used to meet the aims of this thesis have provided these novel contributions to knowledge in this longitudinal study. Without the prospective and longitudinal nature of this thesis it would have been impossible to capture such a rich data set, showing the importance of this type of research within long-term conditions. The novel findings generated will now be discussed for each of the original aims.

8.2.1   To explore participants' beliefs and emotions prior to having a confirmed diagnosis of IA

Overall the findings suggest that even before the diagnosis the physical symptoms (such as pain, fatigue, swelling and for some participants, stiffness) are having a major disruption on their daily lives, from lack of sleep to impact on their work and social situations. There were three compelling factors: the symptoms that led to seeking help (section 5.3.1), the impact of these symptoms on the life of the participants (section 5.3.2) and the stigma of being different (section 5.3.4).

Decisions to seek help were comparable between men and women, that is when the symptoms had an impact on everyday life they sought medical advice. This is contradictory to the small studies of RA that examined men's help seeking behaviour and suggested men were reluctant to seek help (Lack, Noddings and Hewlett, 2011) or in other long term conditions (Wang *et al.,* 2013). It may be that this current sample of patients were more confident to articulate their concerns as during the research interviews all were open with regards to symptoms and impact so therefore this may be a trait within this small sample. Despite their positive help-seeking behaviour several patients did attempt to rationalise their symptoms from a *"strain at work",* to "*I thought I'd over done it"* or just "*old age".* Apart from one participant who was initially diagnosed as having carpal tunnel syndrome, all referrals were done at first GP consultation.

Even pre-consultation the impact felt by the patients from the symptoms meant that changes had to be made (section 5.3.3). From the interview data those patients who already had another illness (diabetes and Perthes' disease) had started to make changes earlier to accommodate their new symptoms in order to

"*make life easier*" (Nicola). Although for these two participants the diagnosis was perceived as important to legitimise their condition in the eyes of friends and work colleagues, they still looked holistically at their routine, incorporating their symptoms into their everyday life rather than focusing on their symptoms and their restrictions separately.

> *"I just have to think a bit more – that's all, I mean they'll tell me what*
> *it is won't they? But until then… like I haven't done my car you see..*
> *well if I get on my knees I can't get up again and so I need to stick*
> *with the things I can do without causing meself any bother"*   Don

Changes could be triggered and affected by the lack of understanding of others, the reliance on others and work issues, depending on the personal importance to each individual. This was underpinned by the disruption to perceived normality (section 5.3.5) and fed into beliefs about their consultation (section 5.3.6). The patients involved in this study showed that the importance of being believed was as important as a diagnosis when dealing with a long-term illness where the symptoms were often invisible to others. Only one participant sought information on the Internet after the GP visit but prior to the consultation. The stigma of perceiving themselves as different led to the importance of social support (section 8.2.3.2) and other people's views and this re-emphasised the need for specialist review. The vivid descriptions of the symptoms during the interviews emphasised the need to be believed, either by family or medical team. Pre-consultation there was a belief that if the diagnosis is known, the problem could be rectified, or dealt with and maybe even eliminated.

8.2.2   To explore and understand the experience of having a diagnosis of IA

In the post-consultation interviews 12 (87%) of participants had received a probable or definite diagnosis of IA, of whom three were waiting for confirmation from x-rays and ultrasound. Ten participants (67%) had also received treatment. The main emphasis of the second set of interviews was the consultation and its outcome. Although some themes post interview were the same, the new themes regarding the influence of this meeting were identified as validation of symptoms, gaining information, starting new treatment and hope for the future (section 5.4).

Receiving a diagnosis appeared to have had a positive effect with a shift post-consultation to relief of being believed (despite being given the diagnosis of a long-term condition) and being able to label the condition (section 5.4). This

suggests that the recognition of a chronic illness is just as important for participants as the treatment of symptoms (Ironside *et al.*, 2003).

In this particularly emotive time the consultation underpinned a positive message both in treatment terms and outlook. It brought about closure of the diagnosis and the start of a long-term relationship both with the illness and the specialist team. Although all clinicians provided clarity in terms of diagnosis there was not a definitive treatment plan started in all cases. In two cases the participants had to wait to see the nurse before they started their medication and a delay in this appointment (three weeks with no treatment) led to emotional distress and frustration. However, even for those who started treatment, the establishment of medication appeared to be not as important as receiving the diagnosis. The advent of aggressive treatment of IA has led to more recent optimism within the consultation and this was portrayed to and perceived by the participants, which may be an important aspect in their journeys. All participants were complimentary about their consultation with no questions raised or unclear understanding. It may be that emotional support is needed at a later stage (section 8.4.3).

Not receiving a definite diagnosis at the first consultation was described in five post-consultation interviews; the challenge for the team is to support the patient through this time. None of these patients received any support while they remained "in limbo". Hehir *et al.* (2008) reviewed the need for nurse support at the onset of rheumatic disease, concluding emotional support to be the overarching theme that underpins other needs in relation to coming to terms with the arthritis. However, this current study shows that there may be a role for emotional support for those waiting for full explanation or test results when suspected diagnosis is apparent. From a pragmatic perspective it could be argued that this is resource inefficient, yet if it can be proven that additional support at this time reduces distress and improves adherence by further research it may improve long-term patient outcome.

8.2.3   To investigate how beliefs and emotions change over the first year, and which factors influence adaptation and adjustment to IA

The concept of a journey provides the clinician with a way of gaining fuller understanding of the changing nature and also the changing impact of the condition (Jablonski, 2004). In addition, using the longitudinal perspective allows the clinician to gain a fuller understanding of the chronic illness (Rolland, 1987) incorporating all aspects of the patient's life (Jablonski, 2004). Understanding the experience of the

chronic illness as told by the person can complement the approach by HCPs (Telford, Kralik and Koch, 2006).

Over one year, the participants in this study showed that patients experience their own journeys yet all appear to arrive at the same outcome of acceptance, but this acceptance is in a different form for each patient. In a qualitative study with women who had fibromyalgia and arthritis, acceptance was defined as "an overall attitude towards pain experience involving acknowledging the condition and a willingness to engage in activities despite pain" (LaChappelle, Lavoie. and Boudreau, 2008). This was evidenced in this thesis when at 26 weeks, experiencing symptoms changed into "*listening to the body"* and "*recognising the symptoms"* as participants began to understand the condition and its implications (section 5.5.1). This involved making changes and rethinking the whole concept of the condition and a "*new me".* Normality became more disrupted despite the shift in pacing and planning, which suggests that adjusting and adapting does not necessarily mean acceptance. LaChappelle , Lavoie. and Boudreau, (2008) purport that acceptance is a process whereby people begin to make choices. Although this may be true when looking at one characteristic of a condition this thesis has shown that acceptance encompasses adjustment, adaptation and renegotiation in the process, with acceptance the outcome of this process. It may be that acceptance changes throughout time for each person and if the condition stabilises but then flares the process of adjustment, adaptation and therefore re-negotiation restarts, to produce another acceptance outcome. These concepts link to the underpinning theoretical models (section 2.6) that are re-examined in section 8.2.3.1.

Another novel finding within this thesis is the role of acceptance, which all participants reached in some form at the end of the 52 weeks, and also the coping strategies used to reach this point. Although not previously presented in the aims of the study, this finding highlighted the value of the iterative nature of qualitative research. This study has demonstrated that the process (adaptation and adjustment) to reach the outcome (acceptance) is underpinned by a range of coping strategies, but the importance lies in the outcome for these participants, which is that acceptance in some form is achievable during the first year of diagnosis. This contradicts a study by Kostova, Caiata-Zufferey and Schulz (2014) who reviewed acceptance in RA patients with a focus on pain, and chose to sample patients over 35 years old who were at least three years from diagnosis, on the stated assumption that acceptance could not be reached earlier. They suggest that acceptance is a process that moves through five main stages: naming the illness, realising the illness, resisting the illness, hitting the bottom and integrating the

illness (Kostova, Caiata-Zufferey, and Schulz, 2014). However, whilst this thesis agrees with the stages it has demonstrated that the stages cannot be seen in isolation (away from social support for example) and are not linear but iterative. Kostova, Caiata-Zufferey, and Schulz, (2014) also suggest that acceptance is the process and as an end point cannot actually be reached; however within this thesis there appeared to be an endpoint of acceptance to different degrees and integration may be part of the endpoint.

> *"Emotionally I feel in a better place as well. That was the – that was the worst thing for me: I just couldn't get my whole head around*
>
> *what it had done to me. Not – not the physical sort of implications more so, but the mental and emotional, you know, what it had robbed off me. And, like I said to you before, I'd find myself, for the first time I'd felt comfortable, and I felt really content in myself, and then this happened – I'm not feeling quite so angry anymore. I'm quite – I'm not looking on it as a burden anymore, it's just something that's part of me now."* Cheryl

However, this end point is unlikely to be fixed permanently, and further renegotiation may be required in the face of changes in disease, health or social circumstances. Acceptance means that the patients in this study have become prepared to deal with restrictions and changes in everyday life imposed by the disease (Zalewska *et al.,* 2007).

> *"It's just – it's just um taking it at face value and sort of saying, OK, well whatever happens, happens, and sort of being flexible with it, letting it not define you as a person, sort of move with it."* Ian

For patients in this study acceptance from the start was about integrating the illness into their everyday lives and re-establishing normality, or adjusting and adapting their lives around the illness. According to Dijkstra *et al.* (2007) acceptance of a chronic illness is the psychological adjustment to this illness. However, findings from this thesis suggest that without a definition of adjustment confirmed, this definition of acceptance should be expanded to include adaptation and defined accordingly. Dijkstra *et al.* (2007) defined their patients' acceptance of pain as willingness to experience continuing pain without needing to reduce, avoid or otherwise change it. In contrast, this thesis suggests acceptance is a broader

outcome arising from adjustment and adaptation to the integration of the illness within life by negotiating and shifting normality. On the basis of this thesis acceptance is "living alongside side an illness, listening to your body and negotiating life within this". As Fiona reiterates:

> *"You learn, it's not a case of giving in that would be - well failure, it's about learning to live with it, listening to your body and negotiating what you what to do and how you do it. You have to be flexible, you have to change…..but that's not necessarily a bad thing"*

If acceptance is deemed a positive process (Telford, Kralik and Koch, 2006) there is a suggestion that denial (the opposite of this) is negative and leads to higher levels of distress with poor illness management and depression. If this were true then it would suggest that Terry has failed in his journey. However, he reached his own acceptance of the situation. Therefore it could be suggested that denial is a form of acceptance with his choices deemed by clinicians as poor adherence; yet from his perception they were rationally thought out. His depression scores reduced at 52 weeks and reducing levels of distress through his interviews show his own level of acceptance, thus reiterating that different adapting, adjusting and coping strategies can reach an outcome of acceptance.

8.2.3.1 Coping strategies and theoretical models

As acceptance is conceptualised as the outcome then the next section of the discussion will focus on how participants reached this point. Chapter 7 suggests that although the end point is achieved, the journeys taken to reach this are very different and can be classified by the different coping strategies (flexible, emotion-focused, problem-focused and minimising). Coping is now a recognised variable in understanding "adjustment" to long-term illness including RA (Ramjeet, Smith and Adams, 2008). Coping refers to the cognitive, emotional and behavioural strategies people employ in their lives in an attempt to manage the consequences of their disease (Lazarus and Folkman, 1984). The different coping strategies were discussed in chapter 3 (section 3.2) where it was determined from the literature that the optimum coping strategy was one of flexible coping. The literature also suggests that flexible coping is continual and used as necessary to combine different coping strategies both within the same situation and across situations (Kato, 2012). In general, individuals who are able to change their strategies in response to the situation demonstrate "flexible" coping (Cheng, 2003). This more varied coping

approach may allow for better matching between the coping strategy and the needs of a particular situation and may suit the fluctuating and unpredictable nature of IA. Based on cognitive flexibility it allows the person to maintain control by assessing the effectiveness of each problem and solution (Kato, 2012) and changing appropriately.

However, from the data produced from the interviews, one main coping strategy was dominant in each journey. The pragmatists showed flexible coping strategies from the beginning and moved through the 52 weeks with minimal problems. Those who were more practical used problem-solving techniques and those who needed more psychological support used emotion-focused strategies. Flexible coping techniques were used in the latter journeys; however it appeared that the coping strategies were developed as the year progressed. In comparison to the model by Kato (2012) the coping strategies were neither fixed, nor apparent from the early stages but developed at different stages. What is not known is the timeline of change. With the interviews conducted at 6-month intervals only a general concept of change can be determined. What is difficult to ascertain and would be an area for future research is the relationship between coping styles and acceptance. It appears that coping becomes more flexible in this whole cohort of patients, yet coping style still seems to separate people in their journeys.

The coping literature uses the terms adaptation and adjustment interchangeably (section 2.6) and for the purpose of the thesis the following definitions were used.

Adaptation is the practical or behavioural changes that the person has to make in order to make their life successful in terms of the activities of daily living.

Adjustment is the psychological change the person has to make in order to maintain a quality of life that they perceive to be satisfying.

However, the participants' definitions of adjustment and adaptation were not neatly separate; in fact the definitions were seen by patients to be irrelevant. An example of this is Betty whose initial definition of <u>adaptation</u> was a practical interpretation:

> *"Adapting I think is more or less for life like I've got things to help screw off tops, it's more of a lifestyle"*   Betty (pre-consultation)

However, her definition became broader and at week 52 also encompassed psychological change:

> *"Adapt is to change, I think adapting is how you feel as well as using*
> *tools to adapt, to make life easier for you"*   Betty (week 52)

Her initial focus on <u>adjustment</u> was about feelings, which confirms the working definition used in this thesis. However, this moves by week 52 towards a definition that appears to encompass practical actions to enable you to live with it as part of your life.

> *"It's about how you feel, it's something you do when the pain is*
> *probably there and which you have to do something temporarily"*
>   Betty (pre-consultation)

> *"A day to day thing that you can do to alleviate what's going on in*
> *your life at that time"*   Betty (week 52)

Alongside descriptions of the disruption of chronic illness, there is a growing body of research literature that documents the path people take to adapt and adjust to their illness. Understanding these concepts may help health professionals support the patient along this journey. However, the definitions by Betty, as from the others, contrast with the working definitions. This indicates that reaching acceptance using coping strategies is a process of adjustment and adaptation; the definitions are not important to the patients, nor is there a consensus of opinion.

In part, concepts or theoretical models have been brought about to explain the diversity of the disruption of having a chronic illness. Early focus on loss and the burden of sickness has now shifted towards health contextualised within illness and more positive themes whereby the focus is on reshaping the self (Yoshida, 1993), empowering potential (Paterson *et al.,* 1999) and optimising health within chronic illness (McWilliam *et al.,* 1996). Within this study the participants reached a point of some acceptance by recognising the symptoms and listening to their bodies and coming to terms through making changes and re-establishing a new normality. The theoretical models (section 2.7) have been examined with reference to IA but this study enables the models to be explored prospectively with people newly diagnosed with IA at the present time.

Participants found that they had to re-evaluate their priorities and come to terms with a diagnosis across the 52 weeks. Shaul (2005) suggests that there are three stages within the process of psychological adjustment, and whilst this study would now suggest the definition of psychological adjustment may not concur with Shaul, the patients in this study have begun to move towards Shaul's "mastery".

Mastery in this thesis was to achieve a satisfying quality of life and manage their roles. Although patients had shown some changes by "battling through" and "positive renegotiation", they were still coming to terms with their personal pre-conceived ideas of normality. However, one aspect of mastery that they had achieved was their perception that the illness was now permanent. If the journeys are taken separately from the inductive findings then there is a suggestion that some patients reach mastery before others (i.e. the pragmatists), while for others it may be that 52 weeks is too early to achieve or even define a satisfactory quality of life.

Paterson's' model of shifting perspective(2001) (similar to Yoshida's Pendulum model, 1993) suggests that living with a long-term condition is an ongoing and shifting process, and differs from Yoshida in its approach to wellness and illness (sections 2.7.2 and 2.7.3). Both models only partially relate to the participants in this study. As the participants move towards the end of the first year the fluctuating illness(that Patterson proposed) is not found through the inductive analysis to be a focus, although participants begin to recognise the symptoms and begin to "listen to their body". Rather the focus is on regaining normality, although at times when the pendular movement (Yoshida's model) of the illness does occur, participants battle and renegotiate. It may be that the concept of illness and wellness becomes more apparent as the illness stabilises over time. To redefine normality there appears to be a response shift needed (Sanderson *et al.,* 2011).

This response shift started after the consultation and formal diagnosis, with participants beginning to re-evaluate their lives. Although a gradual process and for some this process was still ongoing, there was a psychological change by redefining what was important. This was not necessarily due to treatment but due to the legitimising of their symptoms and the concept of "being believed". This study supports Beaton's suggestion that "feeling better" is contextualised within the experience of each individual and not necessarily related to change in disease status (Beaton *et al.*, 2001). "Reprioritisation" as a mechanism of response shift reiterates the importance of personal values within the first year of IA and in this study is pivoted on the disruption and regaining of normality.

Bury (1982) and Charmaz (1983) suggested that chronic illness could be perceived as a biographical disruption, which encompasses a loss of self or threatened identity. Bury (1982) in a review of RA patients proposed the concept of biographical disruption as a way of defining an individual's altered life course when dealing with the impact of chronic illness. The biographical disruption requires a redefinition of the self and the recognising of disability and therefore it may not be

possible to restore a person's past identity, which may have an impact on the journey, processes (adaptation and adjustment) and outcome (acceptance). In this study recognising the symptoms and listening to the body became fundamental in the way that the person could start to accept the illness and make changes towards a new normality. This concept of change in a person's perspective of what is "normal" is a dynamic model that may still change as a person continues through their life with their illness (Dingwall, 2001).

> *"I couldn't open a bottle of wine anymore. Not with these [hands] um...I know we can all live without drinking wine, but it's err...something that normal people do"*   James

> *"Some days I think I'm doing OK – other days I feel old, an old man, I'm not even 50!"*   Tom

Normality has been identified in studies of people with arthritis as both an important outcome and an important aspect of living with the disease (Dildys, 1996, Carr *et al.,* 2003, Fair, 2003). This study with newly diagnosed patients reiterated this finding. However, it was the study by Sanderson *et al.* (2011) that suggested the interaction of concepts of a normal life, normalisation of symptoms and of the illness appear to be dynamic in nature. They proposed a concept of shifting normality, which indicates that biographical concepts need to be seen within the context of the symptoms, adjustment processes and self. Thus as this thesis indicates, the symptoms, the need to make changes and individuality are all within these concepts of shifting normality, rethinking the whole concept of the condition and the "new me". Normality became more disrupted despite the shift in pacing and planning, which suggests that adjusting and adapting is a continual process. However, within the context of self this study has also found the importance of social support to be a prominent factor in the process of adjustment and adaptation.

8.2.3.2   Social support – fluctuating and invisible symptoms

One other main finding, which was not in the original aims, was the vital role of social support within the first year and its impact on the patients' adaptation and adjustment. Jerant, Friederichs-Fitzwater and Moore (2005) discussed barriers to self-management and concluded that there is a concept regarding social and family support and how this might impact negatively on self-management and the ability to

cope. Many participants indicated that their families believed helping a sick person would prevent recovery, with family members disbelieving the fact that the patient was "suffering" as they did not look outwardly "sick". This was reiterated in this study as patients struggled with the invisibility of their symptoms and the constant fluctuating support.

> *"Well he [partner] – he just – he couldn't get his head around it all. He's just – he was a bit like my friends really, it's like, "Well there's nothing wrong with you really, why are you – why are you in bed? Why – why do you need to sleep so much? He couldn't see anything."*   Cheryl

The degree to which the spouse or partner is supportive and the effect of that support, that is whether it is positive (Gallant, 2003) or negative (Manne and Zautra, 1990), may be related not only to the understanding of the disease but also to the differences in the perceptions between partners and patients about the patient's health state, pain and well-being. This was seen clearly in several participants throughout the 52 weeks.

> *"And no one does. I mean 'cause to look at me, I look fine. I know I do, I look, you know, good, pretty good for my age. And um – and it's – and I know if someone says, "Oh I don't feel well, I've got a headache," or, "I don't feel" – you can't see that pain. You'll only see it if they've got a broken arm or there's blood pouring out of a part of the body, you know, then you know. Or if they're er – got a really bad fever or – or sort of desperately ill with something like cancer, with hollow face and grey and at death's door. But a lot of people that have got pain in their joints and arms and legs, unless it's the visual type of arthritis with the big swollen, you know, fingers turning one way and the other, you can't – you can't see it."*   Terry

As Lim and Zebrack (2004) argue, diverging views on an illness can be a cause of strain and stress on family members. It is therefore important to look at ways to promote a more cohesive approach towards chronic illness, especially when facing unpredictable day-to-day living, as is the case with IA. From the patient perspective adjustment may be made more difficult if patients are unable to continue

to meet the expectations of family and friends as to how well they are coping (Bediako and Friend, 2004).

> *"Um err the other thing, I suppose, is um the fact that outwardly I look completely, you know, able-bodied, you know. And um it's – it's trying to explain to people like, you know. Especially, as I say, when I went to the site and he said, "Well I'll give you something light to do." I said, "There's probably nothing light enough." And it looks as though I'm sort of shirking, trying to shirk something. So um I want to be able to just carry on"*   Jacob

If the patient is in pain but no physical signs are evident the partner may feel the illness is not as the patient claims (Cohen and Wills, 1985).

> *"I don't think she appreciates how much pain I was in. I don't get a lot of sympathy off my wife so I don't say too much about it … I think that's just her way, I'm not saying that she doesn't care because I'm sure she does but…."*   Terry

Throughout the 52 weeks family support varied and was influential on the process of adjustment and adaptation. Those who received the support that they needed appeared to adjust more quickly and have more flexible coping strategies in place from an earlier time-point. If support is important then this should be considered during clinical care (section 8.4).

8.2.4   To understand the role of illness beliefs in newly diagnosed patients and whether these beliefs influence adaptation and adjustment to IA.

The literature (section 3.6) suggests that illness beliefs are a profound influence within a person's journey towards "adaptation and adjustment" (acceptance in this thesis). However, analysis of the data shows within this group of newly diagnosed participants with IA that illness beliefs are not only interdependent but are also influenced by external aspects, such as social support and internal aspects such as hope or wishful thinking, which are outside the parameters of the "illness beliefs". The main influence that illness beliefs had within this group of patients was the need for illness identity. This need for a label or diagnosis appeared paramount to achieving control (Scharloo *et al.,* 1998), although it is not certain whether it was the need for the identity or the need to be believed. Some

participants who also felt that the unfamiliar symptoms and trigger factors had left them feeling uncertain about their future reiterated this. The loss of control links to coherence and without an understanding of the illness, perceived helplessness emerged.

From 26 weeks to 52 weeks, the data showed that as patients became accustomed to their illness, their beliefs continued to alter according to their personal situation, with the participants continuing to make psychological changes even at the end of the first year. The emotional responses had become more positive, fluctuating across the 52 weeks, encompassing all aspects from fear and distress (pre), relief (post), a mix of frustration and anxiety (26 weeks) to a positive mental shift at the last interview (52 weeks). The personal and treatment control beliefs became more evident; however, they remained realistically within the fluctuating nature of the illness. People's beliefs about the longer-term consequences of their symptoms were intertwined with their beliefs about normality, their personal expectations and emotional responses. As coherence beliefs develop over the 52 weeks then this appears to link with the inductive findings of coping, thus if a person understands and uses flexible coping from the beginning, then their outcome of acceptance within the first year is met earlier.

8.2.5 To assess and examine quantitatively changes in illness perceptions and adaptation during the first year of living with IA.

This second study was removed before recruitment commenced as requirement to the qualitative arm was slow indicating that sufficient numbers for the quantitative study would be unachievable. There are several factors that influenced recruitment into the qualitative longitudinal study. Patients may have been reluctant to participate in a study when they are dealing with an unknown condition, or if they are not familiar with the medical system, the clinical team, or that research is a feature of the department. In addition, during this study, Site A had no research team available to recruit and therefore this had to be done by busy consultants. Site B had overestimated their number of patients with IA. The research team at Site C had a reduction of their medical team due to sickness therefore their patient throughput was reduced during this time. A pragmatic decision to remove the quantitative arm was therefore taken early to prevent any unnecessary recruitment, and to ensure that an in-depth qualitative study was still achievable. However, the prospective, longitudinal nature of the qualitative

research was an important methodological strength underpinning the identification of the novel journeys.

8.3 Research strengths

8.3.1 The benefits of longitudinal research within rheumatology

This prospective qualitative study was approached analytically in two ways: cross-sectionally in order to look at themes at four time points across participants, and also longitudinally to look for development of themes or trajectories over time. The longitudinal aspect of this study is rare within the literature and within the field of rheumatology, with the practicalities of time and cost meaning that follow-up with detailed interviewing especially from pre-diagnosis is novel. Longitudinal research is a vital source of providing information over the course of someone's life (Schaie and Hofer, 2001) and elicits important evidence regarding relationships between health and psychosocial changes in this year. It involves the repeated assessment of the same persons over a period of time. The commitment of the participants is worthy of a mention, with interviews conducted after work or between jobs, and even in lunchtimes. Two participants moved during the year, one completely out of the area and although this meant her last interview was not completed, she agreed if further participation were needed she would be happy to be contacted. The study participants were committed to the year; however, for any further research, additional participants may be needed to allow for attrition.

This study, unlike previous studies described in the literature review (chapters 2 and 3) allowed prospective information to be gathered rather than retrospective, thus reducing recall bias. This aspect of the research was vital if the aims of the research were to be achieved. Prospective data complements retrospective data by providing unique, detailed information regarding experiences within the context of present day life (Moffit *et al.,* 2010). These multiple, prospective, longitudinal interviews and reflections offered insight into the changes participants made within their social context and allowed the researcher a greater insight into the individual's journey, this was reinforced by the location of the interview. All follow-up interviews, apart from with one participant, were carried out in their homes. One disadvantage of this was the lack of control for interruptions (the interviewer became adept at listening and interviewing with distractions), however the familiarity of the surroundings created a relaxed interviewing environment.

A further strength of this study was the continuity of the same researcher allowing a relationship to develop and consistency in the interviewing style. This allowed different areas of discussion to be revisited as appropriate and relevant without having to be discussed from the beginning, for example the work issues of Cheryl or the discrimination in the work place experienced by Nicola. Longitudinal studies require flexibility and adaptation on the part of the researcher and the participants in order to gain maximum possible data collection.

Within this study the family or partners became part of the research in terms of familiarity and welcoming the researcher into their home, and adding reassurance that the questionnaires would be returned. Although the researcher was not there to "fix" issues but to understand them from the participants' perspective, the relationship was an important aspect (Gale, 1992) and building of trust was needed to enable successful return visits. One of the greatest strengths of this longitudinal study was the relationship between the researcher and the participants, enabling the interviews to become an honest, often emotive, discussion. Only one participant withdrew after her first interview as despite obtaining consent, she initially perceived that the study was a compulsory aspect of her care, she had no prior experience of health care, it was since found that she was lost to follow up and had not attended her outpatient appointment.

8.3.2   Research rigour

"Without rigour, research is worthless, becomes fiction and loses its utility."

(Morse and Richards, 2002: p.2)

Rigour is the means by which researchers show integrity and competence in their studies (Tobin and Begley, 2004). In this thesis interpretive rigour required the researcher to acknowledge any bias, be transparent in her methodology and methods of developing emerging themes (Morse and Richards, 2002). This can be achieved by researcher triangulation by which multiple researchers are involved in the analytical process. This was achieved by two experienced researchers independently analysing a proportion of the data. Their interpretation of the data was then compared to the independent interpretation by two patient partners to ensure the themes were agreed upon by patients not just the researchers. These strategies were completed to ensure rigour and reduce the chance of researcher bias (Cohen and Crabtree, 2008). The overarching themes were then supported by excerpts from the raw data to illustrate findings (Fereday and Muir-Cochrance,

2006) to ensure that the data interpretation remained firmly grounded in the words of the participants.

It is important to acknowledge that with any qualitative research the interviews follow a remit (albeit flexible) in the form of an interview schedule. However, not to acknowledge the interests implicit in the research, or to attempt value-free positions of neutrality, is to assume `an obscene and dishonest position' *(*Shacklock and Smyth, 1998: pgs. 6, 7*).* The study involved one to one interviews that enabled the patient's individual experiences to be understood without the risk of conformity bias and allowed elaboration of individual needs. The researcher introduced herself as a researcher rather than a nurse, thus separating herself from the clinical team but also eliminating any awareness of rheumatology knowledge.

8.4   Implications for clinical practice

8.4.1   Supporting the journey

Journeys, stories or descriptions offer insight, understanding and new perspectives (Divinsky, 2007) and they can help people make sense of how they are coping (Doherty *et al.*, 2009). After developing symptoms of what proves to be a long term illness, the patients and their families start on a journey. Often these journeys are considered a way of making sense of the emotional impact that accompanies the chronic illness (Greenhalgh and Hurtwitz, 1999). Influences on the journeys include prior experience of illness, family support or perceptions of needed support, life skills, coping strategies and expertise available (Doherty *et al.*, 2009), and also HCP support (Woods *et al.,* 2003).

Chapter 7 explored the path or journey taken by each participant during the first year to determine if there were any common journeys within their accounts and found four possible patient pathways. These pathways or journeys are different from the care or clinical pathways defined in policy (NICE, 2013), which are a way of using a longitudinal approach to managing arthritis (Palmer and Miedany, 2012, Briggs *et al.,* 2013) and are familiar to most clinicians. However, the journeys established in this thesis were not determined from a clinical perspective. Care or clinical pathways fail to account for individual aspects of patient journeys, e.g. individual aspirations, and also they are formed from the medical team and HCPs' perspectives (Goodwin *et al.*, 2012) rather than the patients' perspectives. The journeys presented in this thesis bring the patient views and coping strategies into our understanding of the experiences of newly diagnosed patients in order to give the first year meaning and context. The meaning of these journeys has been derived through structuring the

lived experiences of the patients into stories that can be formulated into journeys; this process gives rise to a shared understanding of an experience between participants, clinicians and HCPs. Being aware of these very different journeys may help clinicians and HCPs plan care together with their patients and with their specific needs in mind, with different models of care relating to different patients' experiences, as their physical, social, psychological and spiritual needs can vary. Recognising that people need different support at different times may prompt HCPs to be more responsive to individual needs (Brown *et al.,* 2000).

The journeys indicate that people use specific coping strategies and these are reinforced by their immediate levels of support (section 7.6.2) and how they perceive this support to impact on their illness (section 7.6.3). This novel data set suggests that if the journey taken by individuals is known at the outset then this could assist in the adjustment and adaptation process, thus promoting a more effective care package. For example if the concepts of adaptation, adjustment and acceptance are interlinked with the concept of a journey and redefining a "new me" as this thesis suggests, then HCPs can help patients by understanding what their individual journey might look like. By comparing the patients' journey to the experiences identified by participants in these interviews, they can validate persons' experiences, feelings and struggles.

8.4.2   Instigating treatment protocols

Although limited to only one person, the Minimiser journey was unique but also highlighted the concerns of modern day management where people are categorised and treated by best practice guidelines, pathways and protocols (NICE, 2013) rather than individualised care. Being lost to follow-up has clinical and financial implications for the patient and the NHS by possibly increasing the long-term impact of a disease that is potentially controllable. From a clinical perspective it may be that illness perceptions measured at the start may influence clinical intervention. The Minimiser was the only person to change their causal beliefs about their illness from a spider bite (i.e. short term or temporary) to a perception of long term related to work; it might be this was a contributing factor towards his move away from care and medication. If patients who are likely to decide not to adhere to treatment could be recognised in advance by health care practitioners then it may be their individualised package of care could be better tailored to their needs, thus minimising the chance of losing the patients to follow-up.

8.4.3   Providing support for emotions, coping and self-management

Within the training requirements of specialist practitioners, there is little evidence of training in providing emotional support, with emphasis being on the physical assessments and medication management. The journeys indicate that assessing patients' coping strategies at the first consultation may improve care and acceptance, and therefore consideration as to how to assess these should be given. For example using the RA impact of disease RAID scale (Gossec *et al.,* 2009) (questions 6 and 7) may indicate the level of perceived coping and the emotional distress at the first clinic appointment. Although not validated as individual questions nor used in all types of inflammatory arthritis it may be a useful scale to detect coping strategies in order to implement appropriate support and/or education.

Self-management interventions have been shown to be effective (section 1.7.3) however the journeys have indicated that to gain full benefit from self-management programmes, patients' coping strategies and emotional requirements need to be assessed prior to providing these programmes. Support from rheumatology teams is fundamental in providing good long term care (section 1.7) with a national survey (n= 1210) indicating that 66% of patients would like to access self-management support, (Dures *et al.,* 2014). This suggests that patient response to education may be dependent on the needs of the individual. For example, those following a problem-solving journey may suit the traditional self-management programme with its combination of teaching skills for finding ways to manage fluctuating symptoms, pacing and group support, while those on a pragmatic journey may relate better to information and practical hands on techniques. However, those with an emotional coping style may need a different approach.

Psychological needs resulting from physical symptoms in long term conditions have been conceptualised into a five-level pyramid (Fellow-Smith *et al.,* 2012), from level 1 that describes general difficulties in coping that are common for people with that illness, through to level 5 that describes mental illness that is severe and requires specialist interventions. Approximately 57% participants surveyed in the multi-centre study discussed above required more intense emotional and psychological support (Dures *et al.,* 2014). For this to be achieved HCPs may need more training on supporting patients to manage their emotions using specialist skills such as cognitive reframing to help patients reconsider their situation and approach to coping with it.

This study has shown that illness beliefs are not the only factors that influence patients during the diagnosis and early stages of learning to live with IA. There is also a growing awareness within the literature of the emotional impact of

living with chronic illness and this study has shown the importance of recognising this in enabling people to adapt and adjust. In pain management increasing evidence has shown the beneficial effects of emotion-focused programmes whereby people actively acknowledge and express disease-related emotions. Zangi *et al.* (2011) addressed this gap in knowledge regarding emotion-focused programs in IA by conducting vitality training. This specifically looked at being aware of emotions and of own needs, and also gave skills training in believing yourself to be a credible patient thus promoting self-confidence. Data were collected by means of self-report questionnaires and focus groups. The aim of the group intervention, unlike other self-management interventions, was not to introduce behaviour change or goals, but to increase emotional awareness and habitual patterns, thus creating choices consistent with these needs. Although the length of diagnosis of her study participants varied, this principle may be valuable in those exhibiting emotion-focused problems, and should be tried in early IA.

8.4.4   Providing support for couples and relationships

The interpretation of illness within couples is paramount when working with patients and partners to improve self-management of chronic illness. This has been demonstrated in previous studies looking at other chronic illnesses: for example in cancer patients the differences in pain interpretation between patients and their partners were associated with poor outcome for the patient's mood and quality of life (Miaskowski *et al.,* 1997). Heijmans (1999) found that where spouses minimised the seriousness of Addison's disease, this had a more detrimental effect on the patient's health than where spouses over-inflated the condition.

If the role of social support has been shown to be beneficial or detrimental then further research needs to identify how HCPs can positively support at the point of diagnosis within the context of the patients' individual lives, with friends, partners or work colleagues. Understanding the family support and potential isolation, including addressing when and how people might tell their family, friends or work colleagues. The area is more complex than symptom management and more individualised than the present day education programmes allow.

This study has shown that interactions with close family members and friends have consequences for the emotional and physical well-being of individuals who are starting to come to terms with IA. Therefore a logical step would be to utilise family and social interventions and there is emerging evidence of varying degrees of their effectiveness. Research suggests that family support leads to improved self-

management behaviour through improved self-efficacy, mental health and adjustment to illness (Rosland and Piette, 2010). However, there are limited studies in IA and it is not yet possible to recommend which intervention is effective in each situation.

8.4.5   Understanding illness beliefs

The path of a chronic illness or trajectory begins before symptoms are labeled. Petrie and Weinman (1997) proposed that illness beliefs may not only explain the variety of coping mechanisms utilised for the same illness but are also directly related to such outcomes as adherence, emotional distress and illness related disability and therefore link with the journey. For the patients the greatest impact lies in their perception of the effect that the disease has on their ability to continue with "normal" everyday life, as they perceive it (Hale *et al.,* 2006). For many people the early stages of the disease are experienced without professional support, thus if HCPs could spend some time at the early stages understanding illness beliefs they may be able to reduce emotional distress and correct catastrophic thinking about the future, for example Cheryl was convinced for this IA diagnosis with initial medication control perceived as ineffective, the path would lead inevitably to a wheelchair.

Petrie *et al.* (2002) developed a brief psychological hospital based intervention designed to change inaccurate and negative illness beliefs in patients after their first myocardial infarction (MI). The aim was to modify patients' maladaptive beliefs concerning their MI, as well as to educate them, encouraging patients to develop their own personalised plan of care. Evaluation post hospitalisation and at three months showed that the intervention produced significant changes in patients' beliefs about their illness, their perceived consequences of their illness were improved and level of control increased. They subsequently returned to work significantly quicker than the non-intervention group. In this thesis, at the start of the journey only one participant's perceived beliefs stopped them taking medications. For example Don continued to take the naproxen despite serious nose bleeds which eventually led to his hospitalisation because he felt the benefit of the medication control over his arthritis. In contrast, Terry perceived no immediate benefit from medication, and although he could rationalise potential long term effects, it was not enough and he stopped his drugs. If illness beliefs are influential for outcomes then understanding these should be considered for future interventions to facilitate change (Petrie *et al.,* 2002). However, this novel data set has suggested understanding cannot come from examining illness beliefs in isolation. The ultimate

goal for HCPs is to determine whether understanding illness beliefs enables them to facilitate patient self-management. However, patients may not be aware of their own illness beliefs and how they impact on and influence coping. Despite the evidence highlighting the importance of illness beliefs there is no literature to suggest that HCPs currently examine these at the consultation when a person is first diagnosed with IA.

8.5   Limitations of the research

This study included 15 patients and the wealth and depth of data exceeded expectations. Despite relatively limited recruitment, the study sample covered a range of ages, employment and disease severity, and also recruited consecutive patients from three NHS trusts, therefore accessing a range of care pathways. The sample ratio for women to men was more equal within this study than the IA population. There were no participants from ethnic minority backgrounds and only one participant was born outside the United Kingdom.

The second, quantitative arm of the study was removed prior to recruitment from any site, due to lower than anticipated patient availability and uptake. As this is a novel study it is not known what a quantitative, statistical exploration would have shown with regards to changes in illness perceptions clinical or psychological status, nor how other factors may or may not have influenced such changes in the 12 months studied.

The researcher did not ask patients about the effects of IA on intimacy or relationships in any detail. This was not a deliberate decision and patients did not raise it themselves during interviews. The questionnaires indicated that the relationship support was an important factor in the journeys and this was explored. There was no quantitative measure of self-efficacy, which may be an important variable in acceptance of IA. Another limitation is the lack of a validated acceptance scale to compare acceptance at the start and at the end of the 52 weeks. There is an acceptance scale (Felton, Revenson and Hinrichsen, 1984), however this was deemed not appropriate as its purpose is to compare across different illnesses and is therefore a generic scale that has not been validated in IA. There is also an Acceptance of Disability scale (Richardson, Adner and Nordtröm, 2001), however in IA disability fluctuates as treatments are initiated and therefore evaluating perceived acceptance using this scale of disability would have been unreliable. In hindsight it may have been appropriate to use the Acceptance of Illness Scale (Stuifbergen, Seraphine and Roberts, 2000). In a study of acceptance for living with diabetes,

higher acceptance scores on this scale were related to better metabolic control and better coping scores (Richardson, Adner and Nordstrom, 2001). However, the phrase used was 'functional limitations' and this could mean different things to different people.

The journeys described in this chapter are acceptable possibilities based on the patients within this study; they should be taken on the basis that further research is needed, including validation in larger samples. Those patients in minority ethnic and cultural groups are not represented and they may have their own journeys. These journeys related to the first year and it may be that the journeys change over time, or that after 52 weeks people change course or develop new coping styles as the confounding variables (e.g. disease control) may fluctuate.

These patients accepted the invitation to participate in the research, which raises the question about whether those who did not might have different characteristics, experiences and journeys. The pragmatic method of sampling was needed within the time frame of this research however, it may be that a more personal recruitment method may have yielded a greater number or a wider variety of participants. The invite letter did not encompass those people who are unable to read or those for whom written English is not familiar, as although the study was interview based, participants needed to return the consent form to enable the researcher to make initial contact.

8.6   Implications for research

IA is a chronic, fluctuating and progressive illness, yet little research has been carried out into how people adjust in the early stages of the disease. This study has provided novel data from pre-diagnosis over one year but more research is needed to follow these patients through the next stages of their illness with follow-up interviews at intervals. The fluctuating aspect of this illness dictates a continual need to meet its demands, therefore a more comprehensive understanding of the continuing adjustment processes beyond 12 months may equip HCPs with knowledge to support patients in dealing with the issues that facilitate or hinder this adjustment and acceptance.

Increased social support is related to improved mood in chronic illness (Cohen and Wills, 1985), and this has been identified as the case for patients with RA (Goodenow, Reisine and Grady, 1990; Doeglas *et al.,* 2004). However, there appears to be no such research within PsA and this relationship could be tested in an intervention study in early IA.

Communication and discussion are paramount in building the trust between couples. Couple research has found communication processes to be crucial in facilitating healthy couples' functioning (Olson *et al.*, 1989; Epstein, Baucom and Rankin, 1993; Schmaling and Sher, 2000). Important discussions for couples include understanding the illness and its psychosocial demands over time; what can affect the course; and how to maintain a balanced life (Rolland, 1994). It is suggested that HCPs meeting with couples both individually and together is useful as an initial assessment and would give the clinician a better sense of the current issues, and whether these should be dealt with as a couple or individually. Group education programmes with spousal input have been shown to have a positive effect in RA (Riemsma, Taal and Rasker, 2003). Research into future interventions could explore content aimed specifically at family members in how to support patients' needs to make their own choices. The data from this thesis suggest it is possible that each type of journey requires different forms and levels of support and being aware of how people assimilate information may assist in long-term self-management strategies.

This novel data set has identified four potential journeys towards acceptance. Further clarification of the journeys would be useful to establish more clearly any potential education, support or individualised care pathways needed for different trajectories. This could be achieved by further longitudinal studies reviewing the journeys in a larger cohort to determine the extent to which they are generaliseable.

Further research could usefully find ways to identify the potential journeys individual patients might take (so that tailored support could be offered early). The "Minimiser" patient was lost to follow up, yet if his potential journey could have been identified at the diagnosis phase then support might have been offered to avoid disengagement, and leading to perhaps a more favourable long term outcome. In the midst of a busy clinic, the event of a person not attending can easily go unnoticed or may even be seen as transient relief from the demands of the day. If noticed, one can speculate that the patient forgot the appointment, had other commitments, did not feel that a follow-up was needed at this time, had decided to discontinue care, or switched care providers. Non-attendance reduces clinic and provider productivity and efficiency, compromises access and increases cost of health care, but more so they may impact on long-term outcome. Methods of reducing non-attendance in outpatient settings have been examined for effectiveness and cost-effectiveness and some text messaging, telephone, mail and text/short message service interventions all improved attendance modestly but at

varying costs. Text messaging was the most cost-effective of the three, but its applicability may be limited (Stubbs *et al.,* 2012). However this does not look at why a person will make an active decision to non-attend. In the light of the DH paper and the shift towards patient centered care then the reasons that drive people to opt out of care need to be explored (DH, 2010). A qualitative study reviewed the reasons for patients with type 2 diabetes who failed to attend an education programme. The findings were as expected with regards to the course itself (physical barriers such as time and parking, educational barriers such as not understanding the potential of the course) (Winkley *et al.,* 2014). However, data also demonstrated that the stigma and shame of the disease and not wanting to acknowledge the diabetes was important. This has also been found in patients who did not attend their non-medical appointments (Spikmans *et al.,* 2003).

Although that research was based on an education programme rather than hospital outpatient appointments, it may be that by investigating patients with early IA who chose to opt out of mainstream care similar insights may transpire. It is particularly important to ascertain any barriers at the start of the person's care especially as there appears to be a lack of data with regards to predictors for these IA patients who choose to minimise their symptoms and opt out of follow-up.

Missing appointments is associated with lower adherence rates to prescribed regimens and is the first signal of dropping out of care entirely (DiMatteo, 2004; Neal *et al.,* 2005), and thus should be followed up by the clinic if ongoing care is clinically indicated. Although other studies have shown a link with non-adherence and medication to illness beliefs (Morgan *et al.,* 2015) the one participant in this thesis who was lost to follow-up (Terry) had strong positive beliefs about the effectiveness of his medication yet chose not to adhere to this medication. Therefore, further quantitative research is needed in people newly diagnosed with IA to understand the contribution of illness beliefs or other factors towards adherence and acceptance. In order to assess and examine these issues quantitatively and longitudinally during the first year of living with IA, a multi-center trial would be needed with perhaps an initial approach through a trusted clinician such as the GP. This would increase the possibility of adequate recruitment and potentially provide a diverse sample of participants.

8.7   Thesis summary

This thesis has shown that acceptance is recognised within the first year of IA; however, the path to acceptance is individual to the person. This individuality is

characterised by a person's coping strategy, which develops across the first year of having an illness. The process of coping is one concept of adjustment and adaptation, the definitions of which differ between the patient and HCPs. From the initial symptoms through the first year of the illness, being believed is as important as a diagnostic label when dealing with invisible symptoms and this is reiterated by the necessity of receiving the helpful social support. Quality of life with a long-term illness through successful coping and acceptance is achievable but involves a continual renegotiation underpinned by individual perceptions of normality, which may not necessarily relate to symptom severity.

"A journey is a person in itself; no two are alike. And all plans, safeguards, policing, and coercion are fruitless. We find after years of struggle that we do not take a trip; a trip takes us." John Steinbeck (1962) Travels with Charley.

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Appendices

Appendix 1: Topic guide for interviewing

Interview Schedule Prompt – Pre consultation

Tell me about why you have been referred to the Hospital?

What do you believe is going to happen in the consultation?

Can you tell me about the symptoms you have been having?

Can you describe what happened when the symptoms started?

How long have you had the problem? Has it changed over time?

What do you think brought it on?

What is the main impact on your life at the moment?

Have you changed anything in your life since you have had the joint problem?

Can you tell me whether anything you can do makes things better?

How does it make you feel in yourself?

What do you believe is going to happen in the future?

Interview Schedule Prompt – Post consultation
(May alter depending on outcome/diagnosis confirmed or not)
Tell me you happened in your consultation

Was there anything that you happened that you did not expect?

What is the main impact on your life at the moment?

Have you changed anything in your life since the consultation?

Can you tell me whether anything you can do makes things better?

How does it make you feel in yourself?

What do you believe is going to happen in the future?

Interview schedule prompt for 6 & 12 month follow-up

(May alter slightly depending on the responses from the first two interviews)

Can you tell me about what has happened since we last spoke?

What has changed with your symptoms?

How are you feeling?

Is there anything you feel you do that makes things better?

What changes have you made since we last spoke?

What do you believe will happen in the future?

Is there anything else that you would like to tell me?

What impact is there on your life now?

If you knew then what you know now what would you change if anything?

Appendix 2: Questionnaire package

University of the
West of England
BRISTOL

Date _____/_____/_____   **Study Number_____**

Baseline

Thank you for agreeing to take part in this study.

These questionnaires ask about your thoughts, feelings and the things that you do to deal with the problems with your joints. There are no right or wrong answers, only your opinions - and those are important to us.

Please answer the questions carefully, but don't spend too much time on any one question. When deciding on your answers, don't be influenced by your previous answers. It is important that you answer according to your actual beliefs and not according to how you think you <u>should</u> answer or how you think <u>we</u> want you to answer.

You will find that some of the questions are similar to each other. This is not a mistake!

Each of the questions is there for a specific reason and answers to all of the questions are valuable to us.

Your answers are confidential to the researchers in Bristol. The Rheumatology team caring for you will see the overall results from the 120 patients, but will not be able to link your name to your answers. If you have any queries about this questionnaire package please contact research associate, Julie Taylor on 0117 324 4972.

Why not sit down with a cup of tea and a chocolate biscuit

while you fill these in…………….!

Appendix 3: Hospital and Anxiety scale (HAD)

HAD Scale

Name: .... Study No: [ ]

Date: ....

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

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':
- Most of the time
- A lot of the time
- Time to time, Occasionally
- Not at all

I feel as if I am slowed down:
- Nearly all of the time
- Very often
- Sometimes
- Not at all

I still enjoy the things I used to enjoy:
- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling like 'butterflies' in the stomach:
- Not at all
- Occasionally
- Quite often
- Very often

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

I have lost interest in my appearance:
- Definitely
- I don't take so much care as I should
- I may not take quite as much care
- I take just as much care as ever

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

I feel restless as if I have to be on the move:
- Very much indeed
- Quite a lot
- Not very much
- Not at all

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

I look forward with enjoyment to things:
- As much as ever I did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

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

I get sudden feelings of panic:
- Very often indeed
- Quite often
- Not very often
- Not at all

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

I can enjoy a good book or radio or TV programme:
- Often
- Sometimes
- Not often
- Very seldom

Appendix 4:Arthritis Helplessness Index (AHI)

We are interested in how you view your arthritis

Please tick one column for each statement to show how much you agree or disagree with it

		Strongly disagree	Moderately disagree	Disagree	Agree	Moderately agree	Strongly agree
1	Arthritis is controlling my life						
2	I would feel helpless if I couldn't rely on other people for help with my arthritis						
3	No matter what I try to do, or how hard I try, I just can't seem to get relief from my pain						
4	I am coping effectively with my arthritis						
5	It seems as though fate and other factors beyond my control affect my arthritis						

Appendix 5: RA Quality of Life

Date: _____   Study No:_____

Rheumatoid Arthritis Quality of Life Questionnaire

On these two pages you will find some statements which have been made by people who have rheumatoid arthritis. We would like you to circle 'Yes' if the statement applies to you and circle 'No' if it does not. Please choose the response that applies best to you **at the moment**

1	I have to go to bed earlier than I would like to	Yes	No
2	I'm afraid of people touching me	Yes	No
3	It's difficult to find comfortable shoes that I like	Yes	No
4	I avoid crowds because of my condition	Yes	No
5	I have difficulty dressing	Yes	No
6	I find it difficult to walk to the shops	Yes	No
7	Jobs about the house take me a long time	Yes	No
8	I sometimes have problems using the toilet	Yes	No
9	I often get frustrated	Yes	No
10	I have to keep stopping what I am doing to rest	Yes	No
11	I have difficulty using a knife and fork	Yes	No
12	I find it hard to concentrate	Yes	No
13	Sometimes I just want to be left alone	Yes	No
14	I find it difficult to walk very far	Yes	No
15	I try to avoid shaking hands with people	Yes	No
16	I often get depressed	Yes	No

17	I'm unable to join in activities with my family or friends	Yes	No
18	I have problems taking a bath or shower	Yes	No
19	I sometimes have a good cry because of my condition	Yes	No
20	My condition limits the places I can go	Yes	No
21	I feel tired whatever I do	Yes	No
22	I feel dependent on others	Yes	No
23	My condition is always on my mind	Yes	No
24	I often get angry with myself	Yes	No
25	It's too much effort to go out and see people	Yes	No
26	I sleep badly at night	Yes	No
27	I find it difficult to take care of the people I am close to	Yes	No
28	I feel that I'm unable to control my condition	Yes	No
29	I avoid physical contact	Yes	No
30	I'm limited in the clothes I wear	Yes	No

Appendix 6: Medical Coping Modes Questionnaire

Listed below are several questions asking about your typical thoughts, feelings, and behaviours as they relate to your current illness.

Please circle the answer which applies to you:

1. How much do you want to be involved in decisions regarding your treatment?

    1 = Very much   2 = Moderately   3 = Somewhat   4 = Very little

2. How often do you try to talk about your illnesses with friends or relatives?

    1 = Never   2 = Sometimes   3 = Frequently 4 = All the time

3. In conversations about your illness, how often do you find yourself thinking about other things?

    1 = Never   2 = Sometimes   3 = Frequently   4 = All the time

4. How often do you feel there is really no hope for your full recovery?

    1 = All the time   2 = Frequently 3 = Sometimes   4 = Never

5. In the past few months, how much have you learned about your illness from talking with others who know something about it, such as doctors, nurses, etc.?

    1 = Very little   2 = Some   3 = Quite a bit   4 = Very much

6. How often do you feel that you don't care what happens to you?

    1 = Never   2 = Sometimes   3 = Frequently 4 = All the time

7. To what extent do you like talking to your friends and family because you won't have to think about your illness?

    1 = Very little   2 = Somewhat   3 = Quite a bit   4 = Very much

8. How much has your illness caused you to think about certain things in your life in a more positive way?

    1 = Very little   2 = Some   3 = Quite a bit   4 = Very much

9. When you think about your illness, how often do you try to distract yourself by doing something else?

    1 = All the time   2 = Frequently 3 = Sometimes   4 = Never

10. How often do you ask your doctor for advice about what to do concerning your illness?

    1 = All the time   *2 = Frequently 3 = Sometimes*   *4 = Never*

11 .When friends or relatives try to talk to you about your illness, how frequently do you try to change the subject?

    1 = Never   *2 = Sometimes*   *3 = Frequently 4 = All the time*

12. In the past few months, how much have you learned about your illness from reading books, magazines, or newspapers?

    1 = Very much   *2 = Quite a bit 3 = Some*   *4 = Very little*

13. How often do you feel like giving in to your illness?

    1 = All the time   *2 = Frequently 3 = Sometimes*   *4 = Never*

14. To what extent do you try to forget about your illness?

    1 = Very little   *2 = Some*   *3 = Quite a bit 4 = Very much*

15. How many questions have you asked your doctor about your illness?

    1 = None   *2 = Some*   *3 = Many*   *4 = A lot*

16. When you meet someone with your kind of illness, how much do you talk about the details of the illness?

    1 = Very little   *2 = Some*   *3 = Quite a bit 4 = Very much*

17. How often do you go to the movies or watch TV in order not to think about your illness?

    1 = Never   *2 = Sometimes*   *3 = Frequently 4 = All the time*

18. To what extent do you feel there is nothing you can do about your illness?

    1 = Very much   *2 = Quite a bit 3 = A little*   *4 = Not at all*

19. When close relatives or friends ask you about your illness, how often do you talk to them about it? *1 = All the time   2 = Frequently 3 = Sometimes   4 =*

Appendix 7: Stages of change

In this part of the questionnaire, make your choice based on how you feel **NOW**, not what you have felt in the past or would like to feel. For all the questions about "problems" refer to any difficulties arthritis may have caused in your life (eg pain, fatigue, stiffness, sleep, mood changes etc). For each question, **circle** the number which best represents your views.

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1. As far as I'm concerned, I don't have any problems dealing with arthritis that need changing	1	2	3	4	5
2. I think I might be ready for some self-improvement	1	2	3	4	5
3 I'm doing something about the arthritis problems that have been bothering me	1	2	3	4	5
4. It might be worthwhile to work on my arthritis problems	1	2	3	4	5
5. I don't have any problems with arthritis. It doesn't make much sense for me to get help.	1	2	3	4	5
6. It worries me that I might slip back on a problem with arthritis that I have dealt with, so I want to seek help	1	2	3	4	5
7. I am finally doing some work on my arthritis problems	1	2	3	4	5
8. I have been thinking that I might want to change something about myself	1	2	3	4	5
9. I have been successful at working on my arthritis problems, but I am not sure I can keep up the effort on my own	1	2	3	4	5
10. At times my problems with arthritis are difficult, but I am working on them	1	2	3	4	5
11. Working on arthritis problems is pretty much a waste of time for me because I don't have any problems with arthritis	1	2	3	4	5
12. I'm hoping the Rheumatology service will help me better understand my problems	1	2	3	4	5
13. I guess I have problems with arthritis, but there is nothing I need to change	1	2	3	4	5
14. I am really working hard to change	1	2	3	4	5
15. I have problems with arthritis and I really think I should work on them	1	2	3	4	5
16. I am not following through as well as I had hoped with what I have already changed in terms of dealing with arthritis, and I hope the Rheumatology service will help me to prevent a relapse of the problem	1	2	3	4	5
17. Although I am not always successful in changing I am at least working on my arthritis problems	1	2	3	4	5

Appendix 8: Health Assessment Questionnaire (HAQ

Study No: _____

Health Assessment Questionnaire

Please tick the one response which best describes your usual ABILITIES over the PAST WEEK

	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	Unable to do
1 DRESSING AND GROOMING Are you able to:				
- Dress yourself, including tying shoelaces and doing buttons?	_____	_____	_____	_____
- Shampoo your hair?	_____	_____	_____	_____
2 RISING Are you able to:				
- Stand up from an armless straight chair?	_____	_____	_____	_____
-Get in and out of bed?	_____	_____	_____	_____
3 EATING Are you able to:				
- Cut your meat?	_____	_____	_____	_____
- Lift a full cup or glass to your mouth?	_____	_____	_____	_____
- Open a new carton of milk (or soap powder)?	_____	_____	_____	_____
4 WALKING Are you able to:				
- Walk outdoors on flat ground?	_____	_____	_____	_____
- Climb up five steps?	_____	_____	_____	_____

Please tick any aids or devices that you usually use for any of these activities:

.... Cane   .... Devices used for dressing (button hook, zipper
.... Walking frame   pull, long handled shoe horn etc)
.... Crutches   .... Built-up or special utensils
.... Wheelchair   .... Special or built-up chair

Other (specify) ....

Please tick any categories for which you usually need help from another person:

.... Dressing and   .... Eating
            grooming
.... Rising   .... Walking

	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	Unable to do
5 HYGIENE Are you able to:				
- Wash and dry your entire body?	_____	_____	_____	_____
- Take a bath?	_____	_____	_____	_____
- Get on and off the toilet?	_____	_____	_____	_____
6 REACH Are you able to:				
- Reach and get down a 5lb object (eg a bag of potatoes) from just above your head?	_____	_____	_____	_____
- Bend down to pick up clothing from the floor?	_____	_____	_____	_____
7 GRIP Are you able to:				
- Open car doors?	_____	_____	_____	_____
- Open jars which have been previously opened?	_____	_____	_____	_____
- Turn taps on and off?	_____	_____	_____	_____
8 ACTIVITIES Are you able to:				
- Run errands and shop?	_____	_____	_____	_____
- Get in and 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:

.... Raised toilet seat   .... Bath rail
.... Bath seat   .... Long handled appliances for reach
.... Jar opener (for jars
              previously opened)

Other (specify)..

Please tick any categories for which you usually need help from another person:

.... Hygiene   .... Gripping and opening things
.... Reach   .... Errands and housework

Appendix 9: Personal impact questionnaire

Personal Impact HAQ

Importance of abilities

These questions ask about how <u>important</u> it is to you to be able to do different things <u>yourself</u>.

For example:
You might feel it is not important that you do the gardening yourself - it could be done by someone else. On the other hand you might feel it is important to do the gardening yourself - even though it could be done by someone else

How <u>important</u> is it to you <u>this week</u> to be able to do the following things <u>yourself</u>?

	Not at all important	A little bit important	Quite important	Very important
1 Carry out the tasks involved in dressing and grooming, including tying shoelaces, doing buttons and shampooing your hair?	_____	_____	_____	_____
2 Carry out the sort of tasks that involve getting up (eg from a chair or bed)?	_____	_____	_____	_____
3 Carry out the tasks involved in preparing and eating food?	_____	_____	_____	_____
4 Walk, including flat ground and stairs?	_____	_____	_____	_____
5 Carry out the tasks involved in personal hygiene, including using the bath and toilet?	_____	_____	_____	_____
6 Carry out the sort of tasks that involve reaching up and bending down?	_____	_____	_____	_____
7 Carry out the sorts of tasks that involve gripping things (eg turning taps)?	_____	_____	_____	_____
8 Carry out general activities, such as light gardening, shopping, housework?	_____	_____	_____	_____

Appendix 10: Significant Other Questionnaire

SOS

name: _____   date: _____

Please list below people who are important in your life. Possible relationships include friends, partner, mother, father, children, brothers, sisters, other relatives, work colleagues, and so on. For each person you list, circle a number from 1 to 7 to show how well they provide the type of help listed. The second part of each question asks you to rate how you would like things to be if they were exactly as you would most hope for. Again circle a number from 1 to 7 to show what rating this would involve. Use further *Significant Others Scale* sheets if appropriate.

name/relationship:			*never*			*sometimes*			*always*
1	*a*	can you trust, talk to frankly and share feelings with this person?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
2	*a*	can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
3	*a*	do they give you practical help?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
4	*a*	can you spend time with them socially?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7

name/relationship:			*never*			*sometimes*			*always*
1	*a*	can you trust, talk to frankly and share feelings with this person?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
2	*a*	can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
3	*a*	do they give you practical help?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
4	*a*	can you spend time with them socially?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7

name/relationship:			*never*			*sometimes*			*always*
1	*a*	can you trust, talk to frankly and share feelings with this person?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
2	*a*	can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
3	*a*	do they give you practical help?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
4	*a*	can you spend time with them socially?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7

name/relationship:			never			sometimes			always
1	*a*	can you trust, talk to frankly and share feelings with this person?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
2	*a*	can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
3	*a*	do they give you practical help?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
4	*a*	can you spend time with them socially?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7

name/relationship:			never			sometimes			always
1	*a*	can you trust, talk to frankly and share feelings with this person?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
2	*a*	can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
3	*a*	do they give you practical help?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
4	*a*	can you spend time with them socially?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7

name/relationship:			never			sometimes			always
1	*a*	can you trust, talk to frankly and share feelings with this person?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
2	*a*	can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
3	*a*	do they give you practical help?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
4	*a*	can you spend time with them socially?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7

name/relationship:			never			sometimes			always
1	*a*	can you trust, talk to frankly and share feelings with this person?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
2	*a*	can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
3	*a*	do they give you practical help?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7
4	*a*	can you spend time with them socially?	1	2	3	4	5	6	7
	b	what rating would your ideal be?	1	2	3	4	5	6	7

emotional support: *actual av.____   ideal av.____ ;* **practical support:** *actual av.____   ideal av.____*

Appendix 11: Health Utilisation Questionnaire

This forms looks at any help that you may have received from any members of your health care team both in hospital and in the community. Please think back to when you last saw the consultant

In the past six months have you visited your GP or Practice Nurse about your arthritis (other than for a routine blood test)?

No	Yes	Number of visits

Please give the reason for your visits

_____

_____

Please tick if you are receiving any of the following at present:

1) Physiotherapy ❐ Yes ❐ No

2) Occupational Therapy ❐ Yes ❐ No

3) Counselling ❐ Yes ❐ No

4) Psychology ❐ Yes ❐ No

5) Other therapies ❐ Yes ❐ No

Name of other therapies

Please list your medications

Have you received any steroid injections in the last 6 months?

☐ Yes   ☐ No

Number of injections   _____

Location of injection   _____

_____

Appendix 12: VAS Pain and Fatigue

1)   **Please place a mark on the line to indicate the amount of pain you have had in the last 24 hours.**

No pain |—————————————————————————————| Pain

as bad as it could be

2)   **Considering all the ways your joint problems affect you, please mark on the line how well you are doing.**

Very well   Very badly

|—————————————————————————————|

3   Please circle the number which shows your average <u>level</u> of fatigue

during the past 7 days

No fatigue   0   1   2   3   4   5   6   7   8   9   10

Totally exhausted

4   Please circle the number which shows the <u>effect</u> fatigue has had on your

life during the past 7 days

No effect   0   1   2   3   4   5   6   7   8   9   10   A great

deal of effect

5   Please circle the number which shows how well you have <u>coped</u> with

fatigue over the past 7 days

Not at   0   1   2   3   4   5   6   7   8   9   10   Very well

all well

Appendix 13: Illness perception questionnaire – revised

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Name.................................   *Date*.......................................

YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	I have experienced this symptom *since my illness*			This symptom is *related to my illness*	
Pain	Yes	No	_____	Yes	No
Sore Throat	Yes	No	_____	Yes	No
Nausea	Yes	No	_____	Yes	No
Breathlessness	Yes	No	_____	Yes	No
Weight Loss	Yes	No	_____	Yes	No
Fatigue	Yes	No	_____	Yes	No
Stiff Joints	Yes	No	_____	Yes	No
Sore Eyes	Yes	No	_____	Yes	No
Wheeziness	Yes	No	_____	Yes	No
Headaches	Yes	No	_____	Yes	No
Upset Stomach	Yes	No	_____	Yes	No
Sleep Difficulties	Yes	No	_____	Yes	No
Dizziness	Yes	No	_____	Yes	No
Loss of Strength	Yes	No	_____	Yes	No

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My illness will last a short time					
IP2	My illness is likely to be permanent rather than temporary					
IP3	My illness will last for a long time					
IP4	This illness will pass quickly					
IP5	I expect to have this illness for the rest of my life					
IP6	My illness is a serious condition					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP7	My illness has major consequences on my life					
IP8	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17	My actions will have no affect on the outcome of my illness					
IP18	My illness will improve in time					
IP19	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented (avoided) by my treatment					
IP22	My treatment can control my illness					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My illness is a mystery to me					
IP26	I don't understand my illness					
IP27	My illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of my condition					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse.					
IP33	I get depressed when I think about my illness					
IP34	When I think about my illness I get upset					
IP35	My illness makes me feel angry					
IP36	My illness does not worry me					
IP37	Having this illness makes me feel anxious					
IP38	My illness makes me feel afraid					

CAUSES OF MY ILLNESS

We are interested in what <u>you</u> consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused <u>YOUR illness.</u> You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. _____

2. _____

3. _____

Appendix 14: Covering letter

Local Hospital headed paper

Dear

Your GP has referred you to the Rheumatology Department at NBT for an appointment about your joints.

We are collaborating with Julie Taylor, a PhD a student from the University of the West of England, who is undertaking a research study about understanding the patients' journey from their GP referral to their first outpatient visit. And we are delighted to help her in this important work.

I would be grateful if you could read the enclosed information sheet to see if you are interested in taking part. This is quite voluntary, and if you decide not to take part it will not impact on your medical care.

Your medical appointment will not be altered, whether you take part in the research or not.

Please could you return your reply in the first class envelope provided.

Thanks you for your time,

Yours sincerely

Rheumatology Consultant

Appendix 15: Patient information sheet (qualitative arm)

Patient information sheet

<u>A multi-centre study to understand the patients' journey from their GP visit to their first outpatients'</u>

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives or your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
You have been referred to the musculoskeletal department by your GP to see a consultant. We would like to talk to you before and after your consultation to try to understand what people's experiences through this period are are. We will talk about your symptoms, how you manage them and how you feel. The purpose of this study is to get a better understanding of what people go through at this time and what they feel in themselves.

Why have I been chosen?
You are being invited to take part because you have been referred for advice on your joints and we would like to find out about your experiences. We are inviting 15 patients like you to take part, from three different hospitals up and down the country.

Do I have to take part?
No, taking part is voluntary. It is up to you to decide whether or not to take part. If you do decide to take part we will ask you to sign a consent form and give you a copy of this information sheet and the consent form to keep. If you decide to take part you are still free to withdraw at any time. If you decide not to take part you do not have to give a reason, nobody will be upset and the standard of care you receive will not be affected.

What will I be asked to do if I take part?

You will be asked to complete some questionnaires about how you feel, and how your joints are doing this will happen about a week before you see the hospital doctor. The package contains several questionnaires. It will take about 10 minutes to complete, so it is worth sitting down with a cup of coffee while you do it! The questions only need simple ticks; you do not have to write anything. Don't dwell on the questions – there are no right or wrong answers, only what you feel. At around this time we would also like to interview you. This will be taped recorded and each interview will last approximately 45 minutes the focus of these interviews is to understand how you feel and how you are dealing with your symptoms. We will pay for your travel costs.

We would then like to repeat the questionnaires and the interview about a week after you see the consultant again to find out how you are doing and how you feel, and to see if there are any changes.

We would also like to tape the consultation with your hospital doctor; this is to find out what the doctor says to you in this interview.

No changes will be made to your medical care because of the study; you will be treated just as usual.

What are my responsibilities?

We would like you to discuss with the researcher why you went to the GP, how you feel about your symptoms and what you do generally to help your symptoms, we would like you to be as honest as possible during the interviews and when you are completing the questionnaires, remember there are no wrong or right answers.

If you feel that you would prefer not be interviewed but are happy to complete the questionnaires then please let the researcher know when she telephones you.

What are the possible side effects of taking part?
The research study consists only of two packages of questionnaires and two interviews; therefore we do not expect any side effects, however if you feel upset at all during the interviews you can ask for the interviews to be stopped.

What are the possible benefits in taking part?
We do not expect there to be any benefits for you in taking part. However the information you give us will help us in the care we give for future patients.

Will my taking part in this study be kept confidential?
The researcher may examine your medical records. However, your name will not be disclosed outside the hospital although with your permission, your GP will be informed you are taking part. All tape recording will be kept anonymous i.e. no one will know your name.

What will happen to the results of the research study?
The results of this study will not be known until the last patient has finished in about three year's time. The researcher will let you know the results. The results may be reported in professional publications or meetings but you will not be identified by name.

Who is organizing and funding the research?
This study is being funded by a grant from a charity, the Arthritis Rheumatism Council.

Who has reviewed the study?
The Local Research Ethics Committee and the University of the West of England have approved the study.

What do I do now?
Thank you for considering taking part in this research. The researcher will contact you in a few days. You can ask any questions you have and let her know whether you would like to take part.

**Study
Team**

**Julie Taylor, Research PhD student,
University of the West of England**

**Academic Rheumatology, Bristol Royal Infirmary, Bristol Tel no
01179284872**

**Prof Sarah Hewlett arc Professor of Rheumatology Nursing and
Hon Consultant Nurse, UWE (Supervisor)
Dr Marianne Morris, Principle Lecturer in Health Psychology, UWE Bev Davis,
Patient Research Partner, Academic Rheumatology, BRI**

Appendix 16: Information sheet (quantitative arm)

Patient information sheet

<u>A multi-centre study to understand the patients' journey from their GP visit to their first outpatients'</u>

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives or your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
You have been referred to the musculoskeletal department by your GP to see a consultant. We would like to record some information before and after your consultation, this is to try to understand what people's experiences through this period are. We are looking for information about your symptoms, how you manage them and how you feel. The purpose of this study is to get a better understanding of what people go through at this time and what they feel in themselves.

Why have I been chosen?
You are being invited to take part because you have been referred for advice on your joints and we would like to find out about your experiences. We are inviting a number of patients like you to take part, from three different hospitals up and down the country.

Do I have to take part?
No, taking part is voluntary. It is up to you to decide whether or not to take part. If you do decide to take part we will ask you to sign a consent form and give you a copy of this information sheet and the consent form to keep. If you decide to take part you are still free to withdraw at any time. If you decide not to take part you do not have to give a reason, nobody will be upset and the standard of care you receive will not be affected.

What will I be asked to do if I take part?

You will be asked to complete some questionnaires about how you feel, and how your joints are doing, this will happen about a week before you see the hospital doctor. The package contains several questionnaires. It will take about 10-15 minutes to complete, so it is worth sitting down with a cup of coffee while you do it! The questions only need simple ticks; you do not have to write anything. Don't dwell on the questions – there are no right or wrong answers, only what you feel. We would then like to repeat these about a week after you see the consultant again to find out how you are doing and how you feel, and to see if there are any changes.

No changes will be made to your medical care because of the study; you will be treated just as usual.

What are my responsibilities?
When you are completing the questionnaires, remember there are no wrong or right answers we would like you to complete as many of the questionnaires as fully as possible and then send them back in the stamped addressed envelopes as soon as you can.

What are the possible side effects of taking part?
The research study consists only of two packages of questionnaires; therefore we do not expect any side effects.

What are the possible benefits in taking part?
We do not expect there to be any benefits for you in taking part. However the information you give us will help us in the care we give for future patients.

Will my taking part in this study be kept confidential?
The researcher may examine your medical records. However, your name will not be disclosed outside the hospital although with your permission, your GP will be informed you are taking part.

What will happen to the results of the research study?
The results of this study will not be known until the last patient has finished in about three year's time. The researcher will let you know the results. The results may be reported in professional publications or meetings but you will not be identified by name.

Who is organizing and funding the research?
This study is being funded by a grant from a charity, the Arthritis Rheumatism Council.

Who has reviewed the study?
The Local Research Ethics Committee and the University of the West of England have approved the study.

What do I do now?
Thank you for considering taking part in this research. The researcher will contact you in a few days. You can ask any questions you have and let her know whether you would like to take part.

<div align="center">

**Study
Team**

**Julie Taylor, Research PhD student,
University of the West of England
Academic Rheumatology, Bristol Royal Infirmary, Bristol
Tel no 0117 9284872**

**Prof Sarah Hewlett arc Professor of Rheumatology Nursing and
Hon Consultant Nurse, UWE (Supervisor)**

**Dr Marianne Morris, Principle Lecturer in Health Psychology,
UWE Bev Davis, Patient Research Partner, Academic Rheumatology, BRI**

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Version date: July 2009.

Appendix 17: Pictorial representation of patient perspective from pre-consultation
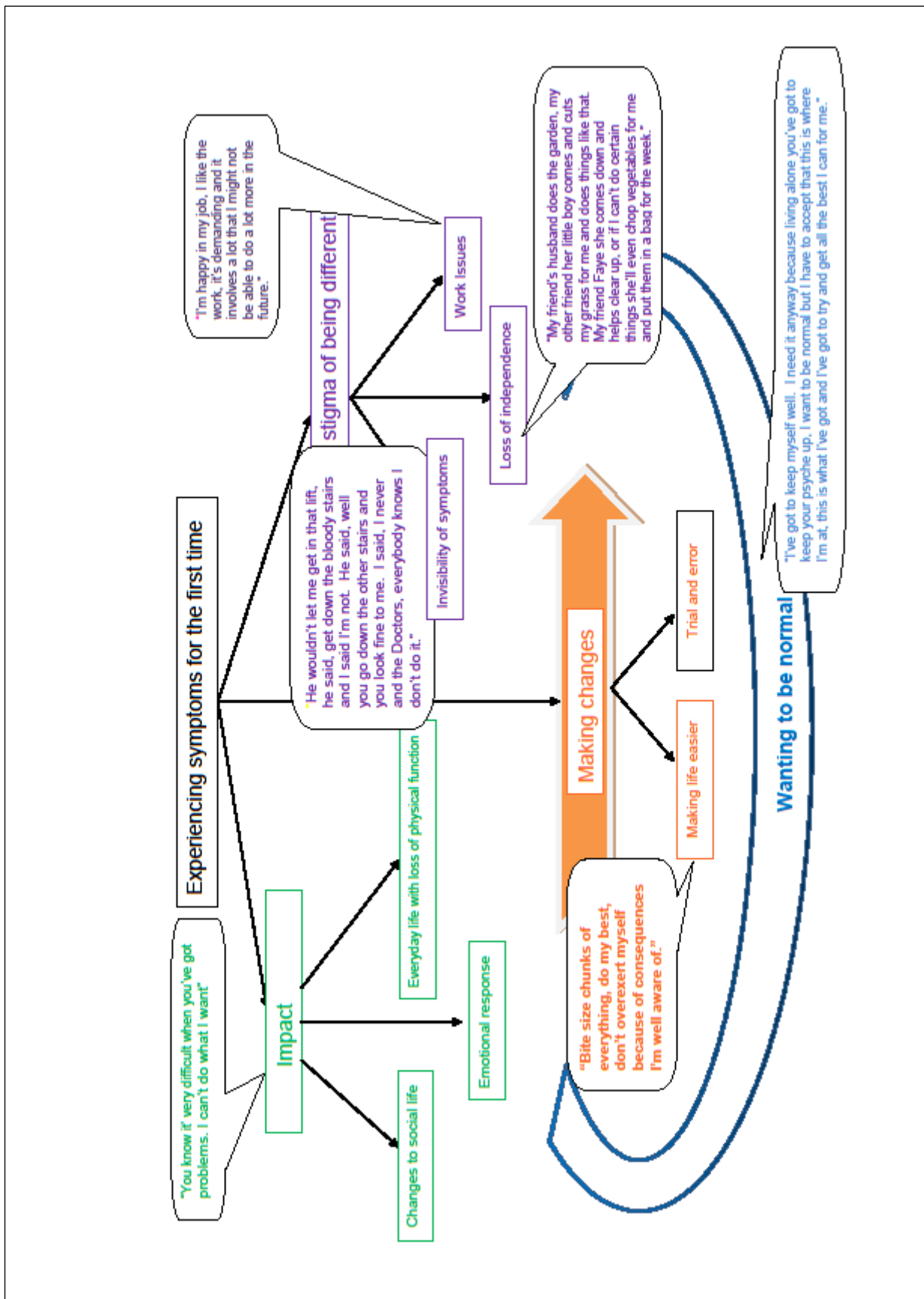
		Terry				Don				Bob				Nicola				Maggie			
Timepoint (weeks)		0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52
Pain	0-100	36	51	58	48	58	60	40	36	22	20	11	7	69	32	52	85	13	13	13	3
GHAS	0-100	54	7	56	37	54	43	30	30	17	15	11	8	50	34		41	17	19	20	9
Fatigue	0-10	5	7	7	5	3	3	3	4	1	1	2	1	8	9	7	8	0	0	2	3
F-Effect	0-10	5	7	7	5	3	4	4	3	1	1	2	1	9	4	7	8	0	0	3	2
HAQ	0-3	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	0.00	0.00	0.00	0.00	1.25	2.38	2.00	2.00	0.00	0.00	0.00	0.50
RAQOL	0-30	21	19	19	17	8	6	6	6	0	0	0	0	29	20	24	22	2	2	8	8

		Jane				Tom				Fiona				James				Jenny			
Timepoint (weeks)		0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52
Pain	0-100	70	70	55		30	20	10	25	76	70	70	68	40	34	20	20	35	30	20	20
GHAS	0-100	80	78	78	60	78	90	13	38	35	40	35	40	20	20	15	15	25	19	17	20
Fatigue	0-10	6	9	7		6	7	3	2	7	7	7	7	2	2	2	2	6	6	6	6
F-Effect	0-10	6	6	6		6	8	2	2	6	7	7	6	0	0	0	0	5	5	5	5
HAQ	0-3	1.50	2.00	1.00		1.00	1.00	1.00	0.87	1.25	1.50	0.12	0	0.12	0	0.12	0.00	1.25	1.00	1.00	1.00
RAQOL	0-30	26	26	28		21	8	3	0	20	22	26	20	0	0	0	0	14	10	10	12

		Jacob				Cheryl				Ian				Betty				Sally			
Timepoint (weeks)		0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52
Pain	0-100	65	40	55	45	63	60	73	60	40	45	30	28	60	40	38	35	55	58	40	45
GHAS	0-100	70	50	50	40	60	60	57	59	30	30	20	15	50	50	40	27	60	60	50	50
Fatigue	0-10	7	6	6	6	7	7	7	7	4	4	4	4	7	7	6	7	8	8	9	7
F-Effect	0-10	8	5	5	5	8	7	8	7	2	2	2	2	5	5	5	5	7	7	7	8
HAQ	0-3	1.50	1.25	1.00	1.37	2.00	2.00	2.00	0.37	0.25	0.25	0.25	0.00	0.87	1.00	0.50	0.50	1.00	1.00	0.62	0.62
RAQOL	0-30	20	20	17	12	26	28	28	26	2	2		.	3	5	3	5	14	16	14	16

Social support for each patient at each time point (n=15)

n/a indicates where participants do not have a partner or have chosen not to indicate a best friend.

	Terry				Don				Bob				Nicola				Maggie			
Time point (weeks)	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**
Spouse/partner																				
Emotional	8	8	8	12	n/a	n/a	n/a	n/a	14	14	14	14	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Ideal	13	13	14	13	n/a	n/a	n/a	n/a	14	14	14	14	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Discrepancy	-5	-5	-5	-1	n/a	n/a	n/a	n/a	0	0	0	0	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Best friend																				
Emotional	11	11	11	12	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	10	11	11	12	n/a	n/a	n/a	n/a
Ideal	12	11	11	12	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	13	11	11	12	n/a	n/a	n/a	n/a
Discrepancy	-1	0	0	0	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	-3	0	0	0	n/a	n/a	n/a	n/a
Spouse/partner																				
Practical	8	7	10	10	n/a	n/a	n/a	n/a	14	14	14	14	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Ideal	13	14	12	11	n/a	n/a	n/a	n/a	14	14	14	14	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Discrepancy	-5	-7	-2	-1	n/a	n/a	n/a	n/a	0	0	0	0	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Best friend																				
Practical	14	13	14	13	n/a	n/a	n/a	n/a	n/a	n/a	n/a	11	11	11	13	13	n/a	n/a	n/a	n/a
Ideal	14	14	14	13	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	11	11	13	13	n/a	n/a	n/a	n/a

Social support for each patient at each time point (n=15)

n/a indicates where participants do not have a partner or have chosen not to indicate a best friend.

Time point (weeks)	Jane 0	Jane 2	Jane 26	Jane 52	Tom 0	Tom 2	Tom 26	Tom 52	Fiona 0	Fiona 2	Fiona 26	Fiona 52	James 0	James 2	James 26	James 52	Jenny 0	Jenny 2	Jenny 26	Jenny 52
Spouse/partner																				
Emotional	14	10	10		14	14	14	14	n/a	na/	n/a	n/a	14	14	14	14	12	12	13	13
Ideal	12	13	14		14	14	14	14	n/a	na/	n/a	n/a	14	14	14	14	14	14	13	13
Discrepancy	+2	-3	-4		0	0	0	0	n/a	na/	n/a	n/a	0	0	0	0	-2	-2	0	0
Best friend																				
Emotional	11	13	13		n/a	na/	n/a	n/a	14	10	10	10	n/a	na/	n/a	n/a	n/a	na/	n/a	n/a
Ideal	13	13	13		n/a	na/	n/a	n/a	11	14	14	14	n/a	na/	n/a	n/a	n/a	na/	n/a	n/a
Discrepancy	-2	0	0		n/a	na/	n/a	n/a	+3	-4	-4	-4	n/a	na/	n/a	n/a	n/a	na/	n/a	n/a
Spouse/partner																				
Practical	11	9	9		14	14	14	14	n/a	na/	n/a	n/a	14	14	14	14	14	14	14	14
Ideal	11	13	14		14	14	14	14	n/a	na/	n/a	n/a	14	14	14	14	14	14	14	14
Discrepancy	0	-4	-5		0	0	0	0	n/a	na/	n/a	n/a	0	0	0	0	0	0	0	0
Best friend					n/a	na/	n/a	n/a					n/a	na/	n/a	n/a	n/a	na/	n/a	n/a
Practical	13	13	14		n/a	na/	n/a	n/a	11	11	11	12	n/a	na/	n/a	n/a	n/a	na/	n/a	n/a
Ideal	13	13	14		n/a	na/	n/a	n/a	11	11	11	12	n/a	na/	n/a	n/a	n/a	na/	n/a	n/a

Social support for each patient at each time point (n=15)

n/a indicates where participants do not have a partner or have chosen not to indicate a best friend.

Time point (weeks)	Jacob				Cheryl				Ian				Betty				Sally			
	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52
Spouse/partner																				
Emotional	13	13	13	13	7	13	5	0	13	12		14	10	10	10	10	13	13	13	13
Ideal	13	13	13	13	4	10	10	12	12	12		14	10	10	10	10	14	14	14	14
Discrepancy	0	0	0	0	+3	+3	-5	-12	1	0		0	0	0	0	0	-1	-1	-1	-1
Best friend																				
Emotional	n/a	n/a	n/a	n/a	7	7	7	12	n/a	n/a		n/a	n/a	n/a	n/a	n/a	12	12	12	12
Ideal	n/a	n/a	n/a	n/a	12	12	10	12	n/a	n/a		n/a	n/a	n/a	n/a	n/a	12	12	12	12
Discrepancy	n/a	n/a	n/a	n/a	-5	-5	-3	0	n/a	n/a		n/a	n/a	n/a	n/a	n/a	0	0	0	0
Spouse/partner																				
Practical	14	14	12	12	14	14	7	3	10	10		10	10	10	10	10	14	14	14	14
Ideal	10	10	12	12	10	10	10	12	10	10		10	10	10	10	10	14	14	14	14
Discrepancy	+4	+4	0	0	+4	+4	-3	-9	0	0		0	0	0	0	0	0	0	0	0
Best friend																				
Practical	n/a	n/a	n/a	n/a	7	7	12	12	n/a	n/a		n/a	n/a	n/a	n/a	n/a	10	10	10	10
Ideal	n/a	n/a	n/a	n/a	13	13	12	12	n/a	n/a		n/a	n/a	n/a	n/a	n/a	10	10	10	10

Illness beliefs for each patient at each time point (n=15)

	Terry				Don				Bob				Nicola				Maggie			
Time point (weeks)	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**
Identity	5	7	5	5	4	4	3	4	3	3	2	3	6	6	7	7	4	4	6	5
Timeline	24	23	23	24	24	21	22	23	23	23	24	24	29	21	25	29	17	17	25	30
Consequences	25	23	23	21	25	25	23	21	18	18	13	16	27	20	22	26	13	23	23	18
Personal Control	20	19	19	19	20	20	20	20	22	22	22	21	17	23	26	21	22	22	25	22
Treatment Control	15	16	13	13	20	22	20	20	20	20	19	20	17	18	13	16	18	20	20	20
Coherence	6	12	16	20	20	20	22	20	20	20	24	19	14	19	17	18	6	6	10	13
Timeline- fluctuating	20	16	16	16	18	18	18	16	12	12	12	12	19	19	20	20	17	17	20	20
Emotional	20	18	20	19	13	14	14	16	15	15	13	14	16	21	23	22	21	21	22	21

	Jane				Tom				Fiona				James				Jenny			
Time point (weeks)	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**	**0**	**2**	**26**	**52**
Identity	3	3	3		5	5	6	6	8	8	7	5	3	3	4	3	5	6	6	6
Timeline	28	28	26		19	30	29	27	28	28	26	28	23	23	24	24	26	30	29	27
Consequences	29	29	29		27	21	24	24	29	29	29	28	18	18	13	16	27	21	27	24
Personal Control	17	18	22		20	24	25	21	17	18	22	22	22	22	22	21	20	24	25	25
Treatment Control	20	20	20		16	16	18	25	20	20	20	22	20	20	22	20	16	20	18	25
Coherence	14	20	20		14	20	19	20	14	20	20	20	20	20	24	19	14	19	19	20
Timeline- fluctuating	15	16	16		14	14	10	13	15	16	16	16	12	12	12	14	14	14	10	13
Emotional	30	30	28		25	19	13	16	30	30	28	26	13	13	13	13	25	19	19	16

Illness beliefs for each patient at each time point (n=15)

	Jacob				Cheryl				Ian				Betty				Sally			
Time point (weeks)	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52
Identity	5	4	5	5	8	8	7	7	4	4	4	3	3	3	3	3	6	6	7	7
Timeline	19	22	26	27	21	21	23	23	19	28	29	27	19		26	27	20	20	23	23
Consequences	27	22	22	24	29	29	29	29	27	21	24	24	20	21	20	21	29	30	29	29
Personal Control	20	22	25	25	20	21	22	21	20	24	25	28	20	24	25	28	16	14	20	21
Treatment Control	16	16	18	25	20	18	18	18	16	18	18	25	16	16	18	25	16	16	18	18
Coherence	14	20	19	20	8	20	20	20	14	20	19	20	16	20	20	20	8	12	20	20
Timeline- fluctuating	14	14	10	13	15	16	16	15	14	14	10	13	14			10	14	15	16	16	15
Emotional	25	19	13	16	30	30	30	30	13	12	13	12	12	12	12	12	30	28	29	30

Psychological status and coping strategies for each patient at each time point (n=15)

Time point	Terry				Don				Bob				Nicola				Maggie			
	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52
Anxiety	10	5	7	7	2	2	7	5	1	1	2	5	10	8	7	9	1	1	4	4
Depression	5	4	5	5	2	2	2	2	2	2	2	1	10	6	5	6	1	1	3	2
Helplessness	18	21	22	20	11	11	22	10	16	16	11	15	26	17	12	20	7	7	11	6
Fatigue - coping	5	6	4	4	3	3	3	3	9	9	9	9	7	9	10	8	10	7	7	8
Coping (MCQ)																				
Confront	19	21	15	15	19	19	19	19	19	19	19	19	18	18	28	25	20	30	30	22
Acceptance	8	6	6	10	5	5	5	5	5	5	5	6	8	7	7	7	9	9	7	12
Avoidance	17	15	17	16	15	15	11	15	15	15	11	15	21	19	17	19	14	16	16	15
Stage of change																				
Pre-Contemplate	16	17	16	21	24	24	22	24	24	24	22	20	11	17	13	14	20	10	10	12
Contemplate	31	20	20	24	30	30	23	30	30	30	23	29	36	33	33	28	27	27	33	13
Action	31	31	31	28	32	32	25	32	32	32	25	24	35	32	33	30	21	23	28	38
Maintenance	29	28	28	22	30	29	21		29		21	25	30	25	29	32	21	21	6	26

Psychological status and coping strategies for each patient at each time point (n=15)

Time point	Jane 0	2	26	52	Tom 0	2	26	52	Fiona 0	2	26	52	James 0	2	26	52	Jenny 0	2	26	52
Anxiety	18	18	16	X	6	9	4	5	16	15	15	15	0	0	0	0	6	4	2	2
Depression	11	11	11	X	8	6	4	6	15	13	13	11	0	0	0	0	2	2	2	0
Helplessness	26	26	21	X	21	18	17	13	20	21	20	21	12	12	11	10	12	13	12	13
Fatigue - coping	9	8	6	X	6	9	9	8	4	5	5	5	9	9	9	9	6	6	7	7
Coping (MCQ)																				
Confront (0-XX)	22	22	21	21	20	19	20	22	22	22	21	21	19	19	19	19	20	19	20	22
Acceptance	12	10	10	12	8	8	6	6	12	15	15	12	8	X	8	6	10	10	8	12
Avoidance	15	15	18	15	12	11	15	12	15	15	18	15	15	15	11	15	12	11	11	11
Stage of change																				
Pre-Contemplate	12	12	13	12	22	17	21	26	10	12	13	12	24	24	22	24	22	22	22	26
Contemplate	13	26	28	28	33	25	30	29	18	26	28	28	30	X	23	29	33	25	30	29
Action	21	17	17	17	32	28	26	25	28	18	17	17	32	X	25	24	32	28	28	28
Maintenance	26	26	26	26	27	23	22	15	26	26	26	26	29	26	21	25	27	23	22	20

Psychological status and coping strategies for each patient at each time point (n=15)

Time point	Jacob				Cheryl				Ian				Betty				Sally			
	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52	0	2	26	52
Anxiety	6	4	4	4	15	15	18	18	0	0	0	0	4	4	4	4	12	11	11	8
Depression	8	4	0	1	13	13	13	13	0	0	0	0	2	2	2	2	2	2	2	2
Helplessness	16	16	11	16	26	26	21	21	12	12	12	11	11	10	12	12	20	18	16	16
Fatigue - coping	3	3	4	3	5	3	6	6	8	8	9	9	7	7	8	8	3	3	5	5
Coping (MCQ)																				
Confront (0-XX)	22	20	20	22	22	22	21	21	19	19	19	19	19	19		19	22	22	21	21
Acceptance	8	8	6	6	12	10	10	12	5	5	5	6	7	7		8	12	10	10	12
Avoidance	12	11	15	12	15	15	18	15	15	15	11	15	11	12		15	15	18	18	15
Stage of change																				
Pre-Contemplate	22	17	21	26	12	12	13	12	24	24	22	20	22	24		20	12	12	13	12
Contemplate	33	25	30	30	13	26	28	28	30	30		29	28	28		29	13	26	28	28
Action	32	30	26	26	38	17	17	17	32	32		24	24			24	17	17	17	17
Maintenance	22	22	22	15	26	26	26	26	29	25	21	25	24			25	26	24	24	26