Capturing daily fluctuations, flare and self-management in rheumatoid arthritis: The patient perspective

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Abstract

Rheumatoid arthritis (RA) is a chronic, progressive and systemic auto-immune disease. However, there is very little research on how patients experience daily symptoms and their impact on life, nor how patients self-manage their symptoms on current treatment regimes. Flares of RA lead to major drug treatment decisions, yet there is no standardised definition of flare to support these decisions. Further, there is a dearth of literature addressing the decision-making process surrounding flare help-seeking. A mixed methods, pragmatic approach was taken to address these issues, employed iteratively in three studies: semi-structured interviews, Q-methodology and a longitudinal survey of daily symptoms for three months, alongside self-management and flare help-seeking.

The interviews identified that even on current aggressive medication, in daily life patients experience continuing symptoms that vary within and between patients, and can be significant. When discussing their RA, patients used metaphors to enhance their explanations of inexplicable phenomena, such as flare. They fluctuate between living with their RA in the background, moving into the foreground, and at times having to deal with RA in the foreground. Each day patients attempt to balance the physical and emotional impact of RA with independence, a sense of normality and identity, by employing a stepped approach to self-management (“Mediation Ladder”), which leads to a life of Fluctuating Balances. When self-management is difficult, the Fluctuating Balances Model tips and their RA shifts into the foreground. The interview themes informed the two Q-methodology studies, which demonstrated four different experiences of daily life: “Feeling Good”, “Taking Active Control”, “Keeping RA in its Place” and “Struggling Through” (reported predominantly by men) and two ways in which patients differed in their decision-making process for seeking medical help for an RA flare: “Definite Decision” and “Cautious Indecision”. Items ranked as important were used to inform the survey studies, which identified that patients do not necessarily experience their highest symptoms when they are in flare. Thus two different flare-types have been identified: “Inflammatory Flare” (defined by pain and inflammation) and “Avalanche Flare” (defined by the cascading effect of inflammatory symptoms, emotions and life events). Patients are prompted to seek help when the impact of the flare becomes unmanageable.

These findings have implications for clinical practice. First, the improved understanding of daily life with RA can be used to talk realistically with new patients about levels of symptoms and the Fluctuating Balances of daily life. Second, there is a need for agreed terminology between patients and professionals to define flare. Third, clinicians need to be aware that men are “struggling through” with their RA. Fourth, using or responding to metaphors may facilitate communication between patients and professionals. Future research needs to develop a greater understanding of men’s experiences of RA and support needs; to design an outcome measure for the novel concept of “Avalanche Flare”; and a fully-powered study to identify daily symptom patterns and potentially predict future symptom/flare patterns that might inform treatment decisions.

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List of abbreviations used in this thesis

AASTT	Animal Attribution Story-Telling Technique
ACR	American College of Rheumatology
AMI	Acute Myocardial Infarction
Anti-TNF	Anti-Tumour Necrosis Factor
ARA	American Rheumatism Association
AS	Ankylosing Spondylitis
ASPH	Ashford and St Peter's Hospital Trust
BRI	Bristol Royal Infirmary
CRP	C-Reactive Protein
DAS	Disease Activity Score
DCCT	Disease Control and Complications Trial
DMARDs	Disease Modifying Anti-Rheumatic Drugs
EMS	Early Morning Stiffness
ESR	Erythrocyte Sedimentation Rate
EULAR	European League Against Rheumatism
FLARE	The Flare Assessment in Rheumatoid Arthritis
HAQ	Health Assessment Questionnaire
HBM	Health Belief Model
HLC	Health Locus of Control
IPA	Interpretative Phenomenological Analysis
MHLC	Multidimensional Health Locus of Control
MS	Multiple Sclerosis
NBT	North Bristol NHS Trust
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NSAIDs	Non-Steroidal Anti-Inflammatory Drugs
OMERACT	Outcome Measures in Rheumatology *(Originally: Outcome Measures in Rheumatoid Arthritis Clinical Trials)*
PI-HAQ	Personal Impact – Health Assessment Questionnaire
PROMs	Patient Reported Outcome Measures
PSS	Primary Sjogren's Syndrome
Pt Global	Patient Global Measure of the DAS
RA	Rheumatoid Arthritis
RCT	Randomised Controlled Trial

RCTC	Rheumatology Common Toxicity Criteria
SCT	Social Cognition Theory
SE	Self-Efficacy
SIG	Special Interest Group
SRM	Self-Regulatory Model
TA	Thematic Analysis
TICORA	Tight Control of Rheumatoid Arthritis
TPB	Theory of Planned Behaviour
UHBT	University Hospitals Bristol NHS Trust
UoB	University of Bristol
UWE	University of the West of England
VPMI	Vanderbilt Pain Management Inventory
WHO	World Health Organisation

Notes to the reader

It is acknowledged that a person with RA has a self-identity that incorporates many roles, and being an RA patient is only one of these roles. However, to conserve words the term ‘RA patient’ has been used throughout this thesis instead of ‘person who has RA’.

Sections of this thesis have been sign-posted thoughout to assist the reader. In order to conserve words these have been written in the format Chapter x.x.x, for example Chapter 6.5.4, although it is acknowledged that this would be Chapter 6, Section 5, Sub-section 4 if reported in full.

Chapter 1: Introduction to the thesis

The intention of this thesis is to explore the daily fluctuation and flare symptoms of people with rheumatoid arthritis, how they self-manage these and their help-seeking behaviours. As an introduction to the thesis, this chapter provides a description of rheumatoid arthritis, the charity that funded this research, the unit where the researcher was based, and the researcher herself. The aims and structure of the thesis are also outlined in this chapter.

1.1 Rheumatoid Arthritis

Rheumatoid arthritis (RA) is a chronic, progressive and systemic auto-immune disease. The disease can progress rapidly, causing synovitis and damaging cartilage and bone around the joints (Emery *et al*, 2008b). The American College of Rheumatology (ACR) criteria for the classification of RA are that criteria 1 to 4 (below) must be present for at least six weeks, and that RA is defined by four or more of these seven variables (Arnett *et al*, 1988):

1. Morning stiffness
2. Arthritis of three or more joint areas
3. Arthritis of the hands
4. Symmetric arthritis
5. Rheumatoid nodules
6. Serum rheumatoid factor
7. Radiographic changes

Inflammation causes pain and fatigue and damage causes disability and loss of mobility. The literature relating to the symptoms and impact that patients experience as part of their life with RA will be explored in Chapter 2 of this thesis.

The prevalence of RA in most industrialised countries varies between 0.3% and 1% (WHO, 2003), with RA affecting more women (70%) than men (Crowson *et al*, 2011). Studies conducted in the 1990s have shown that patients with RA may have shorter life expectancy (Wolfe *et al,* 1994), with mortality being related to systemic effects of the disease, such as cardiovascular co-morbidity, rather than side-effects of drugs (Rasker and Cosh, 1992; Symmons *et al*, 1998). However, more recent studies suggest there is no longer a difference in mortality between RA patients and the general population (Peltomaa *et al*, 2002; Kapetanovic *et al,* 2011), which may reflect better inflammatory control. The aetiology of RA is currently unknown (Yoshitomi and Sakaguchi, 2005) and the condition is presently incurable.

1.2 Arthitis Research UK

Founded in 1936 (as the Empire Rheumatism Council), Arthritis Research UK are the leading arthritis research charity in the UK, funding work which is expected to make a real difference to people's lives (Arthritis Research UK, 2011a). Arthritis Research UK funded the research for this thesis, but they had no influence on the findings or publications.

1.3 Academic rheumatology unit

Based in the Bristol Royal Infirmary, the academic rheumatology unit is a multidisciplinary unit comprising staff from University of the West of England (UWE), University of Bristol (UoB) and University Hospitals Bristol NHS Trust (UHBT). The unit provides care for patients with arthritis and similar conditions and undertakes research into its causes and treatment. The unit also provides education about arthritis for health care professionals, students, patients and the general public. The academic setting in the unit is adjacent to the clinical setting, which provides ready access to patients. The unit has pioneered patient involvement in research (Hewlett *et al,* 2006) and patient-initiated consultations (Kirwan *et al,* 2003; Hewlett *et al*, 2005b), as such this may have created a specific population of patients, and therefore patients in these studies were recruited from more than one NHS Trust to ensure an unbiased view.

1.4 The researcher

1.4.1 Prior knowledge

The researcher began this research project with a grounding in the health psychology of long term conditions, but without any prior knowledge of RA. She started by learning about personal experiences of RA from her patient research partners and through sitting in on rheumatologist and specialist nurse clinics in addition to familiarising herself with the RA literature.

1.4.2 Epistemological position

The researcher considers herself a pragmatist, and therefore has taken a pragmatic approach to this thesis. Pragmatism has been suggested as a framework that has the potential to embrace both qualitative and quantitative approaches (Tashakkori and Teddlie, 1998; Fishman, 1999) and that supports the mixed methods paradigm (Feilzer, 2010), which suits the aims of this thesis. An important philosophical issue in research concerns the relative importance of paradigms, research methods and research questions. It has been proposed that research methods are of secondary importance to research paradigms (Guba and Lincoln, 1994). However, pragmatists consider the research question to be more important than either the method they use or the world-view that underlies the method (Tashakkori and Teddlie, 1998). Pragmatists do not reject epistemologies altogether, but instead reject the ‘top-down’ approach that privileges epistemology over methods and emphasises ontological issues above all others (Morgan, 2007). Pragmatic research is guided by the researcher’s desire to produce socially useful knowledge (Friedrichs and Kratochwil, 2009). Thus the researcher considers herself a pragmatist, as she does not feel bound to any epistemological or ontological standpoint, and the thesis takes a pragmatic approach as the research questions were established prior to the methodology.

1.5 Summary of rationale, aims and research questions

More detailed descriptions of the rationale and specific study aims are provided in subsequent chapters.

1.5.1 Thesis rationale

There is a lack of research examining daily life with RA and how patients self-manage this on current modern treatment regimes. The literature review (Chapter 2) has identified that there is no current agreement on how patients and professionals define flare and only one small qualitative study (Kett *et* al, 2010) could be found that addressed how patients manage their flares and make the decision to seek help for their RA flare.

1.5.2 Thesis aims

- To explore the individual experience and impact of RA in daily life and flare and how patients self-manage these
- To obtain consensus on patients’ experiences of daily life with RA
- To obtain consensus on patients’ help-seeking behaviours in an RA flare
- To characterise the level, variation and clustering of symptoms in daily life

1.5.3 Thesis research questions

- What is the nature and effect of the daily symptoms experienced in rheumatoid arthritis and how do patients self-manage these?
- How do patients conceptualise and describe a flare and differentiate it from normal variation or periodic episodes of disease activity?
- What are the level, variation and clustering of symptoms experienced in daily life and in flare?

1.6 Thesis structure

In order to meet the research aims, the thesis has been divided into ten chapters (including the current chapter). This has been structured in the format of three background literature review chapters, followed by the methods and methodology chapter, which considers all three studies. This is followed by four chapters presenting the results of the three studies and includes a brief discussion relevant to the specific study. Study 1 underwent secondary analysis, hence the additional results chapter (metaphor analysis). The thesis ends with the discussion, which draws conclusions and makes recommendations for clinical practice and future research (Chapter 10).

Chapter 2: Daily Symptoms of Rheumatoid Arthritis and Flare

This chapter explores the literature on the daily fluctuation of symptoms experienced by people with rheumatoid arthritis and how these symptoms affect their psychological status and impacts on their daily life. It explores the literature on the concept of flare and how this differs from the daily fluctuation of symptoms. It also addresses the literature on the potential difference in patients' and professionals' perspectives.

2.1 Fluctuations of RA symptoms in daily life

People newly-diagnosed with RA have many questions concerning the effects RA may have on them in daily life (Radford *et al,* 2008). Due to the unpredictable and fluctuating nature of RA, clinicians often have difficulty in explaining what everyday life with RA is like. This literature review therefore starts by identifying what is known about the symptoms of RA.

2.1.1 Joint stiffness and synovitis

Both swelling (synovitis) and stiffness form part of the criteria for classifying RA according to the American Rheumatism Association (Arnett *et al*, 1988). The revised criteria state that at least four of 7 criteria must be present in order for RA to be diagnosed. These criteria include 1) morning stiffness in and around joints lasting at least one hour before maximal improvement; 2) soft tissue swelling of 3 or more joint areas observed by a physician; 3) swelling of the proximal interphalangeal, metacarpophalangeal or wrist joints; 4) symmetric swelling in 3 or more joint areas; 5) Rheumatoid Nodule; 6) Rheumatoid factor by method positive in <5% normal population; 7) Radiographic changes on wrist/hands: erosions or juxta-articular osteoporosis.

2.1.1.1 Synovitis

Synovitis is inflammation of the synovial membrane that lines joints and tendon sheaths. Joints become swollen, tender and warm, and stiffness limits their movement (Majithia and Geraci, 2007). RA affects multiple joints (it is a polyarthritis), most commonly small joints of the hands and feet but larger joints like the shoulder and knee can also be involved (Majithia and Geraci, 2007).

The clinical measure of inflammation relies on the assessment of tenderness, swelling, warmth and redness by observation and palpation (Buchanan and Tugwell, 1983). Joint tenderness is a subjective sign that depends on the pain threshold of the patient as well as the strength of the stimulus, whilst joint swelling is a semi-objective sign that depends on the perception of the examiner (Thompson and Kirwan, 1995).

Swollen joint counts correlate significantly with the erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP) but less well with pain scores (Thompson *et al,* 1987; Felson *et al*, 1993), which indicates a closer relationship with synovial inflammation than tenderness. However, although joint swelling appears to be a more accurate measure of synovial inflammation than tenderness, the latter has been shown to be more sensitive to change (Thompson *et al,* 1988).

2.1.1.2 Joint stiffness

Joint stiffness can be caused by inflammation of the structures in and around the joints and leads to an increase in the amount of synovial fluid within the joint. This causes the feeling of tightness that patients refer to as stiffness (Hill, 2006). Joint stiffness for RA patients is often accompanied by pain. One study that used a mixed methods approach to investigate early morning stiffness (EMS) in 93 patients with RA and 46 patients with non-inflammatory joint disease reported that 40% of patients studied mentioned pain as often as stiffness (Hazes, Hayton and Silman, 1993). However, it is not clear whether patients only consider joint stiffness when asked about EMS, or whether there is also overall muscle stiffness.

As mentioned in section 2.1.1, EMS in and around joints lasting at least one hour before maximal improvement is part of the criteria for defining RA (Arnett *et al*, 1988), whilst EMS that lasts less than 15 minutes is part of the ACR remission criteria (Ranganath, Khanna and Paulus, 2006). The duration rather than the severity of morning stiffness is often used as a measure of disease activity. However, one study reported that severity rather than duration of EMS was found to be a better discriminator between active and inactive RA (Hazes *et al,* 1993).

An increase in EMS can be an indicator of an RA flare and is experienced by 90% of patients in a flare (Vlieland *et al,* 1997). Further, patients requiring change in disease modifying anti-rheumatic drugs (DMARDs) have greater EMS than patients with stable RA (lasting an average of 75mins versus 8mins) (Soubrier *et al*, 2006). Research suggests that rheumatologists use EMS as a crucial variable in decision-making for changing medication during an RA flare. EMS is the highest or second highest (after swollen joint count) influence on the rheumatologist’s judgement about flare (Kirwan *et al,* 1984; Soubrier *et al,* 2006).

A focus group study with RA patients across 5 countries explored patients’ conceptualisation of RA flare (Hewlett *et al,* 2012). They found that patients named

EMS as an important influence on their decision to seek medication review. However, EMS was not included in the ACR core set for assessing disease activity as it cannot currently be measured with sufficient sensitivity and specificity (Sokka, 2011).

An extensive literature search did not identify any current objective measure for either swollen, stiff or tender joints. The Disease Activity Score (DAS), devised by professionals, is a weighted, composite score comprising what the authors claimed, are 3 objective measures of inflammation (physician-evaluated tender joints, swollen joints, inflammatory markers) and 1 subjective measure (patient opinion, smallest weighting) (Van der Heijde *et al,* 1993). The modified disease activity score (DAS-28: Prevoo *et al,* 1995) includes 28-joint counts instead of a comprehensive joint count. However, joint tenderness is a subjective sign that depends on the pain threshold of the individual as well as the strength of the stimulus. An individual's pain threshold could be influenced by physical and psychological factors quite separate from the inflammation in the joint (Thompson and Kirwan, 1995), whilst the strength of the stimulus has been shown to vary considerably between clinicians (Thompson *et al,* 1991). Similarly, physician-evaluated joint swelling also has a subjective component, likely to become more sensitive to even minor swelling with experience. If stiff and swollen joints are both required to form a working definition of disease activity, it may be necessary for an objective measure of both symptoms to be designed. Patients in remission may have no swollen or painful joints (Pinals, Masi and Larsen, 1981), while those about to change therapies because of flare have at least 3 or more affected joints (Deighton *et al*, 2010), yet this still does not clarify what daily life is like for the majority of patients who are neither in remission nor flare.

2.1.2 Disability

Disability is an umbrella term covering impairment, activity limitations and participation restrictions. Impairment refers to a problem in body function or structure, activity limitation is a difficulty in carrying out a particular task or action and participation restriction refers to a problem experienced by an individual in involvement in life situations (WHO, 2012).

Synovitis (Section 2.1.1.1) can lead to tearing or tethering of soft tissues such as ligaments and tendons, with subsequent impairment. Synovitis also causes erosion of the joint surface and together these events can cause loss of joint stability, leading to impairment, activity limitation and participation restriction (Majithia and Geraci, 2007).

Disability can be measured using the Health Assessment Questionnaire (HAQ) from 0-3 (none to dependency) (Fries *et al*, 1980). Disability was defined by one researcher as occurring at a HAQ value of at least 2 for at least two years (Wolfe, 2002). However, measuring the 'facts' of disability is insufficient to understand the personal effect of limited ability on the patient. The personal impact-health assessment questionnaire (PI-HAQ) demonstrated that patients with similar disability levels have different levels of personal impact arising from that disability (Hewlett, Smith and Kirwan, 2002). Thus a HAQ value of less than 2 with one patient could have a greater impact on them than a HAQ value of greater than 2 has on another person. It is therefore insufficient to reduce patients' disability to a figure derived from one questionnaire (HAQ) measuring only function.

A cross-sectional survey compared the HAQ scores of 1,095 people with RA, with the HAQ scores of 1,533 control participants matched by age and sex found that overall there were greater levels of disability (HAQ score ≥1) in the RA population (Sokka *et al,* 2003). However, whilst RA patients aged 30-79 were above the reference values (>95th percentile of the scores for the control group) in 17-45% of women and 7-32% of men, patients ≥80years were similar to the age and sex matched controls (Sokka *et al,* 2003), suggesting that impact of disability due to RA appears to be greater in younger and middle-aged people than in elderly patients.

Although disability is found in an RA population, tight control of RA disease activity has been shown to have significant association with lower functional disability levels after an average 3.6 years of follow-up when a DAS-28 value of <2.6 was considered tight control (Tanaka *et al,* 2008). The mean HAQ scores have been shown to decrease rapidly at two weeks after the start of Infliximab therapy (from 1.5 to 0.9) and to subsequently remain stable for the following two years (Nagasawa *et al,* 2009). Further, a study (Hallert, Husberg and Bernfort, 2012) comparing the annual incidence of disability pension due to RA (as an estimation of permanent work disability) before (1990) and after (2009) the introduction of biologic drugs found the incidence of disability pension to have decreased. In 1990 the proportion of disability pensions caused by RA was 1.9% of the total disability pensions, which decreased to 1% in 2009. Thus it appears that under current more aggressive treatments the disability outlook for patients may be better than it was many years ago.

2.1.3 Pain

Despite significant advances in drugs treatments many patients with RA continue to experience musculoskeletal pain (Kvien, 2004). In fact survey studies have reported that two thirds of RA patients have inadequate pain relief (Taylor *et al*, 2010), even when their disease is considered to be well controlled (Wolfe and Michaud, 2007). Further, a longitudinal study that followed 15,282 RA patients over 4 years (Courvoisier *et al,* 2012) found pain to be the only significant predictor of psychosocial health, which may suggest that anti-rheumatic treatments have insufficient effect on pain.

Using a 7-point Pain scale (where ‘no pain at all’ was 0 and ‘moderate pain’ was 3) the mean pain rating of 35 RA patients, measured seven-times daily for one week, was 2.1 with a range of 0 to 4.1 (Stone *et al*, 1997). Pain was shown to be highest (with a mean of 2.3) in the early morning, decreased to a mean of 1.9 by noon then remained stable throughout the remainder of the day (Stone *et al*, 1997). The patients in this study appear to be representative of an RA population in terms of demographic and clinical data. However, none of the patients were recruited in either a flare or remission and collecting data for one week may not be sufficient to capture the full picture of the fluctuating nature of RA. Stiffness in the mornings is a common symptom of RA, therefore one possibility is that the patients in Stone *et al’*s study confused pain and stiffness in their responses. Further explanations are that pain and stiffness are related to each other or that each symptom occurs in the mornings independently of each other.

Although treatments for RA are becoming increasingly patient-centred, meaning that patients’ preferences for treatment and disease outcomes are taken into consideration, they do not take into account which of the outcomes are most important to patients (Carr *et al,* 2003). Patients have reported that the relative importance of pain and mobility change over time, with pain being most important in early disease and mobility or independence holding more importance later (Carr *et al,* 2003).

In previous studies, patients have reported pain as their most important symptom (Parker *et al*, 1988; Minnock, Fitzgerald and Bresnihan, 2003). However, these studies are now becoming out-dated as they were conducted prior to the acknowledgement of fatigue as a valid symptom of RA and therefore failed to ask about fatigue.

2.1.4 Fatigue

Fatigue is a significant symptom experienced almost universally by RA patients, often on a daily basis. Fatigue has been highlighted by RA patients as an important treatment outcome (Carr *et al* 2003), with patients making a definite distinction between everyday tiredness and a complete systemic fatigue that was related to their arthritis. One of the first formal studies of fatigue in RA (Belza *et al,* 1993) found that more than 60% of the variance in fatigue in RA was explained by demographic, psychosocial, and 'disease related' factors, the latter explaining two thirds of the variance. In terms of impact and importance, patients rate their fatigue as similar to pain (Wolfe and Michaud, 2004; Hewlett *et al,* 2005a).

Using a 7-point fatigue scale (where 'no fatigue at all' was 0 and 'moderate fatigue' was 3) the mean fatigue rating of 35 RA patients, measured seven-times daily for one week, was 1.6 with a range of 0 to 5.0 (Stone *et al*, 1997). Fatigue was shown to be moderate (with a mean of 1.35) in the early morning, dropping to its lowest levels from 10am to noon (with a mean of 1.05), followed by a steep increase of fatigue for the rest of the day reaching its highest point at 8pm (with a mean of 2.20).

Some patients experience fatigue as 'heaviness or weight' whilst other patients experience an extreme, absolute and exhausting fatigue, leaving them unable to carry on, sometimes with a sudden and dramatic onset (Hewlett *et al,* 2005a). Fatigue seems to vary from person to person and from instance to instance in duration and frequency. RA fatigue is distinguished from normal tiredness as it is 'not earned' (not preceded by activity) and does not resolve with rest (Hewlett *et al,* 2005a).

Patients more frequently select feeling well and less fatigue in their top three important outcomes (20%, 15%) than the commonly measured disease activity outcomes of side effects from drugs (13%), stiffness (12%) and swelling (9%) (Hewlett *et al,* 2005a). An earlier study (Minnock, Fitzgerald and Bresnihan, 2003) reported that 65-69% of patients identified treatment priority as pain compared with only 36% of patients selecting pain within their top three important outcomes in Hewlett *et al'*s (2005a) study. However, Minnock *et al* (2003) were using the AIMS2 which comprises 12 professionally-determined categories, which does not include patient-generated important outcomes such as fatigue and well-being. When the sample was re-surveyed to include the additional option of fatigue, fatigue replaced pain as the most frequent patient priority (fatigue 65%, pain 48%) (Minnock and Bresnihan, 2004)

RA patients believe that professional support for fatigue is rare as the emphasis is on physical problems and disease activity. Most patients will not discuss fatigue with their health professional, but those who do feel it is dismissed (Hewlett *et al,* 2005a). Patients feel uncertain about how to self-manage their fatigue and perceive a lack of support from their rheumatology team around this issue (Hewlett *et al,* 2005a).

A cognitive behavioural therapy (CBT) intervention to improve fatigue self-management has been developed (Hewlett *et al,* 2011). This intervention was delivered by a clinical psychologist and consisted of 6 x 2 hour sessions (weeks 1-6) with a 1 hour consolidation session (week 14). This intervention was compared to a control group of patients who received a 1 hour didactic group session delivered by a rheumatology specialist nurse based on patient information leaflets. The researchers reported an effect of the CBT intervention on fatigue impact, coping and perceived severity.

There is, as yet, no agreement regarding the causes of fatigue with studies on correlates and predictors of fatigue providing contradictory results (Repping-Wuts, van Riel and van Achterbeng*,* 2009). Some patients perceive disturbed sleep as an important cause of fatigue, whilst others report sleeping well, but that the sleep is un-refreshing (Hewlett *et al,* 2005a).

2.1.5 Sleep disturbance

Sleep in people with RA is often disturbed; this could be due to pain, causing a restless night; along with stiffness and disability, which may limit the ability to turn over unaided. RA and sleep appear to have a two-way relationship, with each directly affecting the other.

In a survey of 937 people with RA, arthritis was reported to disrupt sleep in approximately one third of the sample (32.8%, Jordan *et al,* 2000). In a recent study (Goodchild *et al,* 2010), 25 women with RA and 19 women with Primary Sjogrens Syndrome (PSS) were issued with an Actiwatch, which is similar in size and weight to a wrist watch and when worn on the wrist detects restless movements likely to be incompatible with sleep (Lavie *et al,* 1992), and were monitored for 35 consecutive days. Sleep inefficiency (percentage of time in bed not spent asleep) was found to be a mean of 10.3% in the women with RA in comparison to 14.0% in the women with PSS. However, this was not compared to a healthy control group and it is therefore unclear as to what extent the women with RA in this sample differ from the healthy population.

Goodchild *et al* (2010) also found moderate associations between sleep inefficiency and mental fatigue indicating that those who slept less tended to report more problems with impaired concentration and memory. This study also showed that the relationship between discomfort before bed and fatigue the following day depended on sleep that night. On nights when sleep was more disturbed, the association between discomfort in the evening and greater fatigue the next afternoon was stronger.

RA patients with poorer sleep quality report more pain and fatigue; this has been found within patients as well as between patients, with patients reporting more pain and fatigue on days with poorer reported sleep quality (Stone *et al,* 1997). Further, the amount of variance in fatigue explained by discomfort and sleep combined was found to be less than the amount explained by the previous day's fatigue (Goodchild *et al,* 2010), showing clear consequences of sleep disturbance in people with RA.

Patients with self-reported arthritis-related sleep disruption are more likely than those without sleep disturbance to pursue multiple sources of self care and medical care. However, those patients who have a disruption to their leisure activities are less likely to seek medical care than those patients with sleep-disruption (Jordan *et al,* 2000). This raises the question as to whether sleep disturbance is more difficult to live with than disrupted leisure time; people with RA may accept that it is inevitable that they will experience disruption to their leisure activities, but perhaps are not willing to accept disruption of sleep as a consequence of RA.

2.2 The impact of RA on daily life

A qualitative study identified 'uncertainty' as a common theme in RA (Stenström, Bergman and Dahlgren, 1993), and reported that the participants were uncertain about their own interpretations of their symptoms and whether they would be able to receive adequate help to master their disease and manage their everyday lives. Uncertainty was also reported due to unpredictable exacerbations and remissions of disease, and its unpredictable long term course. However, this study is now somewhat dated and therefore may not reflect experiences of daily life with current treatments. Further, this study used only 9 patients (all of whom were female) therefore saturation of ideas may not have been reached. The interviews explored patients' experiences of daily life, but they did not enquire as to how patients manage their daily symptoms or how they are able to distinguish between a 'bad day' and a flare. How patients manage their symptoms will be discussed in Chapter 3 and flare will be discussed in Section 2.3 of this chapter.

Living with RA means having to relate, over time, to an increasingly non-compliant body; a body with RA does not move as desired (Plach, Stevens and Moss, 2004). The fluctuation and uncertainty of RA and a non-compliant body can impact on patients' abilities to continue doing activities that are necessary or pleasurable. This impact will now be discussed.

2.2.1 Loss of participation

It has been widely reported that RA interferes with hobbies, pastimes and with sexual activities (Blake *et al,* 1987; Reisine, Goodenow and Grady, 1987; Tugwell *et al,* 1987; Cornelissen, Rasker and Valkenburg, 1988). In one study 70% of the women surveyed reported that RA interferes with their hobbies and pastimes and 50% reported that their RA interferes with sexual activity (Reisine *et al,* 1987). The intrusiveness of RA has been reported to be greatest in areas of active recreation, work and health (Devins *et al,* 1993) with the intrusiveness of RA increasing as physical function worsens (Devins *et al,* 1992).

Individuals' daily activities are typically composed of a mix of obligatory, committed and discretionary activities (Katz and Morris, 2007). Obligatory activities are those required for survival and self-sufficiency; including hygiene and self-care activities, walking inside, walking outside and using transportation or driving. Committed activities are associated with one's principal productive social roles; these include paid work, household responsibilities, child and family care whilst discretionary activities include socializing, exercising, engaging in leisure activities or other activities that the individual engages in for relaxation or pleasure. Achieving 'balance' in life activities usually involves spending an adequate amount of time in each domain. Having a satisfactory balance of activities makes a substantial contribution to health and well being, whilst time use imbalances are associated with lower life satisfaction (McKinnon, 1992; Katz and Morris, 2007).

Time diaries were used to estimate the allocation of time to various activities of daily life and found that RA patients spent more time on personal care and hygiene, household chores, shopping and errands than the control group (Yelin *et al,* 1987). Due to functional difficulties, RA patients may need to restructure the way in which they use time. A survey of 375 women revealed that individuals with higher HAQ disability scores (mean 1.04) were more likely to spend ≥2 hours each day on personal care, resting and doing things to take care of their RA than those with lower HAQ scores (Katz and Morris, 2007). Those individuals with higher HAQ scores were also more likely to spend no time at all doing housework, paid work, leisure activities, hobbies or volunteer work.

A core set of patient-derived priority outcomes, developed through nominal group technique and postal surveys, has been proposed: the Rheumatoid Arthritis Patient Priorities – Pharmacological Interventions (RAPP-PI: Sanderson *et al,* 2010). The RAPP-PI consists of eight outcomes that were generated and prioritised by patients as being essential in measuring the patient perspective of the impact of RA. These are: pain, activities of daily living, (visible) joint damage, mobility, life enjoyment, independence, fatigue and valued activities. This demonstrates the importance that patients place on participation in both daily activities and valued activities.

A focus group study with 23 RA patients found that patients lose some of their valuable activities, either because it is no longer possible to do them or because it is not worthwhile doing them when they cause pain, stiffness or fatigue. These patients described life as a ‘roller-coaster’ (Lütze and Archenholtz, 2007). However, the patients in this study had a maximum disease duration of 5 years and therefore may not have represented the views of the wider RA population. Over a 5-year period, individuals with RA stopped performing an average of 10% of the activities that they had valued at baseline (Katz, 1995), but this study was conducted 17 years ago and may not reflect daily life with RA on current therapies.

2.2.2 Psychological well-being

The overall effect of RA on individuals’ valued life activities appears to affect their psychological well-being. Loss of the ability to engage in recreational activities and social interactions, in particular has been reported to significantly increase the risk of new onset depression (Katz and Yelin, 2001; n=654). A salient feature of depression is a loss of gratification or pleasure; activities that used to bring satisfaction seem dull and joyless, leading to a loss in interest in hobbies, recreation and family activities (Beck,1979). Katz and Yelin (2001) controlled for this cause/effect issue by excluding patients with high levels of depressive symptoms at any time between baseline and baseline +3 years (when the results for this study were reported from). However, this study was a reanalysis of data collected between 1989 and 1998 and therefore may not reflect life on current modern treatments.

It is possible that the depressive symptoms could be caused not merely by the reduction in activities but by the distinction between what a patient is able to do and what they think they should be able to do (Calman, 1984). This idea was raised in relation to quality of life, hypothesising that quality of life can only be described and measured in individual terms and depends on present lifestyle, past experience, hopes for the future, dreams and ambitions. A good quality of life can be said to be present when the hopes of an individual are matched and fulfilled by experience. The opposite is also true: poor quality of life occurs when experiences do not match prior hopes (Calman, 1984). One model proposed that patients have expectations of how they will be treated, the amount of pain they will have and how effective their treatment will be (Carr, Gibson and Robinson, 2001). It is proposed that when expectations are matched by current experience there is no quantifiable impact on quality of life, but whenever the experience of health falls short of expectations there is an impact. The researchers suggested that the impact of chronic disease on quality of life can be minimised by helping patients to adjust their expectations and adapt to their changed clinical status (Carr, Gibson and Robinson, 2001).

2.2.3 Paid employment and RA

As described in the preceding paragraphs, RA can impact on patients' lives by putting up barriers to being able to go about their daily routine. An even bigger barrier is presented when patients wish to continue paid employment despite their RA. One study, which followed 160 RA patients for a mean of 8.6 years from symptom onset (Barrett *et al*, 2000), found that 4% of participants had stopped working on health grounds within 12 months of symptom onset, 26.3% within two years and 41.6% within 9 years. However, as this study was published 12 years ago, with patients diagnosed for a mean of 8.6 years, it described patients diagnosed over 20 years ago and therefore may not reflect patients' current experiences on modern medication.

A number of studies have estimated the societal economic costs of RA (Yelin*,* 1996; Clarke *et al*, 1997; Merkesdal *et al*, 2001). However, they did not include the cost of the disease-related impacts of reduced performance while at work (presenteeism) nor of changing occupations (Maetzel *et al*, 2004). A more recent study conducted in Canada (n=383; Li, Gignac and Anis, 2006) found that lost productivity due to RA costs $12,352CAN per person per year (£7,842). The majority of this was a result of presenteeism, accounting for 41% of the total loss, followed by wage loss from stopping working or changing jobs (37%), decreased hours of work (12%) and absenteeism (10%).

Interviews with 50 employed patients found that early morning pain and stiffness and difficulty communicating their working needs were the two most striking barriers to employment (Robinson and Walters, 1979). A recent study reported that fatigue was consistently identified as the symptom most limiting patients' ability to work (Lacaille *et al,* 2007). Some participants reported turning down opportunities such as training or promotions due to their fatigue, as this enabled them to preserve energy. However, this was often at the expense of job satisfaction, career advancement and personal fulfilment (Lacaille *et al*, 2007). Patients raised concerns that the daily variation in their abilities to perform tasks due to the daily fluctuation in their symptoms affected their credibility with co-workers and supervisors, while unpredictable arthritis flares and symptom fluctuation made it difficult to plan work and to keep work commitments.

As discussed earlier, pain is highest in the early morning, decreases through to noon and is stable for the remainder of the day, whereas there is a steep increase in fatigue from noon reaching its highest point at 8pm (Stone *et al,* 1997). This could therefore be one of the reasons why the patients in Lacaille *et al*'s (2007) study found fatigue to be the biggest barrier to work. If pain is highest in the early morning and eases off during the day then individuals may be able to predict that the pain will ease off throughout the day and may therefore be reassured about going to work. However, they may be waiting for their fatigue to become worse and worse as the day goes on, therefore feeling the need to preserve energy. Another explanation could be that fatigue creates more barriers as pain is perceived as controllable with the correct medication, whereas fatigue has been described as 'overwhelming and uncontrollable' (Hewlett *et al,* 2005a).

An assessment of 723 RA patients found that the ability to maintain paid work after the onset of the disease is significantly related to reports of both less pain and fewer depressive symptoms, irrespective of disease severity (Fifield, Reisine and Grady, 1991). The paid work effect was still present even after controlling for the effects of pain on depression and depression on pain. They also found that work loss alone is associated with higher levels of pain and depression at all levels of disease severity.

Sections 2.1 and 2.2 reported the range of RA symptoms and the effects of RA on the struggle to maintain valued activities and paid work. At times when inflammation is active these symptoms and consequences will escalate, culminating in an RA flare.

2.3 Flare

"If I were free of flares I would experience life anew, I believe with the joy of a child" (James May, Patient Research Partner, OMERACT 10).

Flare is a term that is commonly used by both patients and clinicians to describe a worsening of symptoms. However, while this word is widely recognised by physicians and patients and adopted in research papers, there are no commonly accepted parameters to define disease worsening, characterise its severity, or describe its onset and duration (Bingham *et al,* 2009a). In UK patient leaflets, the term flare has been used with limited explanation such as *"You may have flare-ups when your symptoms become worse than normal"* (Arthritis Research UK, 2011b)

2.3.1 Patterns of flares

It is not known exactly how patients with RA experience a flare nor whether they return to a non-symptomatic state following a flare, or return to a baseline of constant but manageable RA symptoms. In ankylosing spondylitis (AS), a rheumatological condition in which there is inflammation of the spine (Brophy and Calin, 2002), two main types of flare pattern have been reported: constant symptoms and intermittent symptoms (Stone *et al,* 2008). This study reported that those who returned to a level of constant symptoms clearly predominate over those with intermittent symptoms and that constant symptoms were associated with worse health status measures (Fig 2.1). To discover these patterns of AS, patients were presented with four graphs and asked to choose which graph best represented their disease activity. However, these graphs were constructed by the researchers rather than by patients and are reductionist as patients possibly chose a graph of ‘best fit’ rather than one that truly represented their disease. Despite these limitations, this was the first paper to investigate the idea of patterns of flares in rheumatic diseases and their association with outcome of AS. This idea has yet to be explored in RA.

The following patterns of disease activity are represented graphically. Pattern (A) Flares and remissions. During the remissions patients would be symptom free. Pattern (B) Flares with disease activity in between flares. Pattern (C) Severe flare lasting a long time and followed by return to a baseline for a long period of time without any symptoms. Pattern (D) This was similar to (C) except that patients did not return to a symptom-free baseline but had continued symptoms that were constant in nature over time thereafter.

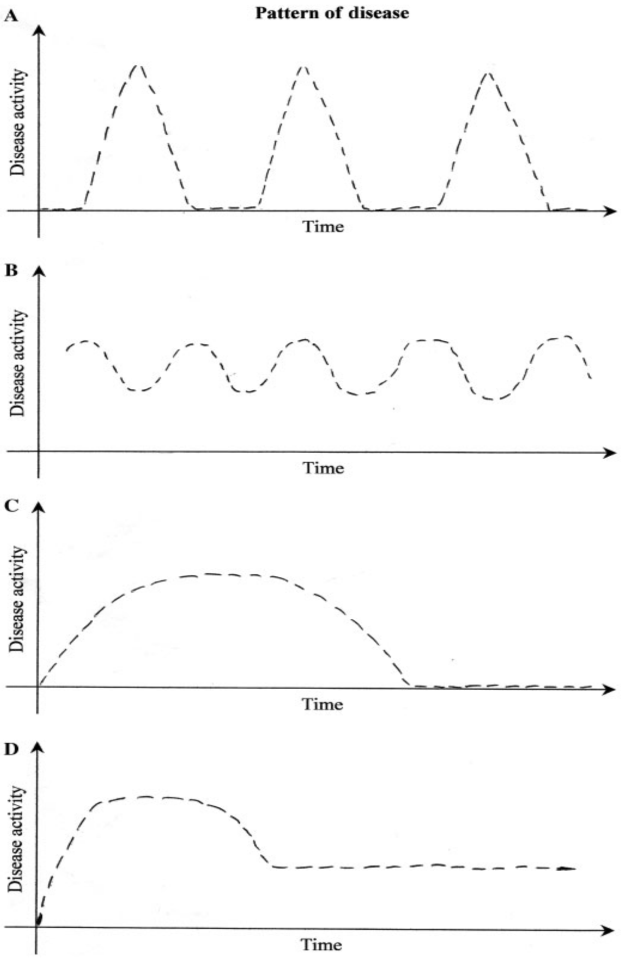

Figure 2.1: The Flare Illustration shown to patients
Stone et al, Rheumatology, 2008 47(8):1213-1218, by kind permission of Oxford University Press

2.3.2 Defining flare in clinical practice

Disease Modifying Anti-Rheumatic Drugs (DMARDs) and biologic agents (e.g. anti-TNF) control inflammation and improve long-term outcome (Emery *et al*, 2008a). They are initiated or changed during episodes of flare. Although flare informs treatment decisions, there is no standardised definition to support these decisions. For instigating and assessing Anti-TNF therapy in the UK, a flare level was agreed by clinicians and The National Institute for Clinical Excellence (NICE) (TA130, 2007) as a DAS-28 of >5.1, sustained over 4 weeks.

2.3.3 Defining flare in clinical trials of medication

An area that is in particular need of a definition of flare is within clinical trials (Bingham *et al,* 2009a). In randomised control trials (RCTs) of RA medications, the lack of a standardised definition means that entry criteria for flare are individually set for each trial, as are the variables and parameters to describe worsening of disease or flare within the RCT. The problem of flare definition is not limited to RA: 10 recent studies of gout-flare all provided different definitions of flare (Taylor *et al,* 2009).

This lack of a standardised flare definition is clearly a problem in RCTs as it limits the validity of conclusions drawn and comparison between studies.

OMERACT (Outcome Measures in Rheumatology) is an informal international network initiated in 1992 aimed at improving outcome measurement in rheumatology. The drug safety working group developed the rheumatology common toxicity criteria (RCTC) in 1999, building on the oncology common toxicity criteria. At OMERACT 8, the drug safety working group determined that a standardised definition of flare was needed for the RCTC effort (Woodworth *et al,* 2007).

A number of RCTs (Den Broeder 2002; De Man 2008; Van den Bemt *et al,* 2008) have used the inverse European League Against Rheumatism (EULAR) response criteria (van Gestel and Prevoo*,* 1996) to define a flare. The EULAR response criteria (van Gestel and Prevoo, 1996) defined a good response as >1.2 improvement in the DAS from baseline, and a DAS attained during follow up of ≤2.4. Non-responders were defined as patients with an improvement of ≤0.6 or patients with an improvement of >0.6 but ≤1.2 and a DAS attained during follow up of >3.7. The remaining patients were classified as moderate responders. Based on this definition, the reversed EULAR criteria defines flare as an increase in DAS-28 exceeding 1.2, or an increase in DAS-28 exceeding 0.6 and a current DAS-28 of over 5.1 (high disease activity). However, although the EULAR response criteria are suitable for defining a positive response, they fail to describe worsening when taking the patient's perceptions into account (Leeb *et al,* 2006). This study found that a DAS-28 reduction of at least 26.5% was necessary for a patient-perceived improvement in disease activity. However, a DAS-28 increase of only 10.5% was needed to identify a patient-perceived worsening in disease activity. In contrast, physician's perceptions of change in disease activity were relatively symmetric (Leeb *et al,* 2006).

Alternative definitions of flare used in RCTs have included a 50% or greater diminution in improvement in the combined swollen and tender joint count from baseline to the time at which response was initially achieved (Rahman *et al,* 2007); an exacerbation of the disease that may have required additional treatment or necessitated a visit to a health care professional (Stone *et al,* 2008); a patient-perceived increase in disease activity leading to the patients' wish to quit the study and/or the requirement for a change in medication (Fransen *et al,* 2001). Some studies failed to provide criteria for flare for the purpose of their study. One study defined a flare as joint inflammation, pain, stiffness, and reduced mobility and function but gave no specific symptom levels (Ostensen, 2001), whilst another reported significantly fewer disease flares as a treatment outcome, but did not define flare (Hammond and Freeman, 2001).

2.3.4 Defining flare from the patient's perspective

The first paper to explore disease flare from the patient's perspective found that AS patients experience localised flares that were characterised by pain and immobility in one body area. In contrast, generalised flares involved the whole body with all symptoms being experienced to the extreme; patients were 'crippled' with pain, which was accompanied by fatigue and emotional distress (Brophy and Calin, 2002). Patients reported flares lasting from a few days to a few weeks and with no specific pattern, they could occur anything from twice in a year to every 5 years. However, the methodology in this study was weak with participants having been recruited from an intensive pain management programme, and therefore only included patients with this one experience of care. Not all interviews were tape-recorded, thus seriously questioning the validity of the data.

In a second qualitative study with AS patients (Mengshoel, 2008), three aspects of living with AS were reported: 'ordinary life condition', 'slowed down life condition' and 'disrupted life condition'. 'Disrupted life condition' was characterised by intense, inexplicable and unmanageable pain that could not be reversed by one's own actions and prevented all or most ordinary activity. In 'disrupted life condition' the reported AS pain fell into 2 patterns; either localised to one part of the body or distributed to several parts. The localised pain was described as a feeling that the joints were locked and as an inability to move whereas the widespread pain was described as similar to influenza and included difficulty in carrying out even the most basic of personal care tasks. Although the word flare was not used in this paper (Mengsoel, 2008), it demonstrates the variation in symptoms that occur within an episode of high disease activity. This paper classified the experience by effect on the patient's life condition and not by symptoms experienced. Although this was a less clinical approach, perhaps patients would be able to relate better to describing their disease according to how it affects their daily activities.

At OMERACT 9 a Special Interest Group (SIG) initiated a process by which a consensus-based definition of flare could be developed that could be used for multiple purposes (Bingham *et al,* 2009b). This group identified a lack of research defining flare from the perspective of RA patients, therefore at OMERACT 9 they invited 11 patient delegates to informally discuss flare in a separate break-out group (in order to limit the influence on their discussion by professional delegates). The 11 patients with inflammatory arthritis (mainly RA) reported flare as a wide range of physical, emotional and cognitive symptoms (Bingham *et al,* 2009b). Pain was recognised as a critical factor in defining flare, and it was reported that pain could be global or related to single or multiple joints, which supports findings reported by Brophy and Calin (2002). The findings from the SIG indicated that patients and professionals potentially have different views on the definition of a flare. Patients reported flu-like symptoms, early warning signs and raised the idea that synovtis does not necessarily have to be present.

The patients that were involved in the breakout group were not necessarily representative of all RA patients as these were patients who have a heavy involvement in the research process, who may have a better sense of self-awareness and may be more educated about their RA than the average person with RA. Whilst the OMERACT SIG reported some interesting findings, this was not intended to be a research study but an informal discussion as a preliminary exploration and the groups were not digitally-recorded, nor data systematically analysed. Therefore the OMERACT SIG suggested that further research is needed in order to explore the new ideas that were raised (Bingham *et al,* 2009b).

To develop the work from the OMERACT SIG discussed above 14 focus groups were carried out across five countries with a total of 68 participants (Hewlett *et al,* 2012). They reported that symptoms and early warnings of flare caused patients to increase their self-management strategies and as those failed; patients began defining this as flare, which led to seeking help. This was underpinned by uncertainty and influenced by the individual context.

Patients are able to differentiate the symptoms of flare from daily RA symptoms by their intensity, quality and constancy. Symptoms include joint swelling and stiffness; morning stiffness; difficulty with functioning; fatigue, which is different to normal RA fatigue; flu-like symptoms; disturbed sleep; cognitive shut-down; and emotional distress (Hewlett *et al,* 2012*).* For a person with RA to be able to define their symptoms as a flare, the symptoms need to be unprovoked, persistent and 'not normal' for their RA; these are the tipping points for patients seeking help as the uncertainty of whether their symptoms are due to flare decreases (Fig 2.2) (Hewlett *et al,* 2012*).*

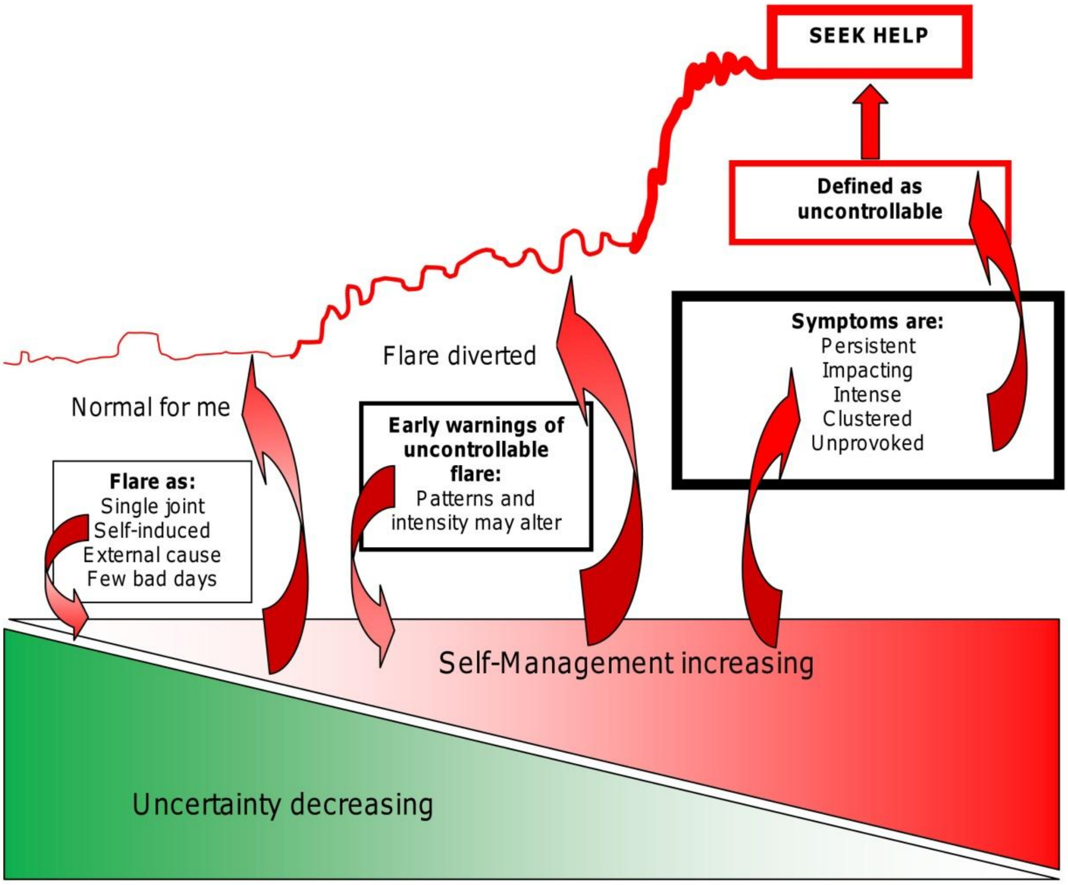

Figure 2.2: The patient journey to seeking help for RA flare
Hewlett et al, Rheumatology, 2012 51(1):69-76, by kind permission of Oxford University Press

Flare definitions and tipping points are individual and may vary with experience. However, the individual context, which influenced the themes identified by Hewlett *et al* (2012), were potentially lost through the focus group methodology. As human beings will conform to the majority even in small groups (Asch, 1958), it may not have been possible to delve into patients' individual stories in a focus group session. Patients' experiences of flare and their tipping points of help-seeking should therefore ideally be explored through one to one interviews. In addition, a longitudinal study is needed to understand daily symptom levels and explore the individual experiences and patterns or typologies of RA flare.

2.3.5 Early warning signs of flare

A prodrome is an early symptom (or set of symptoms) that might indicate the start of a condition before specific symptoms occur. There appears to be no prodrome literature in RA but prodrome is seen in other conditions. Prodromal symptoms occur in 40–60% of people who experience migraines and include altered mood, fatigue, visual aura and stiff muscles, among other symptoms. These symptoms usually precede the headache phase of the migraine attack by several hours or days, and experience teaches the patient how to detect that a migraine attack is near (Kelman, 2004). Patients with refractory, localisation-related epilepsy have been shown to be able to predict their seizures. In a prospective study, patients completed daily measures of the occurrence, time and characteristics of all seizures, if present. Seizure self-prediction was assessed by asking patients ‘Do you think you will have a seizure in the next 24 hours?’ (Haut *et al,* 2007). The researchers acknowledged that the self-prediction of seizures may have reflected a patient’s awareness of their typical seizure pattern. For example, a patient who experiences seizure clusters was potentially predicting the second or third seizure in a cluster.

However, unlike people with RA, people with migraine and epilepsy are free from symptoms in between episodes and therefore may more easily identify early warning signs than people with RA who rarely return to an asymptomatic baseline state. Asthma is a condition in which patients may not always return to an asymptomatic baseline state, but in which a prodromal state has been proposed. A retrospective study of young asthma patients found that 70% of patients recognised an itching sensation on the lower face or anterior neck in association with the asthmatic attacks (Orr, 1979). However, this was a retrospective study and patients were potentially recalling the symptoms with the benefit of hindsight and in addition they were prompted by a specific question to recall itching symptoms.

Some patients in the OMERACT SIG reported early signs of a flare, such as fatigue and/or night/day time sweats which may suggest a prodrome (Bingham *et al,* 2009b). A qualitative study on learning to live with RA reported that women became experts at recognising the onset of flare (Shaul, 1995), but did not specify how. In a focus group study with 67 RA patients across five countries (Hewlett *et al,* 2012), some experienced patients reported noticing ‘early warning’ signs of flare. These patients reported the presence of flu-like symptoms, fatigue or symptoms in particular joints. However, it is possible that these patients were only able to identify the onset of a flare with the benefit of hindsight and this therefore needs testing in a prospective study.

A diary study of daily symptoms would need to be performed to capture both the period of time leading up to a flare and the flare itself in order to be sure that a prodrome of flare exists in RA. Identification of symptoms of early flare (prodrome) might provide an opportunity for a rapid intervention to abort a major flare (e.g. intramuscular depomedrone). Earlier treatment of RA results in greatly reduced risk of joint deformities, physical disability and premature death (Tikly, 2009). Thus the ability to detect early warning signs and provide treatment whilst patients are in the early stages of a flare would have the potential for improved outcome.

2.3.6 Defining flare from the professional's perspective

The existing outcome measures available for rheumatic diseases have been reviewed, with a particular focus on RA (Fransen and van Riel, 2009). It was concluded that a measure of disease activity is needed, but the need for a measure of flare was not specifically highlighted.

The OMERACT 9 SIG had professional breakout groups as well as the aforementioned patient break-out group (Bingham, 2009b). The professional breakout group raised an important concern that the word flare was not translatable or used in all languages. Each of the 4 professional breakout groups indicated that for professionals, joint counts (swelling and tenderness) were critical to include in an overall definition of flare. Other important components that these groups identified included patient and physician reported global assessments of disease activity and patient reported pain and fatigue. As mentioned in Section 2.3.4 this was discussion only, and the group are currently conducting a formal research study. However, the marked differences in the opinions of patients and professionals certainly highlight the need for further research in this area.

2.3.7 Patient versus professional perspective

Lack of agreement between patients and professionals is widely reported. An investigation into the concordance between clinician and patient assessment of physical and mental health status studied 7 clinicians and 166 patients and found 98 cases (59%) of perfect agreement between patients and clinicians (Kwoh *et al,* 1992). On average, the more severe the physical impairment, the more likely the clinician was to rate the disability as more severe than the patient. However, for mental distress, the clinician was more likely to rate low distress as more severe than the patient did. Patients and clinicians may enter the consultation process with different objectives and patient priorities may differ from those of health care professionals (Carr and Donovan, 1998). Kwoh *et al* (1992) raised an important question: If patients and clinicians disagree as to the patient's present health status, how can they determine when the patient's health status has changed? And how, therefore, can they assess the effectiveness of therapy?

In the OMERACT 9 SIG breakout groups, while patients indicated that pain was always present during a flare, they did not necessarily include synovitis, this contrasted with the professionals group who deemed synovitis as essential for a flare and possibly the only requirement. Any definition of flare would need to be developed taking both patients' and professionals' perspectives into account.

2.4 Summary

In daily life, RA patients experience stiff and swollen joints, pain and fatigue, which can mean patients may have to reduce both work-based and leisure activities. However, these studies were largely conducted before current more intensive therapeutic regimes were in use, utilising new drugs and new combinations with tighter control of inflammation. In addition, few studies attempted to explore daily life. Whilst patient-perceived flare often underpins requests for help and treatment decisions, with potentially significant impact on outcome, there is no current consensus for defining flare. Current research suggests a serious mismatch between patient and clinician perception of flare, with patients perceiving a range of flare symptoms and even a prodrome, of which clinicians are unaware.

Little is known about daily variation in symptoms within current treatment regimes nor patient language for flare, nor how they differentiate flare from normal daily variation. If these features can be identified, it may be possible to improve explanations to newly-diagnosed patients, clarify discussions regarding flare, identify disease patterns that are prognostic indicators of outcome and thus potentially target treatments.

Current research suggests that patients experience impact of RA on their lives in both daily life and flare. The following Chapter will therefore address ways in which patients have adapted and adjusted to living with RA, how they self-manage their symptoms in daily life and flare and how these strategies may change with experience.

Chapter 3: Coping, self-management and adaptation

Chapter 2 examined daily fluctuation of RA symptoms and RA flares and how these differ and affect a patient's psychological status impacting on their daily life. This chapter explores self-management and coping strategies used by patients and discusses the process of adapting and adjusting to life with RA.

3.1 Coping

The terms 'coping' and 'self-management' have been used interchangeably in the literature (Kralik *et al*, 2004). However, a qualitative study (Nicklin *et al,* 2010b), which identified items and developed the wording for measures of RA fatigue from a patient's perspective, also found that patients were able to distinguish between coping and managing. Broadly speaking patients suggested that 'manage' related to practical issues, whilst 'cope' related to their emotions (Nicklin *et al*, 2010b). Coping has been described in terms of active versus avoidant coping techniques and emotion-focused versus problem-focused techniques. It is possible that patients making a distinction between coping and managing may be distinguishing between emotion- and problem- focused coping techniques. Thus for the purpose of this thesis, 'coping' is used as an overarching term encompassing self-management as a function of 'problem-focused coping'. Crisis theory (Moos, 1982; Moos and Schaefer, 1986) proposed coping as part of the adjustment process to a crisis situation, which will therefore be explained first to contextualise coping and adjustment.

3.1.1 Crisis Theory

Crisis theory (Moos, 1982; Moos and Shaefer, 1986) claimed that during a crisis, such as having an illness, the adjustment that the person makes depends on their coping process, which is dependent on three factors: illness related factors; background and personal factors; and physical and social environmental factors (Fig 3.1).

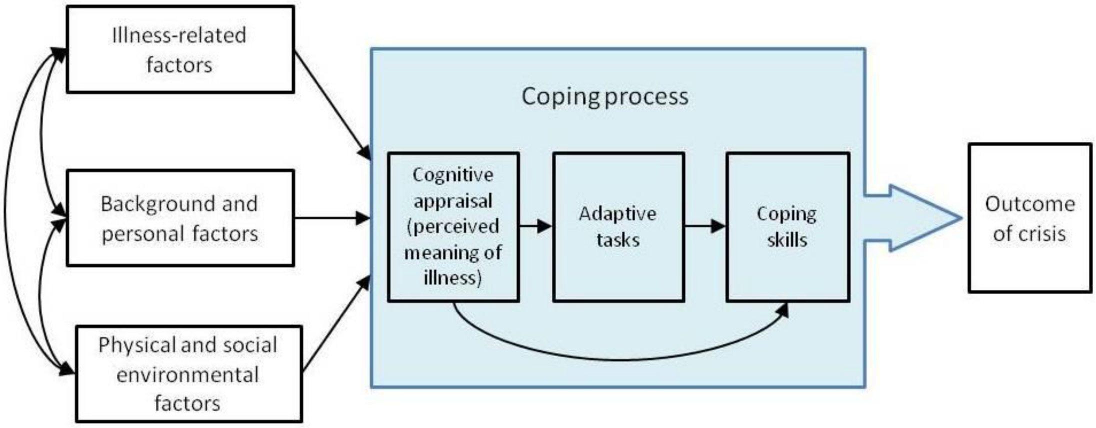

Figure 3.1: Diagram of Crisis Management Theory

Illness-related factors: These are concerned with the threat that patients perceive their health problem poses to them such as being disabling, disfiguring, painful or life-threatening. The greater the threat patients perceive the more difficulty they are likely to have in coping with their condition (Cohen and Lazarus, 1979; Moos, 1982). Thus a patient with RA who perceives themselves as disabled due to their RA may be less able to cope with it.

Background and personal factors: People who cope well with chronic ill health tend to have ‘hardy’ or resilient personalities that allow them to see positives in difficult situations (Pollock, Christian and Sands, 1990). The ways people cope with a long term condition can also depend on age, gender, socio-economic status, philosophical or religious beliefs, emotional maturity and self-esteem (Moos and Schaefer, 1986). The timing of a health problem in the person’s life span can also affect the impact that the condition has on them, for example people who are diagnosed with a disabling condition in early adulthood are more likely to resent losing the chance to develop their lives in the direction they planned (Moos, 1982). Thus it is possible that younger RA patients may have more difficulty coping.

Physical and social environmental factors: The physical environment includes the person’s home, which can impede coping if patients have difficulty moving around their home or performing self-care tasks. Thus it is possible that patients with RA, who have had their home adapted for their needs would have a better ability to cope with their RA. People’s social environments are also important for coping, for example the presence of social support.

Coping process: The three contributing factors discussed above combine to influence the coping process that an individual uses to cope with a crisis, such as a long term condition. Crisis theory has proposed that coping begins with *cognitive* *appraisal* of the meaning or significance of the health problem. The outcome of this appraisal leads the patient to form a range of *adaptive tasks* and to apply a range of *coping skills* to deal with these tasks. For example, one potential *adaptive task* is to control negative feelings and retain a positive outlook for the future, which patients may address through *coping skills* such as minimizing the seriousness of the situation (Moos, 1982).

Outcome of the crisis: For a long term condition, the desired outcome of the coping process is for the patient to learn to adapt and adjust to their condition, which has the potential to improve their quality of life. This can include patients reconceptualising their idea of normality (Section 3.2.1).

This model includes coping skills and an outcome of adjustment, but does not specify the use of a particular type of coping nor what constitutes adjustment. Thus the following sections address coping skills and adjustment relevant to RA.

3.1.2 Action-focused and avoidance-focused coping

The Vanderbilt Pain Management Inventory (VPMI) is a measure of coping that has provided a method of classification of coping: active coping and passive or avoidant coping. This divides coping strategies according to the expected outcome (Brown and Nicassio, 1987).

Active coping strategies are those strategies used by patients when they are attempting to control their pain or to function in spite of their pain, whereas passive coping strategies relinquish control of the pain to others, or allow other life areas to be adversely affected by pain (Brown and Nicassio, 1987). These definitions were expanded by specifying that active coping strategies involve an attempt by the patient to deal with the pain by using their own resources, whereas passive coping strategies are characterised by helplessness and/or reliance on others (Nicholas, Wilson and Goyen, 1992).

Generally speaking active coping strategies, whether behavioural or emotional, are thought to be more helpful ways to deal with stressful events, and passive or avoidant coping strategies appear to be a psychological risk factor or marker for adverse responses to stressful life events (Holahan and Moos, 1987). However, a systematic review of longitudinal studies that examined coping strategies and psychological distress in RA (Vriezekolk *et al*, 2011) found little evidence for passive coping strategies being associated with an increase of psychological distress, but the methodology of many of the studies included in this systematic review were weak. It is suggested that the flexible use of a variety of coping strategies across situations may be beneficial to adjustment to a chronic illness (Zeidner and Saklofske, 1996), this may be particularly important in RA due to the fluctuating symptoms and unpredictable disease course associated with it (Vriezekolk *et al*, 2011).

A cross-sectional study (López-Martínez *et al*, 2008) addressed coping strategies, using the VPMI, in patients with chronic pain. This study found that higher levels of active coping were associated with lower levels of depression and higher levels of functioning, whereas higher levels of passive coping were associated with higher levels of depression, higher levels of pain and lower levels of functioning. However, the cross-sectional design of this study meant that pain coping as a dynamic process was not captured, which would be important to consider in relation to the fluctuating nature of RA symptoms and causal relationships could not be identified.

3.1.3 Emotion-focused and problem-focused coping

Coping has also been divided into problem-focused and emotion-focused coping (Lazarus and Folkman, 1984). Problem-focused coping involves focusing on the specific problem or situation and trying to find a way of changing it or avoiding it in the future. Emotion-focused coping involves managing the emotions associated with the stressful situation, even if the situation itself cannot be changed. This theory appears to relate well to the needs of dealing with a long term condition that has both practical and emotional consequences and will therefore be used as a framework for the self-management and coping strategies discussed in this thesis.

A cross-sectional study with 434 RA patients (Englbrecht *et al,* 2012) found that problem-focused coping contributed to coping effectiveness, which in turn was positively related to general health perception. This suggests that problem-focused coping has a positive influence on the quality of life of RA patients. However, the cross-sectional design of this study meant that a causal relationship could not be identified. An emotion-focused intervention for patients with inflammatory arthritis (Zangi *et al,* 2009) involved 10 x 4.5 hour sessions over a period of four months. Each session related to a different aspect of living with a chronic illness and addressed these through mindfulness-based exercises (in which patients were invited to become aware of disease-related emotions, thoughts and bodily experiences), creative exercises (such as guided imagery, music, drawing and poetry) and reflection on patients' own experiences. This intervention reduced pain and fatigue in patients one year after participating (Zangi *et al*, 2009). However, this was not an RCT and therefore patients' symptoms could have improved naturally or be explained by other factors such as change in medication.

Emotion- and problem-focussed coping techniques have different strategies associated with them. Thus the strategies relevant to RA will be presented individually under their respective coping techniques.

3.2 Emotion-Focused Coping

3.2.1 Normalisation

A qualitative study with RA patients (Sanderson *et al,* 2011a) proposed six distinct typologies of normality. The first was 'disrupted normality', which involves overwhelming symptoms that make normal life impossible. The second was 'struggling for normality', which described patients who will present a normal life, whatever the cost. Thirdly, 'fluctuating normality' in which daily life with RA was considered normal, but being in a flare was thought of as abnormal. The fourth typology was 'returning to normality', which seems to apply to patients whose symptoms are well controlled and feel able to carry on life in the way they used to before their diagnosis. The fifth was 'continuing normality', which relates to patients who have very mild RA and do not appear to have experienced disruption to their normal lives. Finally, 'resetting normality' meant patients had reconceptualised their idea of normality and included their RA and its flares in their definition of normal. Although these specific normality typologies have not yet been explored in other chronic illnesses, the importance of the general concept of normality has been reported (Bury, 1982).

A qualitative study that explored the experiences of mid-life women living with a chronic illness (Kralik, 2002) found that learning to live with a chronic illness involves a process of shifts in self-identity as the patient attempts to hold onto the sense of self that they had before they were diagnosed. This transitional process was called the 'quest for ordinariness' (Kralik, 2002) and involved developing an altered perception of self, so that illness may become part of life. They claimed that shifts in self-identity involve an ongoing process of negotiation between what patients want to do, and what they are able to do. In order to discover this, patients reported pushing the boundaries that their illness imposes on them and taking calculated risks (Kralik, 2002). This 'quest for ordinariness' (Kralik*,* 2002) could also be called normalisation; any behavioural attempt used to maintain a normal life, including strategies of covering up, keeping up and pacing (Wiener, 1975), it holds similarities with Sanderson's (2011a) 'resetting normality' typology.

3.2.2 Social Support

Social support is regarded as a necessary component to promote physical, psychological, social and emotional well-being (Wortman and Conway, 1985). In a qualitative study with 40 RA patients (Ryan *et al,* 2003), social support was identified as a major contributing factor positively influencing control perceptions. However, inappropriate support (e.g. being over-protective) was viewed as a form of social control that had negative consequences for the individual, leading to feelings of helplessness. Further, a cross-sectional study with 229 RA patients (Riemsma *et al,* 1998) found that 'problematic social support' (support that is seen as non-supportive by the patient even though the providers' actions may be well-meant) was associated with higher levels of fatigue. However, the cross-sectional design meant that causal relationships could not be determined.

A descriptive study examining the relationships between quality of life of 68 women with RA and their perceived levels of social support found significant associations between the levels of social support and physical health scales, social activity and affect scales (Minnock, Fitzgerald and Bresnihan, 2003). However, the design of this study meant that a causal relationship could not be identified. Further, this study was conducted only with women and therefore has overlooked the potentially different experiences of male patients, who do not access social support in the same way as women (Charmaz, 1994).

A qualitative study (Radford *et* al, 2008) explored the support needs of RA patients who were either newly diagnosed or experienced patients. This study found that the provision of emotional support was important to patients, who suggested being given more protected time and a safe environment, for professionals to listen to them, to be given help with low mood and to be able to meet others with RA. Thus social support does not necessarily consist of the patient's friends and family alone, but can include the medical team and other patients with RA. However, this study did not include any male patients and only included one younger patient, who may have very different support needs for their RA.

One aspect of social support is emotional disclosure, which is the process of writing or talking about personally stressful or traumatic events. Two studies with RA patients have reported physical improvements following an emotional disclosure intervention. One (Kelley, Lumley and Leisen, 1997) reported improvements in physical functioning, pain and affective disturbance three months after a verbal disclosure intervention. Whilst the other (Smyte *et al,* 1999) reported reductions in clinician-assessed disease activity over a four month period following a written disclosure intervention. A more recent study (Wetherell *et al*, 2005) compared RA patients who wrote or talked about a traumatic experience with a control group who wrote or talked about the events of a particular day. This study found that emotional disclosure had a positive effect on mood outcomes ten weeks after the intervention, but not on clinical or physiological measures.

3.3 Problem-Focused Coping

3.3.1 Self-Management

A wide variety of self-management methods are recommended for people with RA. These are therapeutic activities prescribed, taught or recommended by health professionals in collaboration with the patient, with the aims of reducing pain and inflammation, reducing the risk of deformities and developing and maintaining or improving function (Hammond,1998). A cross-sectional study (Hammond, 1998) identifying self-management strategies used by 41 RA patients found that the majority of patients used technical aids and rest on a daily basis, half used exercise and/or heat (although only half of these patients used these methods daily) and a small proportion of patients used joint protection daily. However, this was a survey study and therefore patients did not have the opportunity to raise self-management techniques that were not included in the questionnaire. Pacing and planning is also a recommended self-management technique for RA patients (Luqmani *et al*, 2006). These previously identified self-management strategies will be discussed.

3.3.1.1 Joint protection

Joint protection includes the application of alternative working methods, balancing activity and rest and the use of technical aids to improve daily task and role performance whilst protecting vulnerable or painful joints from further damage (Niedermann *et al*, 2010). An RCT of an educational-behavioural joint protection programme (Hammond and Freeman, 2001) found that in comparison with the control group, the joint protection group had significantly improved hand pain, general pain, early morning stiffness, number of self-reported flares, number of visits to the doctor and activities of daily living. This suggests that joint protection can help slow the progression of the effects of RA. The separate elements of joint protection (Niedermann *et al*, 2010) are discussed below.

3.3.1.2 Technical aids

Technical aids are gadgets used to reduce stress on joints (Hammond, 1998). One multi-centre survey study examined the use and effect of technical aids with 284 RA patients at one and two years following diagnosis (Thyberg *et al,* 2004). This study found that two years after diagnosis 78% of women and 54% of men were using technical aids. The most frequently reported beneficial effect of technical aids were improved eating and drinking. Further, the patients who reported using technical aids had more severe disease and more pronounced disability than those who did not. This indicates that people who are more in need of technical aids are the ones who use them. However, technical aids for chronic illness can be associated with stigma due to social perceptions of the particular aid, which can be particularly important with younger patients, and the visibility of the illness resulting from the use of aids in public (Parette and Scherer, 2004). Thus patients who do not disclose themselves as RA patients to others may be reluctant to use technical aids in public.

3.3.1.3 Rest

Historically, bed rest was the advised management method of RA due to concerns about the excessive use of inflamed joints (Jones, 1909) and the lack of effective pharmacological interventions to reduce synovitis at that time. This theory appears to have been applied to patient care without validation until 1963, when in an RCT 68 RA patients were randomised into two groups. The first group were treated in bed for four weeks by immobilisation in plaster casts. The second group were also confined to bed for 4 weeks, but performed daily active exercises (physiotherapy). The range of movement and functional capacity improved in both groups, but disease activity was significantly more reduced in the immobilised group (Partridge and Duthie, 1963). However, the risks of immobilisation are now well known. Loss of muscle strength during immobilisation may add up to 1-2% daily (Suzuki *et al,* 1994) and is more pronounced in the presence of joint disease or injury (Rutherford, Jones and Round, 1990), as well as issues of pressure sores, and the social consequences of long-term hospitalization.

In a survey study of 41 RA patients, rest was found to be the second most common method of self-management (after technical aids), which most people used daily (Hammond, 1998). Although rest is important to RA patients, many patients with chronic illness find it difficult to find a balance between activity and rest due to experiencing guilt when resting (Kralik *et al,* 2004).

3.3.1.4 Exercise

Despite the importance of rest in RA, exercise is also now considered an important component in the management of RA, with reported physiological and psychological advantages for the patient. In terms of the physiological benefits, one study that assessed the benefits of a six-week hand exercise programme in RA (Brorsson *et al*, 2009) found that it improved patients' hand force and hand function. However, this study did not compare patients in the programme to a control group of RA patients, but to healthy controls. A prospective RCT (Baillet *et al*, 2009) assessed the ability of an exercise programme to improve patients' disability. The exercise programme involved exercises for the upper and lower limbs being performed five times weekly in a gymnasium (45min/day) and in a hydrotherapy pool (60min/day), whilst the control group received a multidisciplinary information programme. This RCT found that patients who were in the exercise programme had a reduced HAQ and reported better quality of life than the control group. However, this study did not record patients' baseline levels of physical activity, which could influence the changes seen. Further, a programme that involved exercising for 105minutes five times weekly may be unrealistic to expect the majority of patients to manage due to other commitments and responsibilities.

Psychological benefits of exercise for RA patients have also been reported. In an RCT of RA patients following a twelve-week dance-based exercise programme, positive changes in depression, anxiety, fatigue and tension were observed (Noreau *et al,* 1995). However, this study does not take into account the potentially beneficial effects of social support and humour, which this programme may have also provided. Thus it cannot claim that the exercise component of the dance-based programme was responsible for patients' improved affect.

Whilst RA patients believe exercise to be an important factor in treatment, uncertainty about what exercises to do and how to do them without causing harm prevents many patients from exercising (Lambert *et al,* 2000). Patients require knowledge of the specifics of exercise prescription in order to include exercise as part of their RA treatment (Law *et al,* 2010). Significant increases in the use of exercise have been identified amongst osteoarthritis and RA patients after attending the Arthritis Self-Management Programme, a community-based arthritis education programme (Lorig *et al,* 1985). Thus patient education is important in the use of exercise as a self-management strategy for RA.

One barrier to exercising for RA patients is that patients perceive a lack of exercise knowledge in health professionals. Further, patients have reported perceiving contradictions between health professionals in terms of whether pain caused by exercise is related to joint damage or not (Law *et al,* 2010). A further barrier is the joint pain itself; this was found to be a prominent factor in predicting patients' exercise behaviour (Wilcox *et al,* 2006). Pain was described as a barrier in terms of the presence of pain preventing patients from exercising, experiencing pain during exercise reduced their willingness to exercise and pain post exercise discouraged them from exercising in future. Other barriers included fatigue, mobility and co-morbidities, all of which were reported to make exercise more difficult for patients. However, these were qualitative studies and therefore did not assess patients' exercise behaviour at regular intervals to discover how these vary with the fluctuating symptoms of RA.

3.3.1.5 Pacing and planning

It is now considered that rest and exercise are complementary elements of the management of active disease and the best balance should be found between the beneficial effects of rest and exercise for each patient (van den Ende *et al,* 2000). In fact the guidelines for the management of RA (Luqmani *et* al, 2006) suggest that patients are encouraged to pace activities and to recognise their physical activity limits, facilitating a realistic adjustment of their expectations.

A qualitative study in the USA with 20 RA patients and a qualitative study in the UK with 15 RA patients found that patients use re-prioritising and pacing in order to manage their fatigue (Tack 1990; Hewlett *et al*, 2005a). This can involve starting a task, having a rest and then coming back to the task later or choosing one task over another such as spending time with children rather than doing the housework. However, these studies focused on fatigue and therefore did not explore whether patients used pacing and planning to control other symptoms. A qualitative study with 9 patients with arthritis (Kralik *et* al, 2004) found pacing, planning and prioritising to be an important theme. Daily activities were paced to tolerate or not aggravate the pain, whilst planning and prioritising were closely linked with accepting and managing the action needed for change. However, this was a small qualitative study with patients who had either osteo or rheumatoid arthritis, but the difference was not specified. Further, many of the participants had other co-morbidities such as diabetes, osteoporosis and palsy, which may have affected the way in which patients report their self-management due to the potential difficulty of separating out multiple co-morbidities.

A survey study addressing patients' self-management techniques in RA (Hammond, 1998) did not include items relating to pacing or planning, indicating that some clinicians may not consider these as practical management techniques. Further, a review of 145 papers relating to the self-management approach to chronic conditions did not identify the use of pacing and planning (Barlow *et al,* 2002). Thus although pacing and planning is used by patients to manage their symptoms, which has been identified through qualitative studies and anecdotal evidence, it is not a technique included in quantitative studies of self-management, yet it is explicitly taught in RA self-management programmes (Hewlett *et al*, 2001).

3.3.1.6 Hot and cold therapies

The guidelines for rheumatology self-management (Luqmani *et al*, 2006) suggest that heat (e.g. a hot bath) and cold applications (e.g. ice packs) may provide short term symptomatic relief of pain and stiffness. However it is noted that there is no recommendation for long-standing benefit. Heat therapies include hot baths, hot packs and hot wax and work by increasing skin and joint temperature and blood flow and thus reducing joint stiffness (Oosterveld *et al*, 1992; Reitman and Esses, 1995). Cold therapies include ice bags, ice packs, cold baths and cold packs and work by decreasing skin and joint temperature and blood flow and thus reducing inflammation (Oosterveld *et al*, 1992; Reitman and Esses, 1995). Further, cold therapies have been shown to have analgesic effects (Ernst and Fialka, 1994; Schmidt *et al*, 1979). The technique of alternative hot and cold therapies is thought to reduce pain and inflammation by increasing the peripheral circulation by removing metabolic wastes, stimulating the central nervous system and increasing blood flow to the muscles (Calder, 1996).

In one study 30 patients with RA had their pain thresholds measured before and after both a warm bath and an ice massage (Curkovic *et al,* 1993). Both heat and cold were found to significantly raise the pain threshold immediately after the treatment application. Patients' pain thresholds were still raised at 10 and 30 minute time points after the ice massage, but this was not seen for the warm bath (Curkovic *et al,* 1993), indicating that cold therapies may have longer lasting effects than heat therapies. A survey of the self-management techniques of 41 RA patients (Hammond, 1998) found that half of the patients used heat therapies for their RA, with half of these using heat daily. The majority of the patients in this study reported beliefs that heat therapy was beneficial. However, this study did not ask patients about the use of cold therapies. A qualitative study involving interviews with 9 patients about their experiences of managing their RA does not mention the use of hot or cold therapies (Kralik *et al,* 2004). This suggests that whilst hot and cold therapies are used by some patients, they are not considered important to all patients as a tool to manage their RA.

3.3.2 Flare self-management

There is a scarcity of research that addresses how patients specifically manage the symptoms and consequences of their RA flares. One qualitative study (Kett *et al,* 2010) conducted interviews specifically to explore an ethnically diverse group of RA patients. This study found that patients who did not believe there was a cause to their flares were more likely to use strategies aimed at managing their symptoms such as using analgesics or distraction techniques. In contrast, those who believed they could identify the cause of their flare were more likely to use strategies aimed at eliminating these perceived causes such as altering their diet (Kett et al 2010). However, the authors do not explain how the interviews were translated for the purpose of analysis: if they were translated by the researcher this has the potential for researcher-bias in terms of how they translated the data (Temple and Young, 2004). Further, this was a retrospective study with patients who had experienced a flare at some point in their disease trajectory (Kett *et al*, 2010) and therefore did not capture patients' reported self-management techniques whilst they were experiencing a flare.

A further qualitative study (Hewlett *et al,* 2012) used focus groups with 67 RA patients across five countries to explore patients' perspectives of RA flares. This study found that when in a flare, patients increase their usual level of self-management strategies by resting, pacing, applying heat or cold and escalating medications such as gluco-corticoids, often without seeking medical advice. Patients may be able to successfully self-manage early warnings of flare or divert minor flares, whereas unprovoked, persistent symptoms lead patients to redefine their flare as 'uncontrollable' (Hewlett *et al,* 2012, Fig 2.2). Flare symptoms becoming uncontrollable (even with increased self-management strategies) and patients no longer being able to run their normal lives, prompts patients to seek professional help for their RA flare (Hewlett *et al,* 2012). However, this study was not conducted with patients who were currently experiencing a flare. Further, it only identified one tipping point for help-seeking and neither self-management nor help-seeking were the main aims of this study, which was to identify the components of flare.

There is therefore limited literature that addresses patient's self-management techniques when they are in an RA flare. The ability to capture patients' self-management strategies prior to and during an RA flare would provide novel data in this area. Having explored emotion- and problem-focused coping, the literature on adaptation and adjustment will be explored as these are the desired outcomes of effective coping and self-management (Moos, 1982; Moos and Schaefer, 1986).

3.4 Adaptation and adjustment

The terms adaptation and adjustment are often used interchangeably in the literature (e.g. Zautra *et al*, 2008) and will be used interchangeably in this thesis due to the lack of a distinct difference in definitions having been published. In relation to the cancer literature, adjustment has been defined as *"the cognitive and behavioural* *responses the patient makes to the diagnosis of cancer"* (Watson *et al*, 1988, p203). However, this bland definition indicates that adjustment is static. A more recent explanation of adjustment to cancer involves an active psychosocial process, which may include both positive and negative consequences for the patient (Brennan, 2001). Thus adjustment will be discussed in both practical and psychological terms.

3.4.1 Practical adjustment

One qualitative study used focus groups with 23 patients to address how patients adapt to life with RA (Lütze and Archenholtz, 2007). This study reported that patients with RA change their activities according to their energy level so as not to 'pay' for their activities the following day. The authors of this paper use the term 'dose' their activities, which is similar to the concept of pacing (Luqmani *et al*, 2006)**.** RA can be a power struggle between the symptoms and consequences of the disease in everyday life, and the patient's will to experience well-being and gain control over their body (Arvidsson *et al,* 2011). Thus patients will sometimes stretch their limits in order to do something special or just because of the need to feel 'normal' (Lütze and Archenholtz, 2007). This would be a reasoned decision after weighing up that the potential consequences (exhaustion) would be outweighed by the benefits (being normal), and is different to carrying on doing things without thought (boom and bust behaviour).

Patients use a range of different strategies in order to be able perform activities, for example having a shower to relieve stiffness before going to work. Patients report that these strategies have been acquired through trial and error rather than having been taught to use them. They also discuss ways in which they have attempted to adjust their valued activities in order to retain them, such as doing them less often, in another way or finding an equivalent activity (Lütze and Archenholtz, 2007).

Adjustment to another rheumatological condition AS has also been investigated (Mengshoel, 2008), through 12 qualitative interviews exploring the way in which AS patients adapt to everyday life. It was found that although the disease course of AS, like RA, is unpredictable, patients were able to identify three aspects of living with AS, which were characterised as 'ordinary life condition', 'slowed down life condition' and 'disrupted life condition'. The researchers report that during ordinary life and slowed down life, the increased discomfort was prevented or reversed by patients adapting everyday activities and their environment. However, during the disrupted life period intense, inexplicable and unmanageable pain that could not be reversed by one's own actions prevented all or most ordinary activity. This 'disrupted life condition' is particularly relevant to RA flares (Chapter 2.3).

3.4.2 Psychological adjustment

Patients with a long term condition can experience anxiety, depression and other negative emotions (Taylor and Aspinwall, 1996). In comparison with healthy controls or with patients with other long term conditions, RA patients demonstrate poorer psychological well-being (Smedstad *et al,* 1996). How patients cope with these emotions can affect how well they adjust to their condition (de Ridder *et al,* 2008). A cross-sectional study of 59 women with RA (Curtis *et* al, 2005) found that adaptive strategies such as acceptance and active coping had the strongest association with high positive affect, whereas disease status did not. However, the cross-sectional design of this study meant that causal relationships could not be identified.

A qualitative study involving 30 women with RA proposed that patients go through stages in order to adjust to living with RA (Shaul, 1995). The first stage was identified before diagnosis as 'becoming aware', which was characterised by Shaul as 'early twinges'. These were often ignored and not seen as a problem until the first flare occurred, thus proving to the patients that they had a problem, and prompted them to seek help. The second stage labelled 'learning to live with it' was characterised by learning to manage symptoms that interfered with normal functioning. This means that patients would need to reprioritise their daily life and for most this stage also involves learning new ways of doing things, of coping with multiple physical and emotional symptoms and meeting role responsibilities. In this stage patients incorporate their illness into their self image and although the illness is unpredictable, they are better prepared to cope with a flare (Shaul, 1995).

3.4.3 Mastery and self-actualisation

The final stage of adjustment is identified as Mastery (Shaul, 1995). This is the stage in which patients emerge with a new identity that they have constructed, including a different perception of health and a different emphasis on family relationships, work and leisure. This stage does not reflect acquiring mastery over the disease, but obtaining mastery in living with RA and a redefinition of what constitutes quality of life. In order to achieve Mastery, the individual must gain a sense of empowerment over the situation and develop a repertoire of coping strategies (Shaul, 1995).

The idea of Mastery is similar to Maslow's (1968) Self Actualisation which is the pinnacle point he claims we should strive to achieve, topping his Hierarchy of

Needs. The Hierarchy of Needs is often represented as a pyramid and contains 5 layers, with the most basic, lowest level needs at the bottom and Self Actualisation' at the top. According to Maslow one cannot conceive of fulfilling a higher need before the more basic needs are met. The four lower layers of the hierarchy consist of what Maslow called 'deficiency needs' which are respectively; physiological (e.g. the need for food, water, air); safety (e.g. the need for security of employment, family, health etc); love/belonging (e.g. the need for friendship, love, intimacy); and finally esteem (e.g. the need for self-esteem, confidence).

In order to obtain Self Actualisation Maslow states that the previous needs must not only be achieved, but mastered. Maslow describes 'self actualisation' as becoming everything that one is capable of becoming and says this level of need pertains to what a person's full potential is and obtaining that potential. This perhaps has parallels with Shaul's Mastery as patients reach a stage where they are able to identify their limits and by adjusting their daily lives can be the best they can be within and sometimes in spite of the limits. However, RA is a fluctuating unpredictable condition, therefore it may not be possible to maintain a state of Mastery.

Maslow (1954) can be heavily criticised in his ethos that only 'exemplary people' were worth studying (such as Albert Einstein, Eleanor Roosevelt & Frederick Douglas), as he stated:

> *"The study of crippled, stunted, immature and unhealthy specimens can only yield a cripple psychology and a cripple philosophy" p236*

However, it does seem that his theory developed from this 'exemplary' population, or at least a variation on this theory, may be able to be generalised to a population of people with RA who may not be 'exemplary' by Maslow's standards, but who have managed to gain mastery over their lives.

3.5 Summary

A number of self-management and coping techniques exist that patients draw upon. Some techniques may be recommended by health professionals and others the patient may discover themselves with trial and error, either way patients appear to achieve better physiological and psychological outcomes through the effective use of self-management and coping strategies. Effective use of emotion- and problem-focused coping strategies can enable patients to adapt to their RA and obtain Mastery of their RA or Self Actualisation.

Although much is reported in the literature about how patients self-manage their RA, very little is known about whether there is any difference in self-management on current more aggressive drug therapies or how patients self-manage their RA flares. Failure of self-management strategies have been described as the tipping point for seeking medical help for RA flares. However, previous studies have not included patients that were currently experiencing a flare.

Whilst failure of self-management strategies have been identified as the tipping point for seeking help for RA flares, other tipping points for this may also exist. Thus Chapter 4 will review the help-seeking literature, the factors that affect help-seeking behaviours and the psychological models that attempt to explain these behaviours.

Chapter 4: Help-seeking behaviours

Chapter 3 identified that failure of self-management strategies prompt people with RA to seek medical help for their flare. This chapter reviews the literature relating to help-seeking behaviours in RA and/or other health conditions. The importance of patients' help-seeking for an RA flare is discussed, the psychological models that might explain health behaviours are examined and the factors that may affect patients' help-seeking behaviours are explored,

4.1 Benefits of early help-seeking behaviours

Early diagnosis and treatment is crucial in RA (Emery, 2002) to avoid irreversible joint damage, which may lead to permanent disability and increased personal suffering (Townsend *et al,* 2010). Evidence supports the initiation of disease-modifying anti-rheumatic drugs (DMARDs) within 3 months of the onset of RA in order to prevent joint damage (Nell *et al,* 2004).

A literature search from 1806-2012 (search terms: rheum*, arthritis, flare, early, treatment, therapy) identified no studies that have addressed the benefits of treating patients as early as possible when they are experiencing an RA flare. However, it has been found that tight control of inflammation with DMARDs, especially early in the course of RA, reduces long-term morbidity and mortality (Strand and Singh, 2007). In the Tight Control of Rheumatoid Arthritis (TICORA) study, patients who were randomised to the 'intense' treatment arm, where DMARD therapy was escalated to achieve a target low disease activity state, did significantly better in terms of function and radiological damage compared to patients in the routine treatment arm, where disease activity scores were not measured and patients were managed at the discretion of the rheumatologist (Grigor *et al,* 2004). This finding is similar to the Disease Control and Complications Trial (DCCT) in diabetes, which found that intensive therapy reduced complications, improved quality of life and could be expected to increase length of life (DCCT Research Group, 1996). The evidence supporting tight control of inflammation indicates the possibility that patients receiving treatment as soon as possible for their RA flares may have a better long term outcome in terms of joint damage, disability and even mortality.

During the process of diagnosing RA, delay in the presentation to primary care is the main reason why patients are seen late by a rheumatologist (Kumar *et al,* 2007). Further, anecdotal evidence suggests that patients with established RA, who phone the rheumatology helpline in a flare, have already waited a substantial amount of time before contacting the team. Thus considering the potential benefits of early help-seeking for an RA flare, it is important to unpick why patients may wait before seeking help.

4.2 Health and illness behaviours

A distinction has been made between three different types of ‘health behaviour’: health behaviour; illness behaviour; and sick-role behaviour (Kasl and Cobb, 1966). Health behaviour is an activity undertaken by a person believing themselves to be healthy, for the purpose of preventing disease or detecting it in an asymptomatic state. Illness behaviour is any activity undertaken by a person who feels ill, to define the state of their health and to discover a suitable remedy. Sick-role behaviour is an activity undertaken for the purpose of getting well, by those who consider themselves ill. It includes receiving treatment from appropriate therapists, generally involves a whole range of ‘dependent’ behaviours and includes the belief that ill people are not held responsible for their normal roles, thus the person adopts the ‘sick-role’. Illness behaviour and sick-role behaviour may appear similar, but in illness behaviour the patient takes an active role in their health, whilst in sick-role behaviour the patient takes a passive role, in which they depend on others. Illness behaviour seems more appropriate to describe RA patients’ help-seeking behaviours as they take an active role in self-managing their RA (Chapter 3), including seeking help from the medical team when they believe they are in an RA flare in order to receive treatment to control their symptoms (Hewlett *et al*, 2012).

4.3 Psychological models explaining help-seeking behaviours

A number of psychological models have been proposed to describe health behaviours, in the broad sense of the term (Kasl and Cobb, 1966). However, not all these models include the help-seeking aspect of health and illness behaviours, thus the Stages of Change Model (Proshaska, DiClemente and Norcross, 1992) and Conflict Theory Model (Janis and Mann, 1977) have not been included in this thesis, due to insufficient inclusion of help-seeking behaviours. The models that will be discussed below are: Health Belief Model (HBM); (Multi-dimensional) Health Locus of Control (MHLC); Theory of Planned Behaviour (TPB); Social Cognition Theory (SCT); and Self-Regulatory Model (SRM).

4.3.1 Health Belief Model

The Health Belief Model (HBM: Becker and Rosenstock, 1984) proposes that health behaviour depends directly on the outcome of two assessments (Fig 4.1); perceived threat and perceived benefits and barriers. Three factors influence perceived threat: perceived susceptibility; perceived seriousness; and cues to action. In terms of patients' help-seeking behaviours for an RA flare, the HBM suggests that patients assess the perceived threat suggested by their flare symptoms. Patients could assess the likelihood that their symptoms will develop into a flare (perceived susceptibility) and consider the physical and social consequences of being in a flare (perceived seriousness). Cues to action might include the symptoms themselves and the advice patients receive from lay referral from their friends and family. Alongside these perceptions of threat, people evaluate the perceived benefits and barriers of taking action, weighing the pros and cons of performing a particular health behaviour. Therefore in terms of RA, patients may weigh up the benefits of treatment for their flare with the barriers of their other responsibilities, thus not wanting to waste their own time (Sheppard et al, 2008) or not wanting to 'bother' the doctor (Kett et al, 2010).

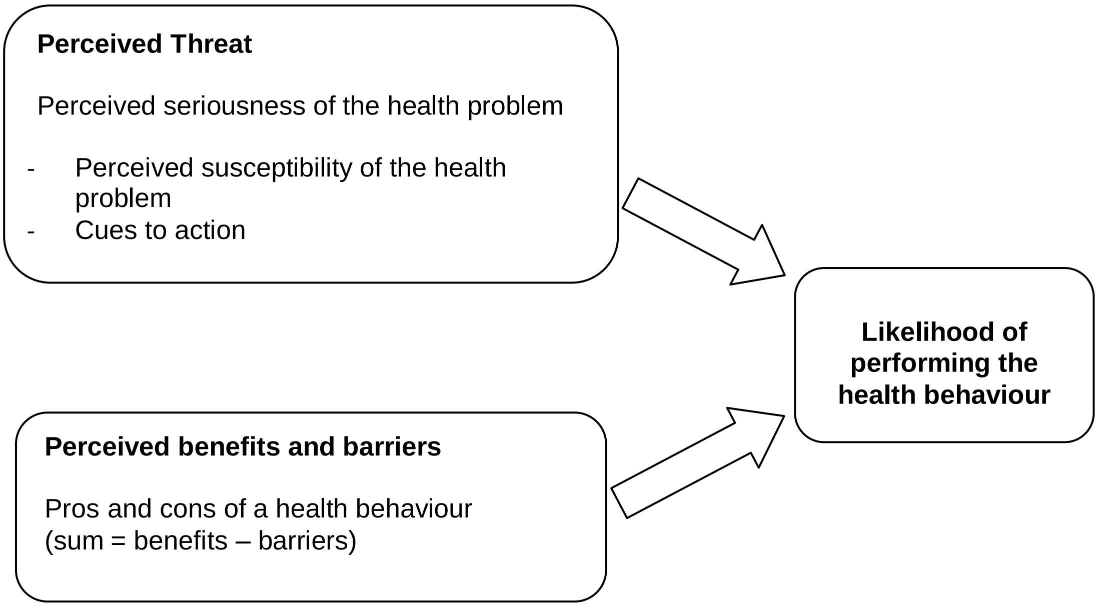

Figure 4.1: The Health Belief Model

Meta-analyses of the HBM have found different results of the HBM's ability to predict behaviour: barriers, benefits and susceptibility were good predictors of behaviour, whereas severity was not (Janz and Becker, 1984); the HBM was predictive of behaviour, but only weakly in comparison to SCT and the Theory of Reasoned Action (Zimmerman and Vernberg, 1994); the HBM produced substantially larger effect sizes in retrospective than prospective studies, suggesting that the HBM does not have predictive ability (Harrison, Mullen and Green, 1992); and that barriers and benefits were good predictors of behaviour, whereas severity and susceptibility were not (Carpenter, 2010).

Whilst some research suggests that the factors described by the HBM do influence decisions of whether and how soon to access health services (Becker and Rosenstock, 1984), others have found a weak relationship between these factors and likelihood of accessing healthcare (Harris and Guten, 1979). This suggests that other factors are also important in decisions to seek treatment, such as influences from friends and family or previous experience of help-seeking.

4.3.2 (Multi-dimensional) Health Locus of Control

The Health Locus of Control (HLC) originated from Rotter's (1954) Social Learning Theory, which proposes that the likelihood of a behaviour occurring in a given situation is a function of the person's expectancy that the behaviour will lead to a particular reinforcement (e.g. *"If I seek help for my RA flare I expect to be given medication that will relieve my symptoms"*), and the extent to which they value that reinforcement. Rotter (1966) proposed that as well as having expectancy beliefs for specific situations, people also have generalised expectancy beliefs that can be applied across situations. Thus the HLC was developed as a generalised expectancy relating to the perceived relationship between a person's actions and experienced outcomes.

The HLC distinguishes between *internal* and *external* locus of control belief orientations. People with an *Internal HLC* believe they have the ability to influence and determine features that affect their lives, thus events are seen as a consequence of their own actions, which they are able to control. In contrast, people with an *External HLC* believe that events are unrelated to their actions and are therefore determined by factors beyond their personal control. Using this model, patients with an *External HLC* would therefore be more likely to believe that there was nothing they could do about an RA flare, whereas patients with an *Internal HLC* may be more likely to be proactive and seek help for an RA flare due to beliefs that they can control their situation.

It was argued that with the external HLC, it is possible to distinguish between external control exerted by powerful others and the influence of chance (Levenson, 1974). Thus a revised version was developed: the Multidimensional Health Locus of Control (MHLC: Wallston, Wallston and DeVillis, 1978). In this revised model, beliefs are measured across three dimensions: *Internal HLC*, which remains the same; *Powerful others HLC*, in which people believe their health is under the control of powerful others; and *Chance HLC*, in which people believe their health is owing to chance. The MHLC predicts that people with an internal HLC would be more likely to engage in health promoting activities. However, in terms of help-seeking for a long-term condition, the belief in the role of powerful others may be advantageous (Wallston, 1989) as patients may be more likely to believe that the medical team are there to help them, and would therefore be more likely to seek help.

There are a number of criticisms of the MHLC as a theory to explain health behaviours. First, the locus of control does not take into account the value that people place on their health, which might be a strong predictor of help-seeking behaviour (Weiss and Larsen, 1990; Wallaston, 1992). There is no theoretical reason to expect the locus of control to predict health behaviours among people that place low value on their health (Wallston and Wallston, 1980). Indeed one study (Weiss and Larson, 1990) found that people placing high value on their health correlated significantly with internal HLC beliefs and a health behaviour index, which was not found for people who placed low value on their health. Second, the MHLC can be criticised for explaining behaviour in terms of generalised behaviour-reinforcement expectancy beliefs (Ajzen and Fishbein, 1977) and it is possible that people hold different control beliefs for different behaviours (Kirscht, 1972). Therefore the MHLC may explain patients' help-seeking behaviours for their RA flares to some extent, but it does not take into account whether their RA is a priority for them, or whether they have specific control beliefs about help-seeking for their RA flares. It is possible that patients with previous experiences of help-seeking for their RA flare may be influenced by this when considering their future help-seeking behaviour.

4.3.3 Theory of Planned Behaviour

According to the Theory of Planned Behaviour (TPB: Ajzen, 1985), an expanded version of the Theory of Reasoned Action (Ajzen and Fishbein, 1980), people decide their intention in advance of most voluntary behaviours, they therefore propose that intentions are the best predictors of what people will do. This theory indicates that three judgements determine a person's intention to perform a behaviour (Fig 4.2), which will be illustrated with a fictitious patient considering seeking help for an RA flare.

Attitude regarding the behaviour: A judgement of whether or not the behaviour is a good thing to do. This judgement is based on two expectations: the likely outcome of the behaviour (such as *"If I seek medical help my flare will be halted"*) and whether the outcome would be rewarding (such as *"If my RA flare is halted I will be in less pain and can go back to my normal daily life"*).

Subjective Norm: This judgement reflects the impact of social pressure or influence on the behaviour's acceptability or appropriateness. This includes beliefs about others’ opinions (such as *“My friends and family think I should seek medical help for my flare”*) and motivation to comply with those opinions *(as in “I want to do what they want”*).

Perceived Behavioural Control: This is the person’s expectation of success in performing the contemplated behaviour (such as *“I believe I will be able to attend a hospital appointment”*). This judgement is similar to the concept of self-efficacy (Bandura, 1986) (Section 4.3.4).

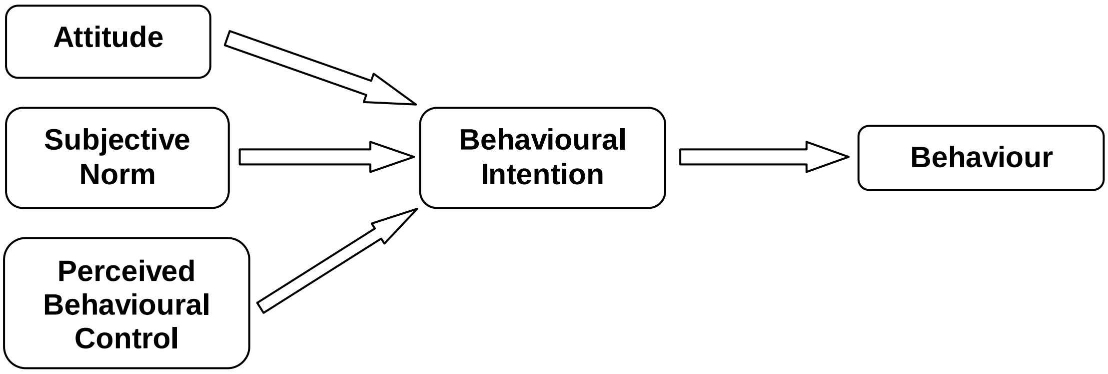

Figure 4.2: The Theory of Planned Behaviour

The Theory of Planned Behaviour proposes that these judgements combine to produce an intention that leads to performance of the behaviour. The individual judgements have been shown by many studies to influence intentions and behaviour (Conner and McMillan, 2004).

One criticism of this model is that the theory does not include people’s prior experiences with the behaviour (Conner and McMillan, 2004), this is an important factor to consider in terms of patients deciding whether to seek help for an RA flare. Previous studies looking at exercising and alcohol and drug use (Bentler and Speckart, 1979; Godin *et al*, 1987) have found that people’s history of performing a health behaviour strongly predicts their future practice of that behaviour. Thus patients who have previously sought help for an RA flare may be more likely to do so in the future, but this potentially predictive factor would not be recognised by the Theory of Planned Behaviour.

4.3.4 Social Cognition Theory

In Social Cognition Theory (Bandura, 1977) people’s motivation and action are assumed to be based on three types of beliefs: situation-outcome (beliefs about what consequences will occur without taking action e.g. *“If I don’t seek help for my flare I might be causing further joint damage”*), action-outcome (the belief that a given behaviour will or will not lead to a given outcome e.g. *“If I seek help for my flare I will be given medication that will relieve my symptoms”*) and perceived self-efficacy (SE) (the belief that a behaviour is or is not within their own control e.g. *"I believe that I could seek medical help for my flare"*).

There is a causal ordering between the three beliefs (Schwarzer, 1992). Situation-outcome beliefs influence behaviour via their impact on action-outcome expectancies (e.g. a patient in an RA flare believes that if they do nothing their flare will get worse and cause long term damage, which motivates the patient to consider actions to minimise the potential consequences). Action-outcome expectancies are assumed to impact on behaviour via their influence on goals, behavioural intentions and SE expectancies. SE expectancies are thought to have a direct impact on behaviour as optimistic self-beliefs predict actual behavioural performance (Bandura, 1992). It also has an indirect effect via its influence on intentions as people generally intend to perform behaviours that they perceive to be within their control (Schwarzer, 1992).

One study comparing self-efficacy for pain and functioning in RA (Somers *et al*, 2010), found that patients with higher disease severity had lower levels of self-efficacy for controlling pain and other symptoms and for performing functional tasks. It is possible that SE may predict patients' help-seeking behaviours. It would therefore be important to discover how patients perceive their access to the medical team and thus if they believe that help-seeking is within their control or whether there are barriers to help-seeking that are outside of their control.

4.3.5 The Self-Regulatory Model

The Self-Regulatory Model (SRM) (Leventhal and Cameron, 1987; Leventhal *et al*, 1997) is a social cognition model, which is also known as The Illness Perceptions Model, The Illness Representations Model, The Parallel Process Model, The Common-Sense Model of Self-Regulation' or simply Leventhal's Model. The model consists of 3 stages (Fig 4.3) that regulate behaviour: Illness perceptions; the action plan or coping stage; and the appraisal stage in which the individual evaluates the success or failure of coping strategies. Illness perceptions are structured around five dimensions (Lau and Hartman, 1983; Leventhal, Diefenbach and Leventhal, 1992): Identity, which are the symptoms and the label given to the illness (e.g. *"My symptoms constitute an RA flare"*); Cause of illness, which can be genetic, environmental or behavioural factors (e.g. *"My flare is caused by the weather"*); Timeline or course of illness; Controllability/Curability; and Consequences, which can be perceived physical, psychological or economic consequences. (e.g. *"My flare affects my ability to do my normal activities"*)

The illness perceptions were revised and expanded to 9 illness perceptions, with two items expanded and two novel items added (Moss-Morris *et al*, 2002). Factor analysis of controllability/curability found that the items loaded onto two separate factors (Moss-Morris *et al,* 2002), *personal control* (e.g. *"There is nothing I can do to control my flare symptoms"*) and *treatment control* (e.g. *"Medication would relieve my flare symptoms").* The timeline subscale was also divided into two separate subscales of *acute/chronic timeline* (e.g. *"My flare will last a long time"*) and *cyclical timeline* (e.g. *"My flare symptoms are very unpredictable"*). Finally two new illness perceptions of *Emotional representations* (e.g. *"My flare makes me feel angry and worried"*) and *Illness coherence*, which is the extent to which people's illness 'makes sense to them' (e.g. *"My RA flare symptoms are puzzling to me"*) were also added (Moss-Morris *et al*, 2002).

Theoretically these revised illness perceptions might explain help-seeking behaviours for RA flares, patients who *identified* their symptoms as an RA flare and who attributed the *cause* of their flare symptoms to fluctuations in disease (rather than an external cause, such as the weather) may be more likely to seek help. Further, patients who believe that their flare will last a long time unless they seek medical help (*acute/chronic timeline*) and whose symptoms are fluctuating uncontrollably (*cyclical timeline*) may be more likely to seek help as these perceptions may lead to the feeling of losing control. Patients with the perception that they are able to manage their symptoms alone (*personal control*) may be less likely to seek help than those who think that they need medication to control their symptoms (*treatment* control). In terms of *emotional representations,* patients may be more likely to seek help if their symptoms cause negative emotions such as anger and worry. Finally, patients may be more likely to seek help when their symptoms affect their quality of life (*consequences*).

The SRM is a parallel processing model, where perceptions of a health threat take place on both a cognitive level for regulation of danger, and an emotional level for the regulation of fear. Each of the two parallel processing systems has a feedback loop, thus if a particular coping strategy is perceived to be ineffective, an alternative coping response may be adopted, which may result in a change in illness perceptions (Lawson, Bundy and Harvey, 2007).

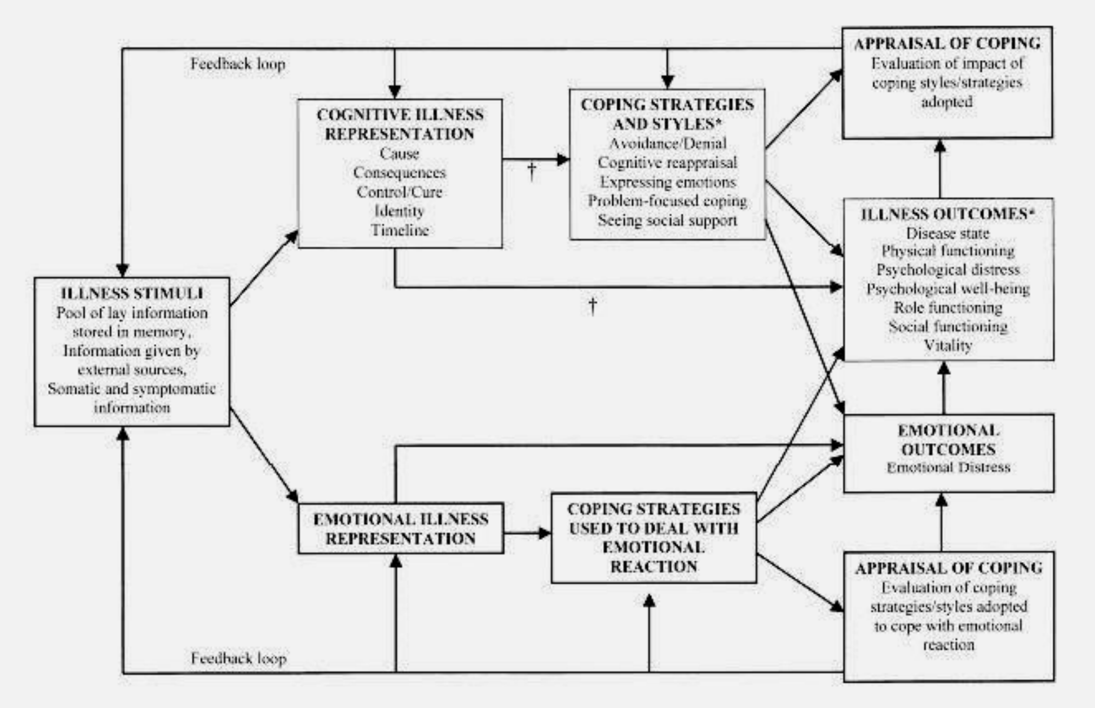

Figure 4.3: The Self-Regulatory Model
Hagger and Orbell, Psychology and Health, 2003 18(2): 141-184, with kind permission Taylor & Francis

4.3.5.1 Application of the Self-Regulatory Model

The SRM has been used to explain health behaviours in a number of health conditions. In RA, a belief in adverse consequences was associated with more visits to the outpatient clinic, fatigue and higher anxiety (Scharloo *et al,* 1999). The SRM proposes that people use common sense in constructing their illness perceptions based on their knowledge and experiences, and they actively test these out by their use of emotion- and problem-focused coping efforts (Hale, Treharne and Kitas, 2007). A study with RA patients found that avoidant coping did not predict fatigue after 1 year and this coping style did not appear to be related to perceiving RA to have serious consequences (Treharne *et al,* 2005). However, the authors note that this could be due to coping scales not being sensitive enough and not being culturally relevant due to having been developed in the United States.

The SRM has also been used in other conditions, such as acute myocardial infarction (AMI). These patients' experiences have been found to support the SRM as they report a sequence of appraisal and reappraisal of symptoms, coloured by emotional responses to the event (Dempsey, Dracup and Moser, 1995). The SRM has been used to design a number of interventions to improve delay times in help-seeking with AMI patients (e.g. Dracup *et al,* 1995; Dracup and Moser, 1997). The SRM has also been used to identify factors associated with non-attendance to diabetes clinics (Lawson, Bundy and Harvey, 2007) and to identify different clusters of chronic pain patients and thus customise treatment (Hobro, Weinman and Hankins, 2004). It has also been used to determine how illness perceptions influence both coping and outcomes in a diverse range of long term conditions e.g. chronic fatigue syndrome (Moss-Morris *et al,* 1996); psoriasis (Fortune *et al,* 2000); and multiple sclerosis (Vaughan, Morrison and Miller, 2003). The SRM has been used in a variety of long term conditions to explain patients' help-seeking behaviours and has been used in RA to explain patients' coping behaviours and to predict potential outcomes. It therefore appears to be a relevant model with which to evaluate the decision-making process and help-seeking behaviours of patients with RA. However, there may be other variables such as gender and social support that influence help-seeking behaviours, which are not included in the models above and will now be discussed.

4.4 Factors affecting help-seeking

One small qualitative study has been identified that reported patients' RA flare help-seeking behaviours (Kett *et al,* 2010). This study was conducted with an ethnically diverse population and found that whilst White British patients' reasons for avoiding help-seeking were due to feeling they could cope and being too proud to ask for help, South Asian patients' reasons were related to the language barrier and lack of rapport with their medical team. This study identified that the prompt for help-seeking was severity of symptoms. However, help-seeking was only one small aspect of this qualitative study and therefore patients' experiences and beliefs have not previously been explored in depth.

Due to the lack of literature discussing RA flare help-seeking behaviours, the literature will be explored for help-seeking behaviours in patients with other health conditions. The literature around patients' help-seeking behaviours during the process of obtaining a diagnosis will also be considered as there may be similarities to seeking help for an RA flare.

4.4.1 Gender

There are conflicting data regarding whether there are gender differences in delay in seeking treatment. Several studies have found no difference in delay times between men and women seeking help for acute cardiac symptoms (e.g. Dracup and Moser, 1997; Moser *et al,* 2005), whilst others found that women delay help-seeking for an AMI longer than men (e.g. Bowker *et al* 2000) or vice versa (White and Johnson, 2000). A qualitative study (Albarran, Clarke and Crawford, 2007) found that women with an AMI present with non-specific or no chest pains, making the symptoms difficult for them to interpret, therefore relying on the symptom of chest pain to detect AMI may delay women in seeking treatment.

There are differences in the reasons that men and women delay help-seeking (Moser *et al,* 2005). Men delay help-seeking when they are unaware of the benefits of treatment, whilst women delay due to not wishing to trouble the medical team (Moser *et al,* 2005). It has also been found that men with cancer are reluctant to seek help as they perceive it is not a masculine thing to do (Smith, Pope and Botha, 2005). People can and do behave in ways that both cohere with and contradict their normative gender behaviours when seeking health care, therefore gender cannot be considered a ‘stand alone’ factor in determining help-seeking behaviours (Galdas *et al,* 2010).

4.4.2 Social Support

When dealing with complex health decisions the majority of people will draw on their social network for advice, confirmation and support (Schoenberg *et al*, 2003). The process of family members and friends assisting in interpreting bodily changes and helping to decide on a course of action is referred to as the ‘lay referral system’ (Freidson, 1960). Lay referral networks can teach and reinforce patterns of self-care, validate or contradict people’s interpretations of their symptoms, encourage or discourage professional consultation, provide reassurance or simply allow people to voice concerns, thus affirming the person’s importance and supporting their self-esteem (Stoller, 1998).

In patients with RA who are pre-diagnosis, family and friends have been used as ‘lay consultants’ to seek advice and validation from before seeking medical help (Shaul, 1995; Sakalys, 1997). These ‘lay consultants’ also advised patients on symptom control, possible cures and occasionally that symptoms may be indicative of RA (Bury, 1982; Sheppard *et al*, 2008). For men, their wives have been found to be the primary lay referral source, possibly due to the traditional health gate-keeping role of women (Stoller, 1998). However, husbands do not necessarily serve the same role for women, reflecting women’s’ wider range of lay referral sources and possibly a desire not to ‘trouble’ their husbands (Schoenberg *et al,* 2003). In diabetes, the quality of the relationship has been shown to correlate to perceived social support and adherence to self-care behaviours in men, but this correlation was not seen with women (Gillibrand and Stevenson, 2007). This may further explain the differences between help-seeking behaviours in men and women (Section 4.4.1). It has also been found that some people have sought people with similar experiences online, instead of friends and family, which has helped them to decide whether to seek help or self-manage their condition (Hay *et al*, 2008; Townsend *et al*, 2010).

Lay referral systems may not always be helpful to patients. Some culturally specific advice, which suggested that symptoms represented a curse or that complementary medicines should be used, caused people to delay longer in help-seeking (Kumar *et al*, 2010). Further, family members, particularly older relatives, who have told patients that they are over-reacting or causing a fuss, can cause them to severely delay seeking medical help (Sheppard *et al,* 2008).

Thus the evidence in pre-diagnosed RA suggests that patients use lay referral networks as part of their decision-making process in seeking medical help. However, these lay referral networks do not always facilitate patients' help-seeking and can sometimes delay it. This supports findings in patients pre-diagnosis for breast cancer (Unger-Saldana and Infante-Castaneda, 2011) and patients who are experiencing an AMI (Schoenberg *et al*, 2003). Further, patients experiencing an AMI are more likely to seek help if a friend or family member phones for help as the responsibility is then removed from the patient and they report feeling less guilty about the possibility of wasting the doctor's time (Pattenden *et al,* 2002).

4.4.3 Symptoms

Patients' help-seeking behaviours can be attributed both to the type of symptoms they experience and the way in which they are interpreted. Patients with RA who are pre-diagnosis often experience joint pain that recurs intermittently, causing a delay in help-seeking (Sheppard *et al*, 2008). This may be due to the uncertainty of whether the symptoms are serious enough to seek help, which would support previous qualitative research (Hewlett *et al,* 2012). Indeed, help-seeking behaviours in patients with RA who are pre-diagnosis have been influenced by the cause that they attribute their symptoms to, and how serious they think their symptoms are (Sheppard *et al,* 2008). In pre-diagnosed RA, there is no association between the age of the patient and the extent of the delay (Kumar *et al,* 2007). This may be due to a different cause being attributed to the symptoms, as patients across the age spectrum report that they feel too young to have arthritis (Sheppard *et al,* 2008); and many patients have developed their own explanatory models for their symptoms based on recent physical experiences (Bury, 1982; Sheppard *et al,* 2008).

These findings in RA support those in other conditions, such as AMI in which patients' help-seeking has been found to be determined by perceived severity of their symptoms, experiencing a stuttering symptom pattern (symptoms came and went) and the anxiety they experience (Moser *et al,* 2005). Some patients experiencing an AMI rationalise their symptoms, for example attributing them to stress, which could slow the help-seeking process (Turris and Johnson, 2008). In contrast to the RA findings, older women experiencing AMI symptoms delay substantially (although not significantly) longer than younger women, it is suggested that this is due to multiple co-morbidities making it difficult for patients to attribute a cause to their symptoms (Dracup *et al,* 1995). In fact patients with diabetes who experience an AMI experience confusion over the cause of their symptoms (Mayer and Rosenfeld, 2006). Further, patients with diabetes (Lawson *et al,* 2005) and patients with AMI symptoms (Turris and Johnson, 2008) were reluctant to seek help when the symptoms were not visible to others. This may be due to the societal discourse that symptoms need to be visible to a bystander in order to be thought serious (Turris and Johnson, 2008). Thus patients who consider their symptoms to be unimportant may be unlikely to consider the potential future consequences of not seeking help (Lawson *et al,* 2005).

Patients experiencing AMI symptoms have expressed concerns that their symptoms may be diagnosed as non-cardiac in origin and have reported fears of embarrassment at having wasted the time of the medical team (Arslanian-Engoren, 2006). Others were concerned that they did not deserve medical help as they felt they had caused the symptoms themselves due to certain activities or poor lifestyle (Turris and Johnson, 2008). Some patients felt guilty about wasting the NHS's resources even though they knew they needed to seek help (Pattenden *et al,* 2002).

4.4.4 Barriers to help-seeking

Barriers to help-seeking in RA patients who are pre-diagnosis have been identified as patients' worries about wasting their own or the doctor's time (Sheppard *et al*, 2008). They also report prioritising other life events and other people over their need to seek help (Sheppard *et al,* 2008).

Patients with diabetes have cited difficulties with attending their clinic appointment as a barrier to seeking help (Lawson *et al*, 2005). Factors that affect this can include appointment time, distance from home and lack of transport (Lawson *et al,* 2005). Patients with diabetes also explained that attending diabetes clinic emphasised the negative aspect of their disease through seeing other patients and listening to the doctor (Lawson *et al,* 2005). However, patients reported that clinic avoidance led to feelings of depression, fear of diabetes, diabetic complications, fear of treatment and an uncertain future. (Lawson *et al,* 2005).

Further restrictions can be caused by work and lifestyle. Diabetes patients are often reluctant to ask their employers for time off work for appointments (Lawson *et al,* 2005). Women experiencing AMI symptoms choose to maintain their normal daily life routine and ignore their symptoms in order to 'maintain integrity', with some women reporting finishing the school run before seeking help (Turris and Johnson, 2008).

4.5 Summary

Early aggressive treatment for early RA and tighter control of inflammation provides significantly better treatment outcomes for patients. It is proposed that patients who receive early treatment for their RA flares will also experience better long term outcomes as this could prevent the long term inflammatory damage. Little is known about the decisions made by patients when they are in an RA flare; how they decide to seek help and why they wait.

Current research suggests that in patients with RA who are pre-diagnosis and in similar long term conditions, help-seeking behaviours are determined by a wide variety of factors. Although all these factors can in some way predict patients' help-seeking behaviours, they cannot be considered in isolation, as patients cannot be expected to always act according to their normative roles and rationality cannot be assumed. Thus an interaction of these factors may contribute to help-seeking.

Psychological models of health behaviours provide a more rounded explanation of patients' help-seeking behaviours taking into account their emotions, beliefs and perceptions rather than demographic characteristics. The self-regulatory model appears to be the most appropriate to explore RA patients' help-seeking behaviours having been used effectively with previous help-seeking behaviour studies and with RA patients. Discovering why patients delay help-seeking for their RA flares would provide important information for clinicians, enabling them to encourage RA patients to seek help sooner, thus improving their long-term outcome.

4.6 Summary of the overall literature review

The preceding literature review chapters have demonstrated that there is a dearth of literature addressing patients' experiences of daily life on current modern treatment regimes and there is currently no agreed definition for RA flare (Chapter 2). Whilst there are a range of self-management strategies suggested to patients, there is a lack of research that address which strategies patients use and how bad their symptoms have to be for them to consider self-managing whilst on current modern treatment regimes (Chapter 3). Finally, although studies have addressed help-seeking behaviours in patients with RA who are in the process of obtaining a diagnosis, only one small qualitative study could be found that addressed patients' decisions for help-seeking in an RA flare, which was only examined by one question. Thus patients' help-seeking behaviours for RA flare have been seriously overlooked in the literature (Chapter 4).

The gaps in knowledge therefore are how patients experience RA in daily life and flare on current modern treatment regimes; how they self-manage; and how they decide to seek-help for an RA flare. Thus the aim of this thesis is to investigate these gaps in knowledge and the following chapter describes the methodology and methods used to address this.

Chapter 5: Methodology and Methods

This chapter presents the rationale for a mixed methods approach. The methods for each of the 3 studies are described and justified. This chapter also describes the involvement of patient research partners in these studies.

5.1 Thesis aims

The aims of the thesis are:

- To explore the individual experience and impact of RA in daily life and flare and how patients self-manage these
- To obtain consensus on patients' experiences of daily life with RA
- To obtain consensus on patients' help-seeking behaviours in an RA flare
- To characterise the level, variation and clustering of symptoms in daily life

Three phases have been designed to address these aims: semi-structured interviews (Study 1) will explore patients' experiences of RA in both daily life and flare, and how they manage these. The variation of these experiences and decisions on help-seeking will then be explored for clusters or patterns, using Q-methodology (Study 2, utilising data from Study 1) presented to a fresh cohort of patients. Finally, the daily symptoms and help-seeking behaviours that patients identified as most important in Study 2, will be examined in quantitative terms through daily measures of symptoms (Study 3a); and a questionnaire regarding help-seeking, capturing patients who phone the rheumatology helpline for an appointment for their flare (Study 3b).

5.2 Mixed methods

There is inconsistency in the literature about exactly what constitutes mixed methods research (Sandelowski, 2000; Bryman, 2007; Tashakkori and Creswell, 2007). However, it has been suggested that the defining characteristics of a mixed methods approach include: qualitative and quantitative methods within the same research project; a research design that clearly specifies the sequencing and priority given to the qualitative and quantitative data; an explicit account of how the qualitative and quantitative aspects of the research relate to each other; and pragmatism as the philosophical underpinning for the research (Denscombe, 2008).

5.2.1 Traditional research paradigms and mixed methods

It is traditionally understood that qualitative and quantitative approaches represent incompatible paradigms (*"the set of beliefs and practices that guide a* *field"*: Morgan, 2007:49), due to being underpinned by fundamentally different assumptions about the nature of reality (ontology) and ways of knowing and understanding (epistemology) (Dures *et al*, 2011). Traditionally researchers have been divided between the positivist scientific model of research (quantitative) and the interpretative or constructivist model of research (qualitative) (Howe, 1985) and the approach in health care research was almost exclusively of the positivist approach, which is still considered by many to be the 'gold standard' (Doyle, Brady and Byrne, 2009).

Constructivism proposes that there are multiple realities and different interpretations may result from any research endeavour, which can be shaped by particular circumstances (Appleton and King, 2002). In contrast, positivism proposes that there is a single reality and therefore seeks to identify the causal relationships through objective measurement and quantitative methods. The positivist viewpoint is that research outcomes are not biased by the values of the detached positivist researcher unlike in the constructivist paradigm, where the researcher is immersed in the work (Firestone, 1987). There is an assumption that positivism is objective, whilst constructivism is subjective. However, it has been strongly argued that no research is wholly free from value judgements (Howe, 1985).

Despite the debate in the literature surrounding the issues of combining qualitative and quantitative research methods (Howe, 1985; Bryman, 2007; Morgan, 2007), it has been proposed that mixed methods constitute a third paradigm, capable of bridging the gap between qualitative and quantitative positions (Johnson and Onwegbuzie, 2004). Thus the philosophy of pragmatism is typically associated with mixed methods (Dures *et al*, 2011). Pragmatism maintains that the consequences are more important than the research process and therefore that 'the end justifies the means' (Doyle, Brady and Byrne, 2009). It therefore advocates choosing the best method to answer the research question, rather than being driven by the researcher's epistemological or ontological standpoint (Johnson and Onwegbuzie, 2004). Further, pragmatists seek functional knowledge and consider the impact of research on practice (Maxcy, 2003).

5.2.2 Rationale for mixed methods

A review of 232 social science mixed methods studies (Bryman, 2006) identified 16 reasons for conducting mixed methods research. These have been summarised to provide 8 individual rationales and benefits of using mixed methods designs (Doyle, Brady and Byrne, 2009):

Triangulation: this allows for greater validity in a study by seeking corroboration between qualitative and quantitative data. In this thesis, any similarities and differences between the findings of the individual studies are discussed in Chapter 10.

Completeness: a combination of research approaches provide a more complete and comprehensive picture. Thus in this thesis it was felt that a mixed methods approach would enable patients' individual experiences to be explored, whilst also identifying clusters of experience and identifying patterns of symptoms, which could not all be explored through either qualitative or quantitative methods alone.

Answering different research questions: It has been argued that mixed methods research enables research questions to be answered that cannot be answered by qualitative or quantitative research methods alone (Creswell and Plano Clark, 2007). Thus as discussed above, this thesis would not benefit from being bound to one methodological paradigm.

Offsetting weaknesses and providing stronger inferences: using a mixed methods approach can allow for the limitations of each approach to be neutralised, whilst strengths are built upon (Bryman, 2006). Thus in this thesis the qualitative approach provided insight and understanding of patients' individual experiences, which could not be identified through a quantitative approach; and the quantitative approach enabled prioritising (ranking) of opinions and a numerical understanding of how patients experience RA symptoms, which could not be identified through a qualitative approach.

Explanation of findings: mixed methods studies can use one research approach to explain data generated from a study using the other research approach. Study 2 used this approach with qualitative and quantitative data complementing each other to explain clusters of experience.

Illustration of data: using a qualitative research approach to illustrate quantitative findings. In this thesis, the qualitative analysis from Study 1 has been revisited throughout the research process in an attempt to explain subsequent quantitative findings.

Hypothesis and instrument development and testing: These have been combined into one item, due to their similarity. A qualitative phase of a study may be undertaken to develop either a hypothesis or items for inclusion in a questionnaire, to be used in a quantitative phase of the study. Thus a mixed methods approach has been used here as the findings from Study 1 were used to provide items to form the Q-set to be used in Study 2, from which the findings were used to provide items for the survey in Study 3.

5.2.3 A qualitatively driven model of mixed methods

The overall research goal for this thesis was to gain a better understanding of patients' experiences and the impact of RA on their daily life and in flare, and how they self-manage these. In terms of sequencing, it was decided to begin with a qualitative approach due to the lack of existing qualitative research into daily life, flare and self-management on current modern treatment regimes, which indicated that patients had not been given a voice in this area, and thus any items or measures developed would be imposed by the researcher's viewpoint. Due to her belief that the design of the subsequent quantitative studies should be grounded in the findings from the initial qualitative study, the researcher chose a sequential mixed methods design (Dures *et al*, 2011), meaning that each study informed the next. This sequential and qualitatively led approach to a mixed methods design has been termed a 'sequential exploratory strategy' (Creswell, 2009).

5.3 Patient research partner involvement

Traditionally a patient's role in research was seen as the 'research object', providing data at the request of the researcher (Schipper *et al*, 2010). However, patients have a personal experience of disease that is not available to most researchers (Hewlett *et al,* 2006) and can therefore bring a valuable and different perspective to a study; enhancing the study design, practicality, recruitment, data interpretation and dissemination (Department of Health, 1999). The involvement of patients in the research process is becoming more widely accepted in both research studies (e.g. White and Verhoef, 2005, Hewlett *et al,* 2006) and conferences (e.g. Kirwan *et al,* 2005). The inclusion of a patient on the research team was crucial for these reasons, and because this research investigates patients' experiences.

The phrase "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; de Witt *et al*, 2011). The PRP is considered an equal member of the research team, sharing the decision-making with the professionals (Abma, Nierse and Widdershoven, 2009). There is the potential for power-imbalance in the research team due to PRPs bringing experiential knowledge rather than scientific knowledge (Abma, 2005). However, this experience is valued equally with other team members' knowledge and experience, such as research methods.

Pam Richards (PRP) has been involved from the beginning of this study, including the design process. Pam has been invited to all the research meetings as a colleague with experience of living with RA, rather than as a patient. The PRP is not representative of all patients, but has a personal experience of living with the condition, which the other researchers cannot contribute. Other PRPs were involved in this research when more than one opinion was needed. Pam has been a PRP for a number of years and is therefore familiar with the research process, whilst her opinions are highly valued as an expert patient, it was at times appropriate to receive input from PRPs who are more “research-naïve”, such as to check understanding of patient information sheets as Pam now has a good knowledge of research and clinical ‘jargon’.

The specific contribution of the PRPs to this research will be outlined separately for each study in the appropriate sections and the detailed methods for each study are now presented.

5.4 Study 1: Understanding the patient perspective (Interviews)

5.4.1 Objectives for Study 1

1. To investigate patients’ perceptions of the range and characteristics of daily symptoms, normal variation, episodic patterns of disease activity and flare
2. To investigate clustering of symptoms and early warning signs of flare
3. To investigate how symptoms are managed and how the decision to seek help is reached
4. To explore a visual representation of disease patterns

5.4.2 Method for Study 1: Semi-structured interviews

One to one interviews were chosen over focus groups as the aims of this study were to explore patients’ experiences. As human beings have a tendency to conform to the majority (Asch, 1955; 1958) it was decided that one to one interviews would ensure that patients’ individual experiences were investigated, rather than obtaining a consensus of the strongest voices.

Semi-structured interviews were conducted as they allow structure to be combined with flexibility; the interviews were based on a topic guide, but with a flexible structure allowing topics to be covered in the order most suited to the interviewee, and for the questions to be expanded or clarification sought (Ritchie and Lewis, 2003). The social science research model sees knowledge as ‘given’ through the interview process, explaining this through the ‘miner metaphor’; this compares knowledge to buried metal: the miner (interviewer) unearths the valuable metal without contaminating it (the interviewer discovers meanings and experiences without polluting the data with leading questions) (Kvale, 1996).

5.4.3 Identification and sampling

Ethics approval was granted by the Frenchay REC (10/H0107/17). Patients were invited to participate if they had had a confirmed diagnosis of RA (Arnett *et al,* 1988) for a minimum of two years, and if they had experienced a flare during their disease trajectory. Patients were purposively sampled to reflect a range of age, gender, disease duration, disability and drug treatment.

Patients were identified as relevant to the study by a member of their care team when they attended a clinic appointment at Bristol Royal Infirmary (BRI), University Hospitals Bristol NHS Trust (UHBT) and Cossham Hospital, North Bristol NHS Trust (NBT) and then introduced to the researcher. The researcher then explained the research to the patient and gave them a patient information sheet with a reply slip to take away with them (Appendices A1 and A2). The researcher phoned all patients who returned the reply slip to arrange a mutually convenient date for the interview.

5.4.4 Interview process

A topic guide (Fig 5.1) was developed by the researcher based on the literature available and in discussion with the supervisory team and the PRPs. The topic guide was used to facilitate discussion and ensure that all the relevant points were covered. Participants were first asked to “tell me what your daily life with RA is like”; the topic guide was then used as a prompt rather than strict interview schedule in order to allow new ideas to emerge. The interviews followed an iterative process (Ritchie and Lewis, 2003), and so as new concepts emerged during data analysis these were explored in subsequent interviews.

Interviews were conducted in the Academic Rheumatology Unit at the BRI and at Cossham Hospital. Patients interviewed at the BRI were interviewed in non-clinical rooms, although still within a medical setting, whilst (due to lack of space) patients interviewed at Cossham Hospital were interviewed in one of the consulting rooms. Interviewing a patient in a consulting room is not ideal as there is the possibility of a power-imbalance being created by the researcher being seen as a ‘professional’ (Richards and Emslie, 2000). The researcher attempted to counteract this by ensuring that the desk was cleared (e.g. the computer keyboard, leaflets etc. all put aside) and by providing the patient with the chair that the professional would take in a medical consultation.

Study 1: Interview topic guide

A. Can you tell me what your daily life with RA is like?
Prompts: Good day/bad day, what's a normal day? How long to get ready? normal? What's difficult regularly?, symptoms?, impact? What would a normal day be like, at the moment?

B. Can you tell me about how your daily symptoms vary?
Prompts: everyday symptoms? How often are they experienced? Variation?

C. How do you manage your daily symptoms?
Prompt: adjustments?

D. What words would you use to describe the daily variation in your symptoms?

E. What happens when you have a period of high disease activity?

F. How can you tell that this period of high disease activity or 'flare' is different from daily symptom variation?

G. Do you get early warning signs that a 'flare' is coming?

H. How do you manage a 'flare'?
Prompt: anything to lessen/control?

I. How do you decide when it is time to see a member of the Rheumatology team?

J. If we could measure a 'flare' on a scale, what would the points on the scale say? – e.g. pain scale

K. Do you have anything else you would like to mention that we've not discussed?

L. If your RA were an animal what type of animal would it be?

Figure 5.1: Interview topic guide

At the beginning of each interview the researcher explained to the patient that she was a PhD student and is therefore non-medical, to allow patients to separate the interviewer from the clinical setting. Participants gave informed consent (Appendix B) and completed a pre-interview questionnaire (Appendices C1 and C2) comprising demographic questions, the Health Assessment Questionnaire (HAQ; Fries *et al,* 1980) and the patient global (Pt Global) measure of the Disease Activity Score (DAS; van der Heijde *et al*, 1993). The HAQ is 20 disability items covering 8 categories (dressing and grooming, rising, eating, walking, hygiene, reach, grip, activities). Patients rate these from 0 to 3 (0: without any difficulty; 3: unable to do), and the worst scores for each category are summed, then averaged to yield a total score of 0 to 3 (high is bad). The patient global measure is a visual analogue scale (10cm), which asks patients to rate how well they are doing with their RA, from very well (0) to very badly (10). These data provided background information and a measure of each participant's level of disability and patient-reported disease severity.

After the interview participants were asked to complete two blank graphs (Appendices D1 and D2). The first graph addressed daily life; the researcher asked the patients to draw a line to represent the fluctuation of severity of symptoms in daily life, across a period of time defined by the patient (e.g. over the past year or since their RA began). The second graph addressed flare; the researcher asked the patient to draw a line to represent the duration and severity of a single flare.

The interviews generally lasted between 45 and 90 minutes. One interview was observed by the researcher's academic supervisor (SH) to check the quality of the interviewing. Two interviews were observed by the participants' husbands as the participants did not wish to be interviewed alone. The interviews were audio recorded and transcribed verbatim. A list of drug names (Appendix E) were provided to transcribers to aid accuracy and instructions for transcribing were given. The researcher checked the transcripts for accuracy and anonymised names and identities.

5.4.5 Patient research partner involvement

The interview schedule was developed through discussions with the PRPs and pilot interviews with PRPs (AK and PR). The initial pilot interview enabled the novice researcher to practice her interviewing skills and to learn from feedback from the PRP (AK) regarding her technique and the question order. Following this pilot interview, it was decided that the graphs should be placed at the end of the interview. This decision was made as the researcher and PRP felt that the interviewer-interviewee rapport was improved by the end of the interview, therefore making the patient more comfortable in carrying out a more abstract task. The second pilot interview (with PR) enabled the researcher to refine her interviewing technique and practice the revised order of the interview schedule.

5.4.6 Thematic analysis

Thematic analysis (TA) is a method for identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes the data set in rich detail (Braun and Clarke, 2006) and allows for interpretation of various aspects of the research topic (Boyatzis, 1998). Both interpretative phenomenological analysis (IPA: Smith and Osborn, 2003) and grounded theory (Corbin and Strauss, 1990) were considered as alternative methods of analysis for Study 1, and the reason that TA was thought preferable for this study will now be discussed.

The phenomenological aspect of IPA involves the use of descriptive and close analysis of lived experience to understand how meaning is created through embodied perception (Sokolowski, 2000), whilst the interpretative element acknowledges that the researcher is making sense of the participant's experience in a way that addresses a particular research question (Smith and Osborn, 2003). Although at first this approach appears relevant for exploring patients' experiences of RA, the strict theoretical framework of IPA explores personal experiences within individuals, trying to understand their individual perceptions of a subject, and does not compare experiences with other individuals (Smith and Osborn, 2003). Further, the in-depth nature of IPA has lead to recommendations of small samples of 3-6 participants (Smith, Flowers and Larkin, 2009). Thus it was felt that IPA was not a suitable method to explore experiences across a range of RA patients.

In contrast grounded theory aims to generate a plausible and useful theory that is grounded in the data (McLeod, 2001) and requires analysis to be directed towards theory development (Holloway and Todres, 2003). It was felt that this approach was too constrictive for the aims of Study 1 and would not allow individual experiences to emerge. It may be possible to carry out a grounded theory-lite approach (Braun and Clarke, 2006), in which the researcher subscribes to the theoretical commitments of grounded theory, but does not necessarily produce a full worked-up theory. However, the researcher agreed with Braun and Clarke (2006) in that a 'named and claimed' thematic analysis enables equally effective analysis as a grounded theory-lite approach, but without being constricted by any theoretical commitments.

TA is not wedded to any pre-existing theoretical framework and can therefore work both to reflect reality and to unpick or unravel the surface of 'reality' (Braun and Clarke, 2006). This creates a more flexible approach in comparison to IPA (Smith and Osborn, 2003) or grounded theory (Corbin and Strauss, 1990). 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. It was therefore felt that TA would effectively meet the aims of Study 1 and that the flexible epistemology would complement the pragmatic approach of this mixed methods thesis.

In TA, themes within the data can be identified in one of two ways; an inductive ("bottom-up") way (Boyatzis, 1998) or in a deductive ("top-down") way (Crabtree and Miller, 1999). Inductive analysis is a way of coding the data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions (Braun and Clarke, 2006). In contrast, deductive analysis begins with an a priori template of codes and attempts to fit the data into these. Inductive TA has therefore been chosen for the initial analysis of these data because it is data driven rather than analyst driven and the aim of Study 1 was to explore patients' experiences, which may not fit into a pre-existing coding frame. Deductive TA was then used for the secondary analysis of these data, which involved identifying both prompted and unprompted metaphors used by patients. The prompted metaphors were in response to the question 'if your RA were an animal what type of animal would it be?' and the unprompted metaphors were those used by patients throughout the interview, prior to answering the animal question. For the purpose of this study metaphors included any rhetorical figures of speech that acheive their effects through association, comparison or resemblance. Thus antithesis, hyperbole, metonym and simile were all considered types of metaphor (McArthur, 1992).

5.4.7 Thematic analysis process

There is no clear agreement in the literature about what TA is and how one should carry it out (e.g. Boyatzis, 1998; Tuckett, 2005). However, Braun and Clarke's (2006) method has been followed since it provides a rational and detailed approach:

5.4.7.1 Coding

Phase 1: Familiarisation with the data: The first stage of the TA 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 read and re-read the transcripts to search for meanings and patterns. The transcription process itself is a way to familiarise oneself with the data (Riessman, 1993) 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. Codes identify a feature of the data that appears interesting to the researcher and refer to the most basic element of the raw data that can be assessed in a meaningful way (Boyatzis, 1998). Thus units of meaning were extracted and a code was applied that described its meaning.

The researcher coded the data using the software package NVivo 8 for Windows (QSR, 2008) as a management tool. This involved tagging and naming selections of text from each interview to create 'free nodes'. At this stage the researcher coded as many potential units of meaning as possible, even if a link could not be seen to the aims of the thesis. Quotes from the interviews were placed in as many ‘nodes’ as they fit into and at the researcher’s discretion, surrounding data for each relevant quote was included to retain its context (Bryman, 2001).

Phase 3: Searching for themes: This phase re-focuses the analysis at the broader level of themes, rather than codes; it involves sorting the different codes into potential themes, and collating all the relevant coded data extracts within the identified themes. At this stage different codes may combine to form an overarching theme, or an initial code itself may form an overarching theme. The researcher used NVivo 8 (QSR, 2008) to manage this process (rearranging the ‘free nodes’ (initial codes) into ‘tree nodes’ to create different levels of themes (main overarching themes and sub-themes within them)).

Phase 4: Reviewing themes: This phase involves refining the themes created in the previous phase. Data within themes should cohere together meaningfully (internal homogeneity), whilst there should be clear and identifiable distinctions between themes (external heterogeneity) (Patton, 1990). The researcher reviewed and refined the themes to produce a thematic map that has validity in relation to the data set and reflects the meanings evident in the data set as a whole (Braun and Clarke, 2006).

Phase 5: Defining and naming themes: In this phase the themes are defined by identifying the ‘essence’ of what each theme is about and determining what aspect of the data each theme captures.

Phase 6: Rigour and reflexivity: To ensure rigour in qualitative research it is recommended that the analysed data should be auditable (Guba and Lincoln, 1985). In this context, auditable means that another researcher could arrive at the same or comparable, but not contradictory, conclusions given by the researcher’s data (Sandelowski, 1986). Thus a proportion of the transcripts were independently analysed by two researchers and a PRP (PR), who reached comparable conclusions to the researcher.

Further, the researcher constantly engaged in reflexivity throughout the analysis process (Mays and Pope, 2000). The researcher did not have any previous experience with rheumatoid arthritis prior to beginning this thesis, but had begun a literature review prior to conducting the interviews. Thus the researcher’s preconceptions of what patients would tell her were minimal. Further, the researcher acknowledged that due to her age, she may have built a better rapport with younger participants and it was therefore important that their stories did not dominate over other participants’. This impact on the analysis was reduced by the researcher keeping a research diary and constantly acknowledging these influences (Koch, 1994).

Data from the qualitative interviews (Study 1) were carried into Study 2, in which clusters or patterns of experience were sought relating to patients' daily life with RA and their process of decision-making in an RA flare.

5.5 Study 2: Elucidating clusters of experience (Q-methodology)

5.5.1 Objectives for Study 2

1. To obtain consensus on the experience of living with RA from day-to-day
2. To obtain consensus on patients' decision-making surrounding help-seeking behaviours when in a flare

5.5.2 Methods for Study 2: Consensus methods

Q-Methodology is one technique that can be used to obtain diverse opinions in a subject area, aiming to sample the range and concordance of views expressed, not to make claims about the percentage of people expressing them (Kitzinger, 1987). Nominal Group Technique (NGT; Gallagher *et al,* 1993) and the Delphi Technique (Jones and Hunter, 1995) were considered as alternative methods for this study as they both aim to provide one overall consensus of opinion (Fink *et al,* 1984). NGT uses a structured meeting to gather information from relevant experts about a given issue. It consists of two rounds in which participants rate, discuss and then re-rate a series of items (Gallagher *et al*, 1993). Delphi Technique involves the presentation of a questionnaire to relevant experts to seek their opinion on a particular issue, the questionnaires are then returned, the data are summarised and a new questionnaire is designed based on the responses. This second-round questionnaire is then returned to each participant showing the overall group response and the participant's own response from round one. Participants are asked to reconsider their initial response considering the first round's overall results. Repeat rounds of this process are carried out until consensus has been reached (Jones and Hunter, 1995). This section explores the idea of consensus and whether it is truly achievable.

The first issue is that are no firm rules for specifying acceptable levels of agreement and establishing when a consensus is reached. With NGT the researcher facilitating the group is responsible for deciding when each step in the process has been adequately completed and deciding when agreement has been reached (Fink *et al,* 1984). With consensus in NGT being at the discretion of the researcher it is therefore somewhat subjective and open to bias.

Determining consensus in a Delphi study is also subject to interpretation. Consensus has been claimed to be reached at different degrees, for example 80% of participants' votes fall within two categories on a seven-point scale (Ulschak, 1983) or at least 70% of participants rate 3 or higher on a 4-point Likert-type scale (Green, 1982); or stability of participants' responses in successive iterations

(Scheibe, Skutsch and Schofer, 1975). It therefore appears that defining consensus itself is problematic.

A further problem is whether consensus techniques are able to adequately represent the opinions of the population being studied or whether they are only able to provide the 'bland generalities' that represent the lowest common denominator of the debate (Rennie, 1981). Jones and Hunter (1995) warn that the existence of consensus does not mean that the 'correct' answer has been found and there is a danger of deriving collective ignorance rather than wisdom.

Instead of deriving one overall consensus, which can be criticised as an unrealistic average of beliefs, Q-methodology typically derives between one and five factors each representing groups or clusters of opinions or beliefs. The factors produced from a Q-methodological study are orthogonal (they are independent and at 90° to one another). Each factor therefore represents a different and independent understanding of the issue (Stainton Rogers, 1995).

5.5.3 Consensus technique comparison

One of the issues used to compare Q-methodology, NGT and Delphi was conformity bias. This is the tendency to behave similarly to others in a group, even if doing so goes against your own judgement. This was famously demonstrated in Asch's (1955; 1958) conformity study, in which participants were seated in groups of 8 to 10 other people, who they believed to be other participants, but were in fact confederates of the researcher. The group were asked one at a time which of the lines in 'Exhibit 2' (Fig 5.3) were the same as the line in 'Exhibit 1' and the confederates all gave the same incorrect answer. When the real participant was asked the question second to last in the group, 37 out of 50 (74%) participants conformed to the majority and chose the incorrect answer at least once. It is of note that during debriefing after the experiment, the majority of participants said that they did not truly believe their conforming answers, but had agreed with the group for fear of being thought of as 'peculiar' (Asch, 1955; 1958).

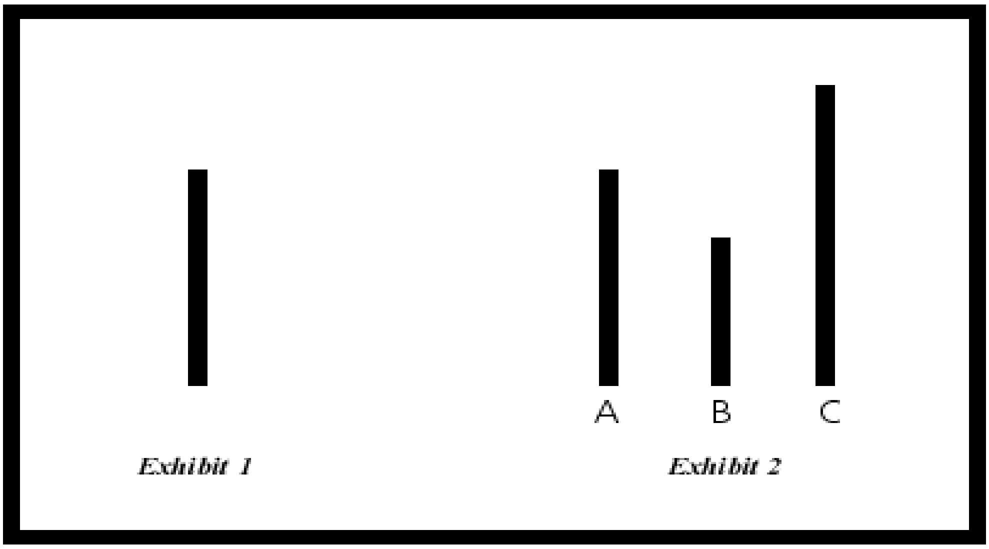

Figure 5.2: Diagram presented to participants in Asch's (1958) conformity study
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The Delphi technique claims to achieve consensus and has less chance of bias due to conformity than NGT. However, Delphi is time-consuming, it eliminates personal contact, it creates the opportunity for moulding participant opinions and participants still feel a subtle obligation to conform to the rest of the group when group scores are included in each round; Delphi's liabilities outweigh its assets (Sackman, 1975).

NGT also claims to achieve consensus, it is the least time consuming of the three methodologies and involves personal contact with the participants. However, NGT creates the potential for bias in the form of conformity to the group participants and the level of consensus is decided by the researchers. Although NGT is preferable to Delphi, the consensus it reaches seems to eliminate the individual context from the research and therefore would not be the most appropriate method for this thesis.

Q-methodology does have its faults; it is time consuming, limitations are placed on participants due to predetermined statements and the analysis is subject to the researcher's interpretation. However, the latter two arguments will be addressed (Section 5.5.5) and the time-consuming aspect is not a sufficient reason to dismiss a methodology. Q-methodology provides participants with personal contact, anonymity, removes any bias due to conformity and will effectively retain the individual context obtained through the Study 1 interviews, whilst still providing an averaging of ideas (see Table 5.1 for a summary of this comparison).

Table 5.1: Comparison of methods considered for Study 2

Method	Process	Advantages	Disadvantages	Example Study
Q-Methodology (Brown, 1996; McKeown and Thomas, 1988)	• Each participant 'Q-sorts' the statements across a forced distribution grid from 'disagree' to 'agree' • Q-Sorts are entered and analysed using PCQ for Windows to produce correlations, by-person factor analysis and factor scores • Factors are then interpreted qualitatively using the statements, comments booklets and demographic and clinical data	• Individual differences are retained • Anonymity of participants • Involves personal contact with participants • Participants complete the Q-sort individually, therefore removing any chance of conformity bias	• Time-Consuming • Participants are given statements to sort rather than generating them themselves • Interpretation lies with the researcher, thus there is a risk of bias	• Four different patterns of fatigue in rheumatoid arthritis patients: results of a Q-sort study (Nikolaus *et al,* 2010)
Nominal Group Technique (Gallagher *et al,* 1993)	• Individual participants rank items, followed by a group discussion of ranking followed by a second individual ranking • Importance / agreement scores are calculated across the group	• Participants generate the ideas • Least time-consuming consensus method • Involves personal contact with participants	• Anonymity of participants is not possible • Chance of conformity to the majority • Individual differences lost in one overall consensus • Level of consensus is decided by the researchers	• Utilizing qualitative data from nominal groups: Exploring the influences on treatment outcome prioritization with rheumatoid arthritis patients (Sanderson *et al*, 2012)
Delphi Technique (Jones and Hunter, 1995)	• Two or more rounds of postal questionnaires are sent to participants to ascertain level of agreement / importance on items • Group results and the individuals results are returned to participants so others' opinions can be taken into account	• Participants generate the ideas • Systematic process which allows for change in opinion • Anonymity of participants is possible	• Time consuming (minimum administration time 45 days, Delbecq *et al,* 1994) • Eliminates personal contact with participants • Chance of conformity to the majority • Individual differences lost in one overall consensus	• Identifying core domains to assess flare in rheumatoid arthritis: an OMERACT international patient and provider combined Delphi consensus (Bartlett *et al*, 2012)

5.5.4 Q-Methodology

Q-methodology involves participants sorting a set of statements into the order of their agreement. They are sorted across a normal distribution grid, thus allowing a small number of statements into the high and low agreement spaces and forcing the majority of the statements into a neutral stance. Q-methodology was invented in 1935 by William Stephenson, evolving from factor analytic theory (Brown, 1996; 1997). Stephenson believed that life as lived from the standpoint of the person living it, is typically passed over by quantitative research methods and therefore was interested in providing a way to reveal the subjectivity involved in any situation (Brown, 1996). Q-methodology combines the strengths of both qualitative and quantitative research (Dennis and Goldberg, 1996), providing a bridge between the two paradigms (Sell and Brown, 1984). Q-methodology involves 3 stages; developing a set of statements to be sorted; participants sorting the statements along a continuum of preference; and analysing and interpreting the data (Brown, 1993).

The set of opinion statements for use in Q-methodology are most typically collected through personal interviews and focus groups. In addition, sources such as journal articles or any other sources relevant to the issue may be used; this collection of items is called the ‘concourse’ (Brown, 1993). From the concourse a subset of statements is selected to form the Q-sample (the group of statements to be rank-ordered by the participants). The concourse should be sampled systematically and the sample statements should be tested in one or more pilot studies to ensure content validity (Valenta and Wigger, 1997).

Once the statements are finalised, participants are asked to rank-order statements (agree to disagree), which is known as ‘Q-sorting’. The statements are opinion only, not fact; Q-methodology assumes that opinions are subjective and can be shared, measured and compared (McKeown and Thomas, 1988; Stainton Rogers, 1995). The sorting matrix (Fig 5.2) provided for participants in Q-methodology forces the Q-sort into the shape of a quasi-normal distribution. There are fewer statements that can be placed at the extreme ends and more that are allowed to go into the middle area (the middle area represents almost neutral reaction). The symmetry and predetermined numbers of statements in each category facilitate the quantitative methods of correlation and factor analysis (McKeown and Thomas, 1988).

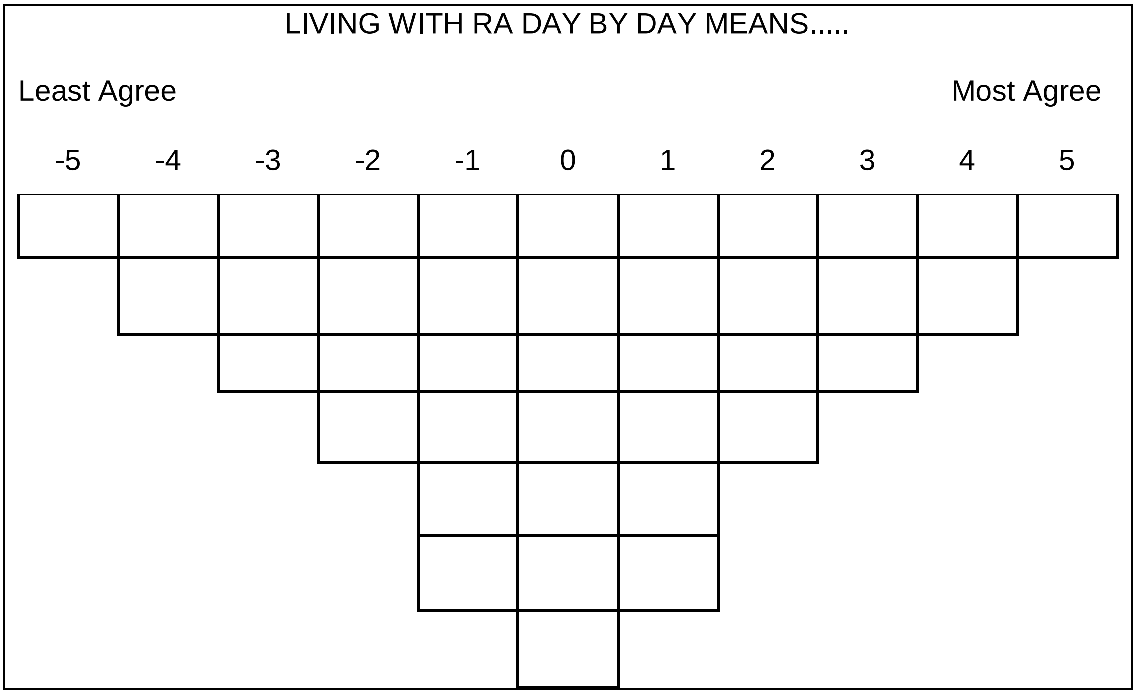


Figure 5.3: An example of the sorting matrix/grid used in Q-Methodology
Nb: This example shows a grid for 39 statements (as used for the Daily Life Q-sort in Study 2)

In Q-methodology, data analysis uses correlation and by-person factor analysis, meaning that statistical analysis is not performed by variable, trait or statement, but by person. People correlate with others with similar opinions based on their Q-sorts. Q-methodology therefore results in the grouping of expressed opinion profiles based on the similarities and differences in which the statements are arranged by each participant (McKeown and Thomas, 1988).

Q-methodology has its roots in educational psychology (Stephenson, 1935), although it is now most widely used in health psychology (Stainton Rogers, 1991). To date it has been used in a wide variety of research fields including; chronic pain (Eccleston *et al,* 1997); irritable bowel syndrome (Stenner, Dancey and Watts, 2000); self-harm (James and Warner, 2005); smoking behaviours (Collins, Maguire and O'dell, 2002); quality of life (Stenner *et al,* 2003); partnership love (Watts and Stenner, 2005a); and feminism (Kitzinger, 1999; Senn, 1993). Q-methodology has been described as a 'fun instrument' in which the participants enjoy moving the statements until they are fully satisfied (Prasad, 2001).

5.5.5 Limitations of Q-methodology

Unlike NGT and the Delphi technique where participants themselves generate the ideas to be sorted, in Q-methodology predetermined statements are used, therefore placing limitations on participants (Cross, 2005). However, the statements are generated by sampling the concourse (including items generated in either individual or group interviews) then the statements are sifted, ordered and condensed, and should therefore provide a representative pool of opinions for participants to sort (Stainton Rogers, 1995). In Study 2 the majority of the statements were produced from individual interviews, which were conducted until data saturation was reached, along with statements identified through a literature review. The Q-set was also trialled with a patient partner, rheumatology professionals and the researcher's supervisory team until the researcher was satisfied. To further confirm the validity of the study, participants can be asked to report any statements they feel are missing from the Q-set. Whilst additional statements cannot be included in the Q-set as it would disturb the normal distribution, this information can demonstrate how accurately the Q-set captures the opinions of the participants (Stainton Rogers, 2009). Participants were invited to do this in Study 2.

Q-methodology can also be criticised due to the risk of bias at the interpretation stage, as this task lies with the researcher (Pope, Ziebland and Mays, 2000); *how* the researcher interprets the factors may be influenced by their personal stance, for example their professional background (Stainton Rogers, 1995). However, strategies to protect the rigour include; creating an account of method and data which can stand independently so that another trained researcher could analyse the same data in the same way and come to essentially the same conclusions; more than one researcher from different disciplines analysing the data; and being constantly reflexive about the entire research process (Mays and Pope, 2000). These strategies have all been used in Study 2.

A further criticism of the reliability of Q-methodology is that when it is repeated on the same participant it does not necessarily yield the same results (Cross, 2005). However, Brown (1980) maintained that Q-methodology can be replicated with 85% consistency even up to a year later. Either way, there is no expectation that participants will express the same view on two separate occasions as it is the idea being captured, not the person (Stainton Rogers, 1991).

5.5.6 Identification and sampling

Ethics approval was granted by the South West 4 REC (10/H0102/77). Patients were invited to participate if they had had a confirmed diagnosis of RA (Arnett *et al,* 1988) for a minimum of two years, and who had experienced a flare during their disease trajectory. Patients were purposively sampled to reflect a range of age, gender, disease duration, disability and drug treatment. Patients were identified as relevant to the study by a member of their care team when they attended a clinic appointment at the BRI, UHBT, Cossham Hospital, NBT and St Peter's Hospital, Ashford and St Peter's Hospital Trust (ASPH) and then introduced to the researcher. The researcher then explained the research to the patient and gave them a patient information sheet with a reply slip to take away with them (Appendices F1 and F2). The researcher phoned all patients who returned the reply slip to arrange a mutually convenient date to take part in the study.

5.5.7 Q-methodology process

5.5.7.1 Developing the set of statements (Q-set)

The statements were developed from the Study 1 interviews. The transcripts were thoroughly read and each new idea was recorded as a statement for the Q-sort. Two lists were created, one relating to daily life with RA and the other to RA flare help-seeking behaviours. Three of the flare help-seeking statements in the final draft of items came from a literature review rather than the interviews (Chapter 8.3), to ensure that all the ideas forming the concourse were represented in the Q-sort. Whilst every attempt was made to retain the Study 1 participants' original wording, this was not always possible to ensure that the items would be understood by all Study 2 participants. The items were reworded to form a statement which finished either the sentence 'Living with RA day by days means...' for the daily life Q-sort; or "When I am in an RA Flare..." for the flare help-seeking Q-sort.

The drafts were then shared with the full supervisory team including PRP (PR) and refined to ensure that the statements were comprehensible, would not cause any emotional distress and sufficiently sampled the concourse. Further, any duplicate items or items that had the polar opposite meaning of items that were retained, were removed because participants can sort each statement positively or negatively and therefore the opposing viewpoint is not necessary. The final items for the daily life and flare help-seeking Q-sorts were printed onto cards, the size of an individual space on the sorting grid, and laminated. The Q-sorting grids were printed onto A1 size laminated posters (Appendices G1 and G2). Velcro was attached to both the cards and the posters to ensure patients were able to pick up the cards easily and so that once the cards were attached to the posters they could not be dislodged.

5.5.7.2 Participant numbers (P-set)

Large numbers of participants are not required for an effective Q-study because in Q-methodology participants are the variables and the number of variables employed in a single research study is invariably limited (Watts and Stenner, 2012). In R-methodology (conventional factor analysis), a minimum ratio of two participants to every study variable is suggested (Kline, 1994) and it has been argued that this ratio is inverted for Q-studies, suggesting a minimum of two Q-set items to every participant (Kline, 1994). However, in practice this could be problematic as a small Q-set could lead to the P-set being too small to encompass the range of beliefs held (Watts and Stenner, 2012) for example one Q-study (Watts and Stenner, 2005b) used a 60-item Q-set and 50 participants. Whilst 40 to 60 participants have been recommended for a Q-study (Stainton Rogers, 1995), Stephenson (1953) proposed that good quality studies and analyses could be conducted with as few as a single participant.

5.5.7.3 Sorting the statements

Patients were given the option of taking part in the study at their own home or in the hospital. All patients who completed the Q-sorts at UHBT and some patients who completed the Q-sorts at ASPH were provided with non-clinical rooms. Due to lack of space, patients who took part in the study at NBT and the remaining patients from ASPH carried out the Q-Sorts in one of the consulting rooms. The researcher made attempts to reduce the power imbalance as described in section 5.4.4.

Although Q-methodology does not usually require one-to-one attention from the researcher, it was decided that with an RA population one-to-one attention would ensure that the researcher was able to help patients who may not have the dexterity and reach of a healthy population. The researcher explained to each patient that she is a PhD student and is therefore non-medical. This was intended to allow patients to separate the researcher from the clinical setting. Participants gave informed consent (Appendix H) and completed the same pre-interview questionnaire as in Study 1 (Appendices C1 and C2).

First participants were asked to do the daily life Q-sort. They were given all of the statements and asked to sort them into piles of “Agree”, “Disagree” and “Neutral”. Participants were then asked to take their “Agree” pile and place these in order of agreement onto the grid. They were then asked to do the same with the “Disagree” pile and finally the “Neutral” pile. Participants were offered rubber thimbles to assist with their grip and for the researcher to place any statements that the participants felt unable to reach.

Participants were then given the opportunity to review and alter their Q-sort. Once they were happy with their selection the researcher asked them to comment on the reasons they had chosen the 3 statements at each extreme end of the grid, and any thoughts and feelings they had about those statements. Participants were then free to comment on any other statements that they wished to. Participants were also asked whether they thought any statements were missing from their options. The researcher recorded these comments in a comments booklet (Results: Chapter 8.2). The researcher then recorded the numbers from the back of the statements onto the corresponding spaces on an A4 scale version of the Q-sort grid. Following the daily life Q-sort participants were asked to repeat the process with the flare help-seeking Q-sort. The entire study process lasted no longer than one hour. The results were then anonymised, allocating each participant a reference number.

5.5.8 Patient research partner involvement

The draft statements used in the Q-sort were reviewed by the PRPs for content and comprehension. Through the advice of PRPs some statements were re-worded for being either too complex or too negative. PRPs were also consulted about the practical implications of conducting a Q-methodology study with an RA population, which resulted in the statement cards being laminated and rubber thimbles being made available to participants. The Q-sort was piloted with PRPs to ensure that statements could be placed on the grid without them over-stretching and that patients would have enough strength in their hands to detach the statements from the grid.

5.5.9 Q-methodology analysis

Q-methodology has been termed a quasi-quantitative or quali-quantological method (Stenner and Stainton-Rogers, 2004), both of which aim to explain the hybrid nature of the method in which qualitative and quantitative methods are combined to produced a rounded interpretation of the data, rather than a mixed methods approach (section 5.2) in which individual qualitative and quantitative studies are carried out within the same research project. Thus the Q-methodology analysis process involves factor extraction, factor rotation, and factor interpretation.

5.5.9.1 Factor extraction and rotation

All the Q-sorts that have been gathered in the Q-study overall, i.e. all the viewpoints that the participants have expressed, represent 100% of the meaning and variability present in the study, which is known as the study variance (Watts and Stenner, 2012). The function of factor analysis is to account for as much of the study variance as possible i.e. to explain as much as possible about the relationships that exist between the many Q-sorts in the group, through the identification of any sizeable portions of shared meaning that are present in the data. These shared meanings are the factors, which will be considerably less than the number of Q-sorts in the study, hence factor analysis is known as a data reduction technique (Watts and Stenner, 2012).

In Study 2 centroid factor analysis has been used, which is the oldest factor extraction technique and is highly regarded by Q-methodologists due to its computational ease and simplicity (Brown, 1980). It is recommended for novice Q-researchers (Watts and Stenner, 2012) and it is the only method of factor analysis currently offered by Q-methodology computer software programmes (PQMethod: Schmolck, 2012; PCQ for Windows: Stricklin and Alemida, 2001).

Centroid analysis involves first deciding on how many factors to extract (Section 5.5.9.2). The PCQ for Windows software then searches for a first shared pattern (or sorting configuration) in the data and thus extracts the first portion of common variance (Factor 1). The factor loading provides information on the extent to which each individual Q-sort can be said to exemplify, or is typical of the pattern produced by Factor 1. The software then searches for the second portion of common variance (Factor 2) and so on. In factor analysis, the first factor extracted will usually account for the largest amount of study variance (Watts and Stenner, 2012).

Eigenvalues (EVs) and variance provide further information, with these relating to each factor rather than each Q-sort. A factor's EV is calculated by summing the squared loadings of all the Q-sorts on the particular factor. The following calculation is used by the software package to determine each factor's EV, where Q-sort N is indicative of the total number, or final Q-sort in the study (Brown, 1980: 222):

EV for Factor 1 = (Q-sort 1 loading on Factor 1)^2 + (Q-sort 2 loading on Factor 1)^2 + (Q-sort 3 loading on Factor 1)^2 + ... (Q-sort N loading on Factor 1)^2

A factor's variance is then derived from its EV using the following equation (Brown, 1980: 222):

Variance for Factor 1 = 100 x (EV ÷ no. Of Q-sorts in study)

The final set of factors should account for as much of the study variance as possible (Brown, 1980) and thus high factor EVs and variance are desirable (Watts and Stenner, 2012).

Following factor extraction, the factors were rotated using orthogonal varimax rotation. The purpose of this is to ensure that each Q-sort defines (has a high factor loading in relation to) only one of the study factors. Thus the factors are positioned so that the overall solution maximises the amount of study variance explained. Varimax rotation is easy to use, effective with larger data sets, objective and reliable (Watts and Stenner, 2012).

5.5.9.2 Deciding how many factors to extract

The reasons for the number of factors extracted specifically for each of the two Q-sort studies in Study 2 will be described in the results (Chapter 8.4.2). This section provides an explanation of two theories that exist for this decision-making process, which have each influenced the decisions made in Study 2.

The Kaiser-Guttman criteria (Guttman, 1954; Kaiser, 1960) states that the cut-off point for extraction of factors should be those with EVs less than 1.00, this is because an extracted factor with an EV of less than 1.00 accounts for less variance than a single Q-sort (Watts and Stenner, 2005b). However, whilst being an effective cut-off point for rejecting factors, if used as a criterion to retain factors this often results in an overly large number of factors (Kline, 1994; Wilson and Cooper, 2008).

In contrast, Brown's (1980) 'magic number seven' criterion (Brown, 1980) suggested that seven factors is the default number for extraction and that this is the point to start from. However, more recently Watts and Stenner (2012) have proposed that whilst the objective criteria of both the Kaiser-Guttman technique and magic number seven should still be taken into consideration, the decision should rely more on the feel of the data and the researcher's experience. They suggest starting with extracting one factor for every 6 to 8 participants, but emphasise that this is based not on an objective criteria, but on their own experience (Watts and Stenner, 2012).

5.5.9.3 *Z* scores and factor exemplifying Q-sorts

Once the factors have been extracted the total weighted scores for each item are produced, showing which items each factor have ranked as most positively or most negatively. However, these weighted scores do not allow for cross-factor comparisons due to different numbers of Q-sorts contributing to the total in each factor (Watts and Stenner, 2012). In order to facilitate cross-factor comparisons, the total scores are converted into *z* (or standard) scores. The following calculation is used by the software package to determine each factor's *z* score:

Z score for Statement 1 (in relation to Factor 1) = (Total weighted score for Statement 1 – Mean of total weighted scores for all items) ÷ SD of total weighted scores for all items

The *z* scores for each statement are then converted into a single factor exemplifying Q-sort, which is a single Q-sort configured to represent the viewpoint of a particular factor. The factor exemplifying Q-sort always conforms to the same distribution used in the original data collection (e.g. Fig 5.3) and is constructed with reference to the size and rank order of the *z* scores, thus the item with the highest *z*-score would be placed in the +5 position on the exemplifying Q-sort.

5.5.9.4 Factor interpretation

Once the exemplifying Q-sorts were created, they needed to be interpreted for meaning. The holistic nature of Q-methodology has been emphasised in terms of interpretation (Stephenson, 1936) and the aim is to combine individual items in the identified factor to create one gestalt (holistic) explanation (Watts and Stenner, 2012). Previously, there has been no guidance for how to conduct this interpretation (Brown, 1980), but the researcher was personally advised by Dr Simon Watts to use a crib sheet and abductive logic, followed by the use of demographic data and patients' comments to aid interpretation (since published: Watts and Stenner, 2012):

The Crib sheet: This is a way of organising the data and ensuring that no important issues are overlooked. It also provides a wider system of organisation for the interpretative process and encourages holism by comparing every item in a factor. The crib sheet, or table of by-factor rankings presents the relative rankings for each statement given by each factor (Results Tables 8.5 and 8.15). The researcher highlighted all of the items that ranked either higher or lower in one factor in comparison to the other factors. This enables the issues about which one factor viewpoint is polarised to be identified and shows how that viewpoint is polarised relative to other factors. The aim is not to isolate individual items, but to identify the items that make the most important contributions to the viewpoint displayed by the particular factor.

It is important not to immediately discount items that have been scored in the neutral zero position. A previous Q-study (Watts and Stenner, 2005b), which focused on the punishment of youth offending, identified that whilst one factor scored the statement *"parents of young offenders should be punished for their child's crime"* at zero, the remaining factors scored the same statement negatively. Thus the authors claimed that the opinion of the factor scoring the statement at zero was cautious agreement with the statement, which was supported by participants' comments. In Study 2, this inclusive nature of analysis has been employed, with all statements and factor scores interpreted where possible.

Abductive logic: This element of the interpretative technique requires the researcher to consider the ranking of each statement by asking: why is it ranked where it is?; what does it mean?; what is it trying to tell me? This creates a preliminary hypothesis, which can be considered to see whether it is sustained or disproved by the ranking of other items, participant comments or demographic data.

Thus the researcher's attention continually moves between the individual items and the overall viewpoint. Each statement is considered in terms of whether it confirms or changes the current understanding of the viewpoint and in this way the researcher continually confirms or adjusts the understanding of each factor viewpoint. The researcher attempted to apply abductive logic to the interpretation of Study 2.

<u>Demographic data and comments booklet:</u> It is advised (Watts and Stenner, 2012) that these are related to the factors *after* interpretation to ensure that each factor is approached on its own terms, without being influenced by pre-conceived ideas that the researcher may hold. The demographic data and participants' comments can therefore confirm ideas arising from the factor interpretations and provide clarity and insight into who holds the beliefs represented by the factor. The interpretation was carried out in this order for Study 2.

<u>Bi-polar factors:</u> These are defined by having both positively and negatively loading Q-sorts. An explanation of the negative viewpoint is achieved through interpretation of the exemplifying Q-sort that is the direct opposite of the exemplifying Q-sort created for the positive viewpoint. Thus a statement ranked at +4 by the positive viewpoint would be ranked as -4 by the negative viewpoint or a statement ranked as -2 by the positive viewpoint would be ranked as +2 by the negative viewpoint. This reversal of the factor exemplifying Q-sort is performed manually and the negative factor exemplifying Q-sort is then subjected to interpretation in its own right (Watts and Stenner, 2012). This was necessary in Study 2 as one of the daily life Q-study factors was bi-polar (Results: Table 8.9 shows the positive exemplifying Q-sort and Table 8.10 shows the negative exemplifying Q-sort). Further, one of the daily life factors and one of the flare help-seeking factors had only negative loadings, thus this manual reversal was used to produce their factor exemplifying Q-sorts (Results: Tables 8.12 and 8.19).

5.6 Understanding daily life and flare help-seeking (Exploratory and feasibility survey)

5.6.1 Aims and objectives for Study 3

The aims of Study 3 were:

1. To explore the range, variation and level of patients' symptoms over time
2. To explore patients' tipping points for seeking help
3. To explore the feasibility of collecting daily data
4. To explore the feasibility of collecting data from patients in a flare

Thus the objectives of Study 3 were:

1. To assess the recruitment and attrition rates
2. To assess the acceptability of the questions and the rate of completion
3. To assess the effect of missing data and how to handle this
4. To provide pilot data on the range and variation of experiences over time

5.6.2 Methods for Study 3: Daily life and flare help-seeking survey

To establish the range and variation of patients' symptoms over time symptoms were measured using a variety of patient reported outcome measures (PROMs). To contextualise this daily data, weekly measures of impact and self-management were used. The symptoms and issues to be measured were developed from Studies 1 and 2 and where possible validated PROMs were used (Chapter 9: Tables 9.1 and 9.2). Daily assessments were chosen to capture fluctuations in symptoms between individual days and to reduce retrospective bias. However, although data were collected daily, they were not real-time assessments of patients' symptoms, but immediate retrospective measures in which patients rated their symptoms at the end of each day.

Once a day assessments were chosen to reduce the burden on participants of having to complete PROMs more than once a day for three months. However, it is noted that a study comparing the real-time and retrospective reported pain of people that had undergone painful medical treatment (Redelmeier and Kahneman, 1996) found that retrospective reports of pain focus on either the peak pain (intensity of pain at the worst moment) or the end pain (intensity of pain at the final moment). Thus it is possible that these assessments could be capturing patients' worst point throughout the day, or the way their symptoms are at the point of completing the PROMs.

As symptoms were being measured for only three months, the researcher was concerned that this would not capture patients in an RA flare and thus flare symptoms may not be addressed. Further, the daily assessments would not provide information on patients' decision-making processes for seeking help due to an RA flare. Thus a second survey was developed using items from Studies 1 and 2 and with validated PROMs where possible (Chapter 9: Table 9.3) to target patients who contacted the rheumatology helpline in an RA flare.

5.6.3 Identification and sampling of patients

Ethics approval was granted by the South West 5 REC (11/SW/0103). Different recruitment criteria were used for Studies 3a and 3b.

5.6.3.1 Study 3a: Daily life: Identification and sampling

Patients were invited to participate if they had had a confirmed diagnosis of RA (Arnett *et al,* 1988) for a minimum of two years, and if they had experienced a flare during their disease trajectory. Patients were purposely sampled to reflect a range of age, gender, disease duration, disability and drug treatment. Patients were identified as relevant to the study by a member of their care team when they attended a clinic appointment at the BRI, UHBT, Cossham Hospital, NBT and St Peter's Hospital, ASPH and were then introduced to the researcher. The researcher then explained the research to the patient and gave them a patient information sheet including a sample of the daily measures, with a reply slip to take away with them (Appendix I1 and I2). The researcher phoned all patients who returned the reply slip to arrange a mutually convenient date to begin completing the daily PROMs.

5.6.3.2 Study 3b: Flare help-seeking survey: Identification and sampling

Patients were invited to participate if they had a confirmed diagnosis of RA (Arnett *et al,* 1988) and had contacted the UHBT or ASPH rheumatology helpline (on which patients leave a message and a rheumatology specialist nurse calls them back) in a self-defined RA flare to seek help. Patients were identified as relevant to the study by the nurse who returned the patient's phone call. The nurse asked the patient if they would be willing to be contacted by a researcher about their motivations for seeking help for their flare. The contact details of patients who agreed were then passed to the researcher, who phoned the patient to further explain the study and arrange to meet them prior to their clinic appointment for their RA flare. The researcher put a patient information sheet in the post to patients who had agreed to meet her prior to their clinical appointment (Appendix J). Thus patients were able to opt out of the study prior to meeting the researcher.

5.6.4 Study 3a: Daily life process

A daily life questionnaire comprising 8 items relating to patients' symptoms (Appendix K1) and a weekly questionnaire comprising 12 questions related to patients' self-management techniques and the impact of RA (Appendix K2) were developed by the researcher (based on Study 2: Section 5.6.2). Patients who agreed to take part were contacted by phone to arrange a date to begin completing the questionnaires and given the option of completing with pen and paper, online or for the researcher to phone them daily for their responses.

The paper versions of the daily questionnaires were printed on coloured paper, stapled into 'one week' packs, with the weekly self-management questionnaire at the end of the pack. Different coloured paper was used for each week to provide diversity and retain patients' interest. The online versions were created using Qualtrics (Qualtrics Labs Inc, 2012), which enabled the PROMs to be easily replicated online. Participants had their own secure link to complete the questionnaire, which was designated as invitation-only, which removed any chance of a non-participant finding and completing the questionnaire online. Further, the online version of the questionnaire was secure, with only the researcher having access to all participants' responses.

Patients gave informed consent (Appendix L) at their respective hospitals and were sent the same pre-study questionnaire that was used in Studies 1 and 2 (Appendices C1 and C2), this questionnaire was not made available online. Then patients who chose the pen and paper option were sent one month's worth of questionnaire packs with one return envelope for every week of data entry. Patients who chose the online option were sent their own personal link to the online questionnaire with instructions of how to complete and their own personal reference number. No patients chose the telephone option.

It was explained to participants that if they forgot to complete the questionnaire for a day it would be better to leave it blank than to complete in retrospect. Further, patients were reassured to continue with the rest of the study, even if they missed a day. When there was a delay in the questionnaires being returned or online data were incomplete, the researcher contacted the participant to discuss any problems and to encourage them to continue with the study.

After each month of data collection all patients were sent a hand-written note-card thanking them for their participation in the study so far and encouraging them to continue. Patients who chose the pen and paper option were also sent their next month of questionnaire packs at this point. Patients who remained in the study over the Christmas period were also sent a Christmas card, which thanked them for continuing with the study at that time. At the end of the three month data collection period, patients were contacted to advise that the study had ended and to thank them for their time.

5.6.5 Study 3b: Flare help-seeking survey process

To establish the level of patients' symptoms when they are in a self-reported flare and their motivations for seeking help, a Study 3b pack of questionnaires (Appendices M1-3) were developed by the researcher. This comprised the same daily questionnaire given to patients in Study 3a; a flare help-seeking questionnaire, comprising PROMs relating to the impact of RA on patients’ lives, their self-management and tipping points for seeking help. The specific domains to be measured in the flare help-seeking questionnaire were developed from Studies 1 and 2 and where possible validated PROMs were used (Chapter 9: Table 9.3); and a flare early warning signs questionnaire, comprising 11 items relating to early warning signs of a flare (Bartlett *et al*, 2012). The individual questionnaires were printed on different coloured paper to distinguish them and stapled together in one questionnaire pack.

Patients who agreed to take part were met in clinic prior to their urgent appointment. Patients gave informed consent (Appendix N), completed the pre-study questionnaire used in Studies 1, 2, and 3a (Appendix C) and then completed the flare help-seeking questionnaire pack (Appendices M1-3). Four weeks after their clinic appointment, when it was anticipated that patients would no longer be in a flare, they were sent the daily measures questionnaire to complete again with a pre-paid envelope to return it, enabling symptom comparison between Time 1: in flare and Time 2: not in flare. Participants’ data were anonymised with their own personal reference number.

5.6.6 Patient partner involvement

The questionnaires used in both Study 3a and 3b were reviewed by a PRP (PR) to assess them for content and comprehension. The burden of completing measures daily was discussed with this PRP, and a maximum of one A4 page of questions to complete daily was thought reasonable. The options for completing the daily measures were also discussed with this PRP and a range of response method options were provided to participants based on this discussion.

5.6.7 Data analysis

Study 3 was an exploratory and feasibility study and was not powered for statistical significance. The data were therefore analysed for descriptive statistics: mean; standard deviation; range; frequency. The daily questionnaire data from Study 3 were also visually analysed to identify patterns. The researcher created individual graphs of each patient’s symptoms in order to visually identify patterns or similarities between patients’ experiences of RA. Patients were clustered together in groups according to whether they had experienced a flare or not during the data collection period and patterns within these groups were identified.

5.7 Summary

Three studies have been designed to qualitatively explore patients' experiences of daily life and flare with RA and how they self-manage these, to identify clusters of experiences and to quantitatively address patients' variation and fluctuation of symptoms. The results of these studies will be presented in Chapters 6 to 9.

Chapter 6: Study 1: Understanding the patient perspective (Interviews)

This chapter presents the results for Study 1, in which the patient perspective of daily life, flare and self-management have been explored through semi-structured interviews.

6.1 Summary of background information

Rheumatoid Arthritis (RA) is a systemic, inflammatory condition causing synovitis and pain in multiple joints, which can result in permanent disability. RA is also accompanied by fatigue, which is an invisible yet debilitating symptom. The fluctuation and uncertainty of RA and a non-compliant body can impact on patients' abilities to continue doing activities that they consider necessary or pleasurable. However, current research does not address how patients experience RA, in terms of either symptoms or impact, since the use of modern more intensive treatment regimes.

RA is characterised by disease flares, which often prompt patients' decisions to seek medical help. However, there is currently no agreed definition of flare, with clinicians and patients prioritising different outcomes. It is also unknown how patients distinguish a flare from daily symptom fluctuation and at what point a 'bad day' becomes a flare.

There is a range of self-management and coping strategies recommended to patients to minimise the impact that RA has on their lives. However, there is currently a lack of research that addresses which strategies patients use, how bad their symptoms have to be before they use these techniques and how long they self-manage and/or cope for before seeking medical help for an RA flare.

6.2 Objectives for Study 1

1. To investigate patients' perceptions of the range and characteristics of daily symptoms, normal variation, episodic patterns of disease activity and flare
2. To investigate clustering of symptoms and early warning signs of flare
3. To investigate how symptoms are managed and how the decision to seek help is reached
4. To explore a visual representation of disease patterns

6.3 Summary of Study 1 methods

One to one semi-structured interviews were conducted with 15 RA patients, who had been diagnosed for at two least years. Prior to the interviews patients were asked to complete a questionnaire (Appendix C) comprising demographic questions and the Health Assessment Questionnaire (Fries *et al,* 1980). Inductive Thematic Analysis (Braun and Clarke, 2006) was used to analyse the data from the interviews. At the end of each interview patients were asked to complete two blank graphs, one to describe how their symptoms fluctuate in daily life (Appendix D1) and the other to show how their symptoms behave during an RA flare (Appendix D2). Patients have been given pseudonyms to protect their anonymity. For the full study methods and interview topic guide see Chapter 5.4 and Fig 5.1.

6.4 Results

6.4.1 Participants

65 people with RA from UHBT and NBT were invited to participate and 15 (23%) agreed to take part. Reasons for declining to take part included being busy with other commitments and having recently taken part in another research study. Data saturation was reached by interview 13. The majority of the participants were female and ages ranged from 35 to 77 years (mean: 51.13yrs; SD: 11.78) (Table 6.1). Patients were on a range of treatment regimes and had a disease duration of 3 to 30 years (mean: 14.8yrs; SD: 8.57), and a wide range of self-reported disease activity (DAS global) and disability (HAQ). Three participants considered they were in a flare at the time of their interview. Three men were successfully recruited, although they all came from the same NHS trust and had a small age range (47 to 56 yrs: Mean = 50.3yrs). Whilst three men agreed to participate, others expressed a reluctance to take part in an interview study. A fourth man did agree to participate, but cancelled the appointment twice at short notice due to other commitments, after which he could not be contacted again. All the patients in this study were White British in ethnic origin. Patients from other ethnic groups were approached during recruitment, but declined to take part with the most frequent reason being either the language barrier or that they felt they would get too emotional when talking about their RA. This may not be due to their ethnic origin; it could be that these particular patients were still reasonably early in their disease trajectory (data not systematically collected).

Table 6.1: Study 1: Individual interviewees' demographic and disease-related data (n=15)

Patient ID	Gender	Age (Yr)	Dis Dur (Yrs)	HAQ	Pt Global	Current medication	NHS Trust*	In Flare?	Work status	Help at home	Dependents
Amelia	Female	67	9	2.38	7.8	DMARDs	1	Yes	Retired	Husband	None
Charlotte	Female	37	19	0.63	2.4	DMARDs NSAIDs	2	No	Employed	None	None
Chloe	Female	42	17	1.75	4.8	DMARDs Steroids	1	No	House-wife	Husband	2 children
Debbie	Female	44	23	2.75	3.8	Anti-TNF DMARDs NSAIDs	2	No	House-wife	Parents (not living with)	3 children
Emma	Female	42	20	1.00	3.3	DMARDs	2	No	Employed	None	None
Isabelle	Female	45	25	2.38	4.0	NSAIDs	1	No	Incapacity	None	None
James	Male	47	5	0.00	0.9	DMARDs	1	No	Employed	Wife	1 child
Jane	Female	65	16	2.75	2.8	Anti-TNF NSAIDs	2	No	Retired	Husband	None
Kate	Female	35	4	1.50	1.7	DMARDs	2	Yes	Employed	None	None
Linda	Female	52	23	1.88	1.9	DMARDs NSAIDs	2	No	Employed	Husband	None
Liz	Female	59	3	0.88	3.1	DMARDs	1	No	Retired	Husband**	Husband**
Mary	Female	77	30	Incomplete	4.6	Anti-TNF DMARDs	2	No	Retired	Husband**	Husband**
Michael	Male	48	10	0.25	3.0	Anti-TNF DMARDs Steroids	1	No	Employed	Wife	Wife***

Table 6.1 continued overleaf

Roger	Male	56	13	0.25	3.5	Anti-TNF DMARDs	1	Yes	Employed	Wife	1 child
Sophie	Female	51	5	0.13	1.1	DMARDs	1	No	Employed	Husband	None
Mean		**51.1**	**14.8**	**1.30**	**3.3**						
Stan Dev		**11.8**	**8.6**	**1.00**	**1.7**						
Range		**42**	**27**	**2.75**	**6.9**						

*Nb: NHS Trusts have been distinguished by numbers due to concerns about retaining patients’ anonymity
**Nb: These patients both care for and depend on their spouse
***Nb: In contrast to the other patients who listed their spouse as a dependent, Michael considers his wife as a dependent as she relies on him for financial support rather than care

Key:
Dis dur = Disease duration
HAQ = Health Assessment Score 0 – 3 (3 is most disabled)
Pt Global = Disease activity score patient global measure (0 = doing very well, 10 = doing very badly
Medication: Anti-TNF = Anti-tumour necrosis factor; DMARDs = Disease modifying anti-rheumatic drugs; NSAIDs = Non-steroidal anti-inflammatory drugs; Steroids = Glucocortico steroids

The results from the pre-interview questionnaire indicate a diverse sample of participants (Table 6.1). The majority of participants were employed rather than retired or on incapacity benefits. This was unexpected due to the research population and may indicate increased RA control. This is further supported by the low HAQ and DAS patient global scores by the majority of participants. The majority of participants had support at home, generally from their spouse or partner and very few participants had anyone that depended on them. Three participants were in an RA flare at the time of the interviews, but had not been in flare at recruitment. Patients who were in a flare at the time of recruitment were often not interested in participating due to their flare, or were no longer in a flare by the time of the interview, whilst others who had agreed to participate later cancelled due to an unexpected flare. This indicates the unpredictable nature of RA and highlights the difficulty of including an unpredictable variable (flare) in the recruitment criteria. Two female patients (Amelia and Jane) asked for their husbands to be present during the interview. The decision was made to allow the husbands to be present, as it was felt this was preferable to losing the interview. However, it should be noted that a spouse present in an interview may mean that a shared story is presented to the interviewer that protects the image of a harmonious marriage, rather than the patient’s individual experience (Boeije, 2004).

6.4.2 Free-form graphs

The free form graphs were completed by 8 of the 15 participants. The remaining 7 participants did not have time (due to other commitments) to complete the graphs at the end of their interview. One of the 8 participants who completed the graphs was unable to grasp the concept of the axes, despite the researcher’s attempts to explain. This participant drew a line made up of different colours to indicate the fluctuations of her RA that did not correspond to the y-axis and RA flare that did not correspond to the x-axis, which made it difficult to interpret variation (Fig 6.1 and Fig 6.2). One participant incorporated daily life and flare into a single graph (Fig 6.9), which will be discussed below.

6.4.2.1 “How does your RA change?”

This graph aimed to capture the patterns of daily fluctuations and was successfully completed by 6 participants. One participant (Liz) drew a straight line, to indicate that her RA does not change on a daily basis (Fig 6.3). The other 5 participants all drew a fluctuating line that changes within individual days as well as across time (Figs 6.4 to 6.8). One participant incorporated daily life into the “What does a single flare look like?” graph (Fig 6.9), this also identified a fluctuating pattern of symptoms. Whilst the majority of the graphs depict a fluctuating condition, it is impossible to pinpoint any common patterns to the graphs, particularly in this small sample.

6.4.2.2 “What does a single flare look like?”

This graph aimed to capture how patients’ symptoms change during a single episode of flare and what happens to patients’ symptoms following a flare. This graph was successfully completed by 7 participants and 3 different experiences of flare could be identified. One participant (Fig 6.10) identified a flare as coming on instantly without any warning. This participant described that symptoms go from ‘no symptoms at all’ to ‘worst symptoms imaginable’ instantly, and then within 2 days return to ‘no symptoms at all’. The second type of flare (n=2; Fig 6.11 and 6.12) is one which gradually gets worse, building from low or no symptoms and eventually reaching worst symptoms imaginable. Participants report that this flare will not go away until they receive a steroid injection, at which point they report the symptoms instantly drop back to their original pre-flare level. The final type of flare identified (n=4 Fig 6.9 and 6.13 to 6.15) begins with a moderate baseline level of symptoms, which gradually increases (over days and weeks) to a much higher symptom state. These patients do not report their flares ever reaching the worst symptoms imaginable as they experienced much worse symptoms at the time of diagnosis, when their disease was uncontrolled and they remain hopeful that *“it’s never going to be that bad again”* (Charlotte, 37). These participants report the need for a steroid injection, which does begin to alleviate the symptoms. However, it is only with self-management and time that these participants’ symptoms return to their baseline state, but never back to an absence of symptoms.

Figure 6.1: How does your RA change? Free form graph completed by Jane

Key: Brown = Worst symptoms
Green = In pain, but better than brown
Grey = In pain, but better than green
Pink = Best possible symptoms
(still not pain free)

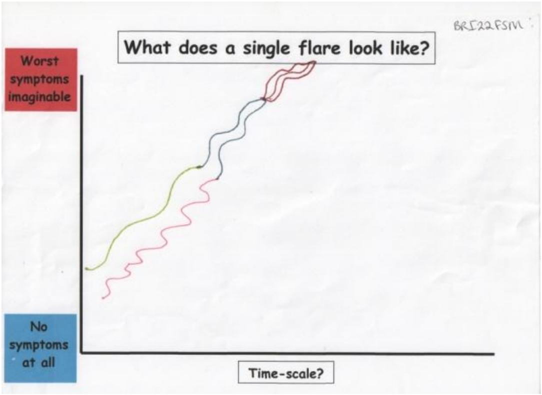


Figure 6.2: What does a single flare look like? Free form graph completed by Jane

Key: Brown = Worst symptoms
Green = In pain, but better than brown
Grey = In pain, but better than green
Pink = Best possible symptoms
(still not pain free)

Figure 6.3: How does your RA change? Free form graph completed by Liz

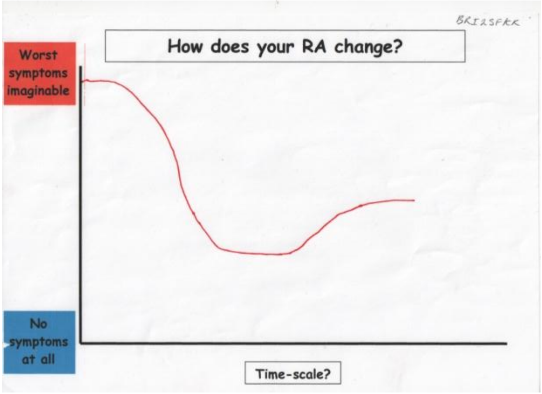


Figure 6.4: How does your RA change? Free form graph completed by Linda

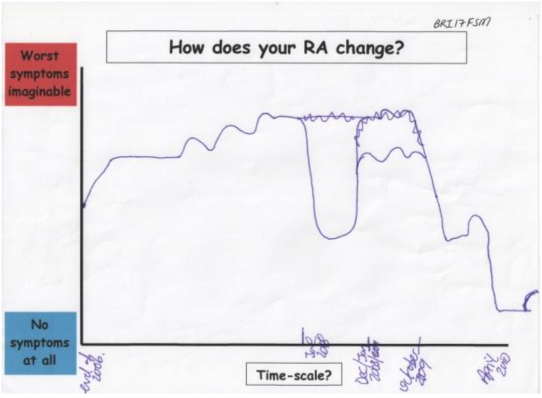


Figure 6.5: How does your RA change? Free form graph completed by Kate

Nb: The timescale that Kate added to this graph is end of 2006 to April 2010.

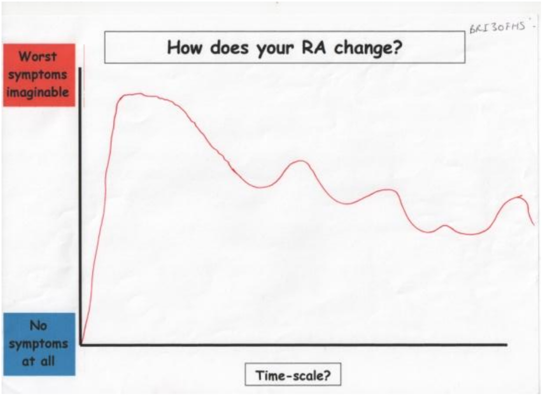


Figure 6.6: How does your RA change? Free form graph completed by Charlotte

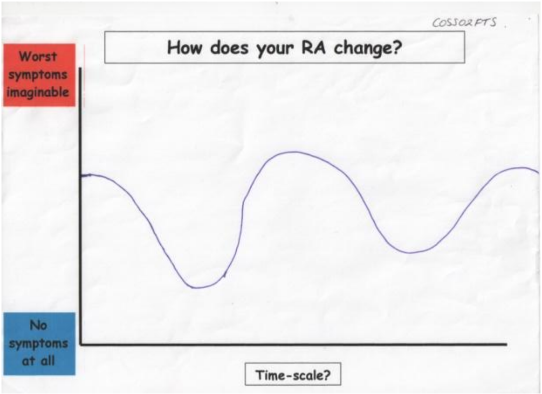


Figure 6.7: How does your RA change? Free form graph completed by Isabelle

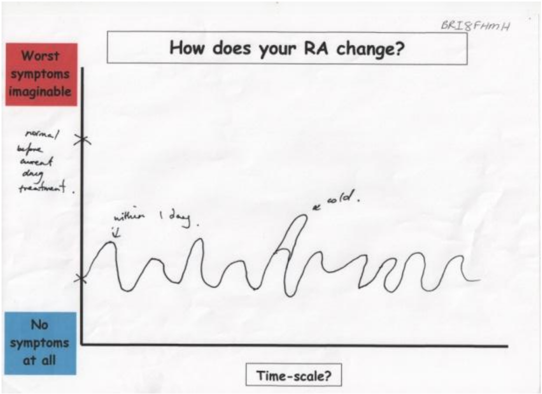
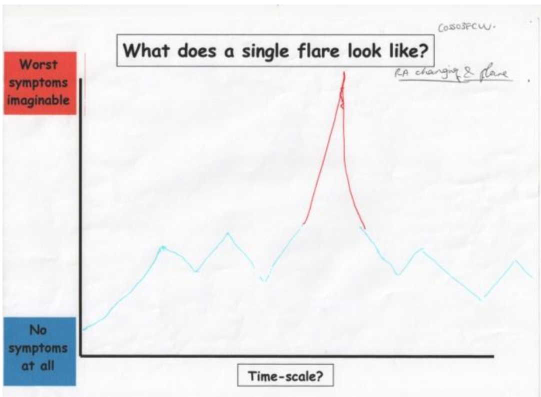


Figure 6.8: How does your RA change? Free form graph completed by Mary

Nb. The spike in symptoms relates to the cold weather



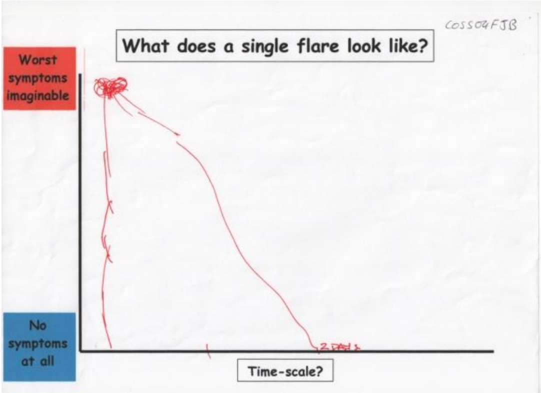
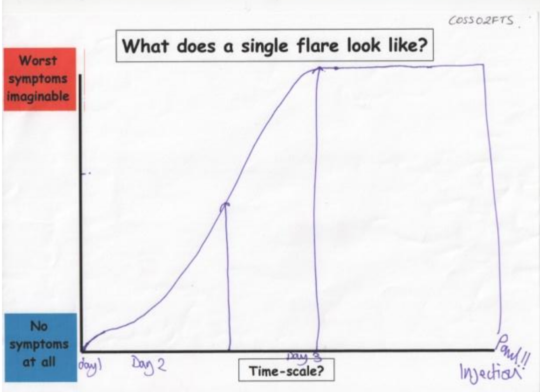


Figure 6.9: What does a single flare look like? Free form graph completed by Sophie

Sophie has incorporated both daily life and flare onto one graph. The blue line represents daily life and the red line represents the flare.

Figure 6.10: What does a single flare look like? Free form graph completed by Liz



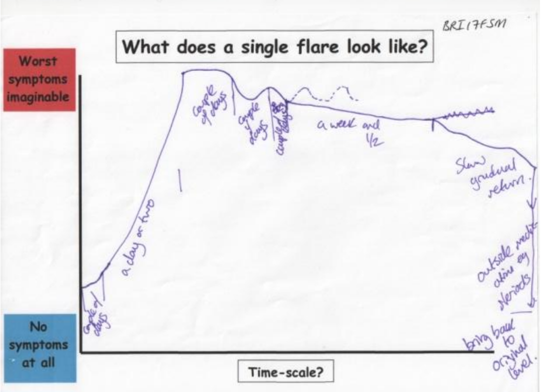


Figure 6.11: What does a single flare look like? Free form graph completed by Isabelle

Figure 6.12: What does a single flare look like? Free form graph completed by Kate

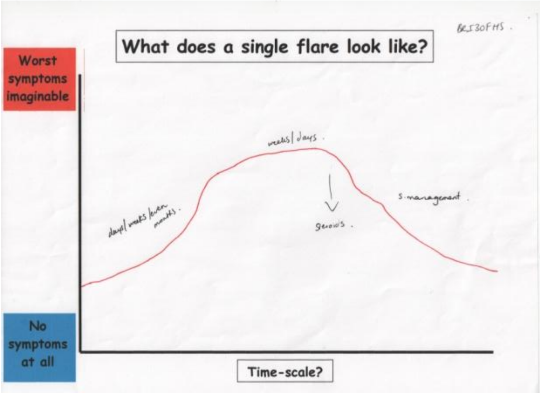


Figure 6.13: What does a single flare look like? Free form graph completed by Charlotte

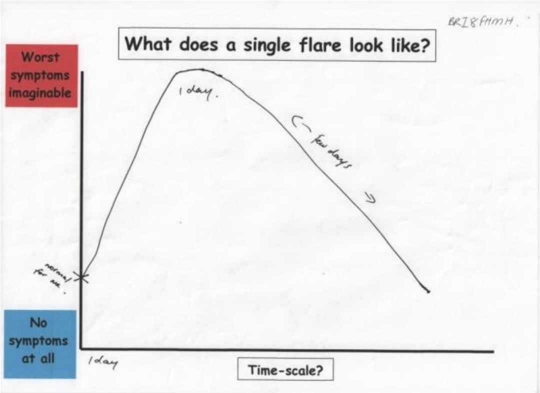


Figure 6.14: What does a single flare look like? Free form graph completed by Mary

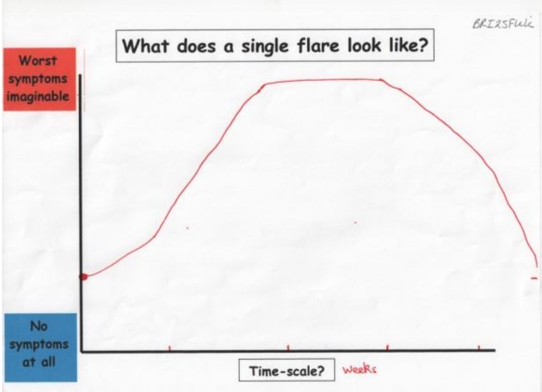


Figure 6.15: What does a single flare look like? Free form graph completed by Linda

These graphs provide a summary of how patients perceive their daily life with RA and experience of flare. The individual characteristics of patients' experiences of living with RA will now be presented.

6.5 Thematic analysis of the qualitative interviews

Three overarching or global themes were identified that related to the experience of living with RA, with an underpinning theme of Balance across all of them (Fig 6.16). Within each of the three overarching themes there are sub-themes, which are summarised below.

<u>Theme 1: Living with RA in the background</u>

- Mediating the impact of RA on daily life
    - "It's not going to get the better of me": Physical impact and its mediation
    - "It just makes you snap": Emotional impact and its mediation
- Re-defining 'me'
    - "I am really fiercely independent": Retaining independence
    - "You just accept it as normal": Adapting normalities
    - "It's just part of me": Incorporating RA into identity
    - "You need to be positive": Cognitive adjustment

<u>Theme 2: RA moving into the foreground</u>

- Unwelcome reminders
    - "I'd forgotten about that RA": The unpredictable nature of RA
    - "It's hard for other people to understand": Perceptions
- Trying to make sense of fluctuation
    - "It's always playing it by ear": Uncertainty
    - "It might go away": Avoiding seeking medical help

<u>Theme 3: Dealing with RA in the foreground</u>

- Trying to regain control
    - "Just keeping my fingers crossed: Attributing fluctuations to luck
    - "I just try anything": Crisis management of a flare
    - "You just go into hibernation mode": Social withdrawal
- Losing Control
    - "It's like a 'Game Over'": Unmanageable impact
    - "I was in agony and I couldn't do anything": Seeking medical help

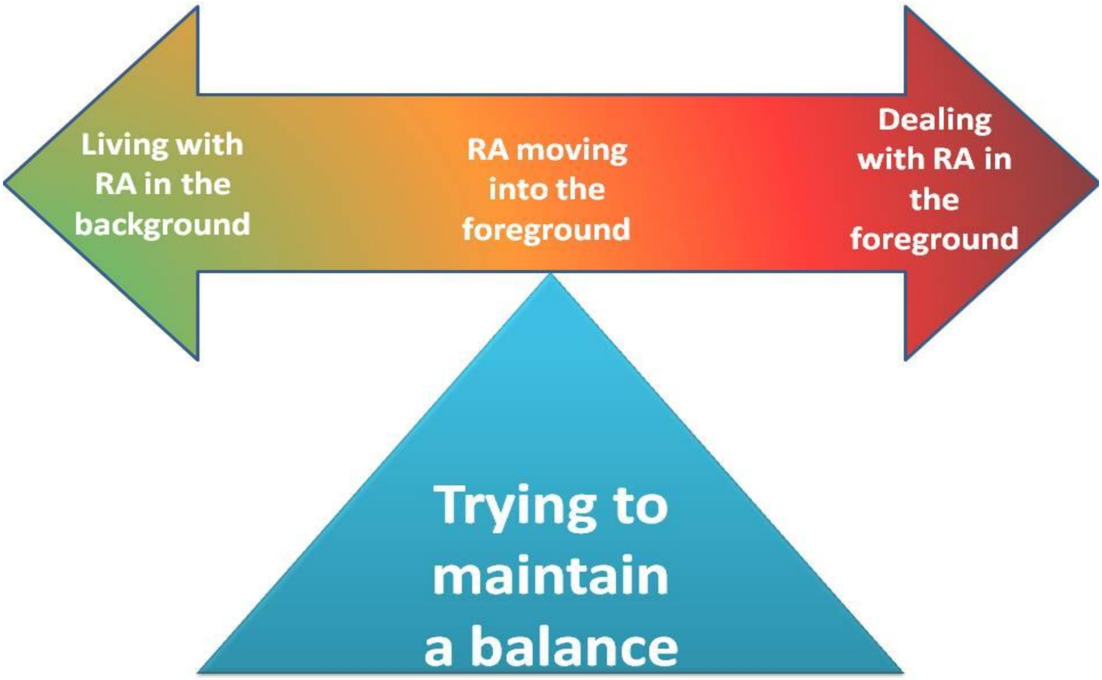


Figure 6.16: Overview of the overarching and underpinning themes

6.6 Underpinning theme: "It's like a juggling act": Trying to maintain a balance

An important part of managing RA is trying to maintain a balance, which patients reported being aware of in every aspect of their lives. The main issues relating to balance are covered in this section, but the concept of balance is woven throughout the results as an underlying theme. Patients spoke of the need to balance various aspects of their management strategies, as neither extreme episodes of rest nor of persevering with activities is helpful to them. Patients reported the need to keep a healthy balance between resting and staying active; *"it's like a juggling act"* (Charlotte, 37). If a patient does too much activity and pushes themselves too hard, they are risking over doing things and causing a flare. However, if a patient rests too much their joints may stiffen, causing decreased mobility and function. Patients also worry that not enough exercise will cause them to put on weight, putting extra stress on their joints:

> *"It's sort of a balancing job really. If I use more than my share of energy for one day, it will affect the next"* (Debbie, 44)

> *"I do like to eat well and drink well, but you know you burn it off by running or you know doing exercise, that keeps the balance sheet in check really, but now that's gone and you can't do that....and that adds weight then to your joints and um, you know that sort of compounds things a little bit. So you know I try to sort of*

> *watch my diet a little bit and exercise, do what I can, you know walking, which is, you know, what I try to do to compensate for that"* (Michael, 48)

Patients reported the need to find a balance in activities of daily living such as doing chores or something pleasurable. This was a particularly salient topic for women with young children who consider it more important to spend time with their children than making sure the house looks perfect:

> *"It's just a balancing thing. There's some things that have to be done and those things that don't have to be done sometimes aren't done. So, and there will be things around the house rather than, you know, where I concentrate on the children rather than the house"* (Debbie, 44)

> *"I plan that [cleaning] over the week 'cos I find I'd be, I'd be so worn out by the end of the day that I wouldn't have time for the children when they came home from school and cooking tea and stuff like that"* (Chloe, 42)

When patients have to ask for help they are reminded of their RA, as this threatens their independence. However, if patients do not ask for help when they need to they may bring their RA into the foreground by aggravating their symptoms. Thus patients need to find a balance between asking for help and remaining independent:

> *"I think it's trying to find that happy even isn't it, between off-loading stuff to other people, yet remaining independent"* (Linda, 52)

Some patients do not find that they are able to maintain a balance in their daily life, although they are aware of the need for it. For some patients this is due to being unable to discipline themselves into taking a period of rest. However, for other patients this can be due to a deliberate decision not to give in to their RA and although they have weighed up the consequences, they choose to reject the idea of balance. This is one way of keeping RA in the background, although by rejecting the idea of balance, RA may only be kept there temporarily:

> *"I think 'Oh I can wash up and I can go and do a bit of tidying up' and then I think 'I'll have to go and sit down in a minute', but I don't sit down I'll go fussing with something else you know, and then course after that well, yes I've got to go and sit down you know, and that's the end of it"* (Mary, 77)

> *"I'm going to have it for the rest of me life so I might as well have the most fun as I can for as long as I can and screw the consequences"* (Kate, 35)

Patients who value the importance of balance in their lives find that it is not always possible to maintain this when they are in a flare. Fulfilling responsibilities and staying mobile can lead to exacerbated symptoms:

> *"If you rest too much then you, you sometimes, you've got to push yourself because otherwise you're going to lose what mobility that you have got, so it's just, even when I'm really bad, you know, I've still got to get the kids to and from school and all their activities and running around after them so, um, in a way that keeps me going I suspect in a way...You know sometimes it feels like there's nothing left for me, you know there's no energy left for me"* (Debbie, 44)

6.7 Theme 1: Living with RA in the background

In normal daily life patients experience RA as a constant background reality. They are aware of a level of symptoms that, most of the time, can be put to the back of their mind. However, in order to keep their RA in the background patients seem to micromanage both their symptoms and their daily lives to accommodate their RA.

6.7.1 Mediating the impact of RA on daily life

Patients discussed the impact of RA on their daily lives in terms of the restrictions that it imposes on them and the way this can make them feel. Many patients are able to mediate this impact by overcoming or working around the restrictions, or cognitively reappraising their expectations of their abilities. These sub-themes are presented with data on impact initially, followed by data on the strategies patients used to mediate that impact.

6.7.1.1 "It's not going to get the better of me": Physical impact and its mediation

Patients experience a number of physical restrictions on their daily life due to their RA symptoms, which they often find ways of overcoming. These restrictions can include every day tasks that the general population would take for granted, such as getting dressed and choosing clothes according to style rather than practicality:

> *"I mean clothes-wise I've adjusted the way that I um, that I dress. I can't do little buttons and things like that or zips at the back, so everything has to be sort of pulled on"* (Linda, 52)

RA can prevent patients from doing things in the way that they would choose or are used to, which is particularly unwelcome when RA interferes with personal preference. Kate was forced to replace her motorbike with a car when she was no longer able to change the gears on the motorbike:

> *"Not even with wanting to climb up a mountain and do er, outdoor stuff. Just what car, what transport I've got is dictated by the fact that I've got arthritis"* (Kate, 35)

It is possible that this decision was especially difficult due to motorcycling being seen as a way of life and an identity, rather than just a mode of transport.

Many patients experience physical restrictions on the activities that they consider valued or pleasurable. Some patients feel that they have had to stop certain activities altogether. This can be due to not feeling able to keep up with others any more or due to bad experiences during their early RA, when their disease was less well-controlled:

> *"I used to do a lot of walking with the local rambling club, um I've had to stop doing that"* (Roger, 56)

> *"I used to go running. I could go out road running, nothing drastic, with friends or walking and we'd play badminton, but when I first had RA that all went out the window, I couldn't do anything. I couldn't even hold the racquet, so um I stopped doing any sport like that"* (James, 47)

Although patients experience restrictions on their abilities, they are often determined to reduce the impact that RA has on their lives. Some patients deal with this by pushing through their pain and other symptoms in order to carry on with their normal lives. By managing in this way it is possible that patients are causing themselves more long-term damage to ligaments and tendons. However, pushing through may allow them to maintain or regain perceived control of the situation and to fight back:

> *"For the kids' sake as well, I try and do as much, even if it's really really painful and it's really sort of 'Ohhh', you know I do it and I think 'No, it's not going to get the better of me'"* (Chloe, 42)

> *"I just couldn't be kept in the house so it would still be agony and I would try and drive [demonstrates steering with elbows]"* (Isabelle, 45)

Other patients will find alternative ways to do the things they want to do. They are aware that their RA can restrict their abilities, but are able to employ strategies to ensure that RA does not change the activities that make up their normal everyday life:

> *"I think even when I've had a swollen knee I've got on the bike and just pedalled more with one leg than the other"* (Emma, 42)

The idea that patients only need to manage their RA when their symptoms are exacerbated is a misconception. Of particular note is that even with new treatment regimes, which are deemed more effective, patients feel the need to micro-manage their symptoms and activities on a daily basis. Patients take this proactive, preventative approach to ensure that their symptoms are kept at bay.

Charlotte described how she incorporates a level of micro-management into her working day:

> *"If I was just printing something I will get up and go to the printer I won't just wait and print a whole load and then go up at one point or get someone else to get it for me, I will get up and move around and go for a coffee and yeah have a little wander round the office or something. I just find it helps a lot because otherwise you do seize up and that causes a lot more pain, a lot more trouble"* (Charlotte, 37)

Patients use self-management techniques such as planning, pacing and delegating tasks, to try and ensure that they can maintain the equilibrium between 'life' and RA:

> *"I knew that I'd be doing a lot of walking so I made sure that the next day was empty"* (Debbie, 44)

> *"So it is pacing your day so that you can do that little bit of work and then the household things that you have to do um, and then just trying to hand over things that perhaps you don't need to do yourself"* (Linda, 52)

Self-managing RA on a daily basis becomes normal for patients and therefore many patients are automatically employing these self-management techniques. It is possible that there is a subconscious element to self-management, with some people (e.g. Kate) reporting that they do not self-manage when directly asked in interview, but going on later to describe their self-management techniques. This indicates that although Kate is aware of the need to plan and pace, she considers this a part of her life with RA, rather than a conscious way of managing her symptoms:

> On direct questioning: *"I don't really know what I do to manage it and I think that's part of the problem, is I'm really bad at managing it"* (Kate, 35)

> Later spontaneous comment: *"I do burn the candle at both ends. I absolutely know that. The difference is, is I do know that once I've done that for a while I then need to have like a weekend where I just don't do anything"* (Kate, 35)

Due to their refusal to allow RA to impact on their lives, many patients are able to carry on with activities that are important to them, such as spending time with their family:

> *"We go swimming and take her [daughter] out and do things and like I say, when the snow was around we went sledging"* (James, 47)

Some patients are even able to take part in more physically demanding activities, as they are determined that their RA will not stop them doing what they want to do. These patients are aware of the consequences of overdoing things, but make a conscious decision that the rewards outweigh the costs:

> *"If I want to go white-water rafting I'll go white-water rafting and believe me I have. I did pay for it the next day but you know, I enjoyed it at the time"* (Charlotte, 37)

6.7.1.2 "It just makes you snap": Emotional impact and its mediation

RA has not only a physical, but an emotional impact on patients' daily lives. Many patients reported frustration due to being unable to do the things that they used to be able to do:

> *"I do get frustrated, 'cos I've always been active. I mean I was post-lady for the last sixteen years of me working life; running up and down steps in roads I mean and we've always gone cycling, swimming, walking, haven't we [to husband], I can't do cycling."* (Amelia, 67)

Patients with RA begin to accept a slower pace of life, but they still experience frustration due to their body not being able to keep up with their mind:

> *"You just have to slow right down you know so, but it's really frustrating when your brain's going zzzzz you know you're working ten to the dozen and you just want your body to follow and it just doesn't"* (Isabelle, 45)

One patient, an ex-rugby player, explained how he has learnt to change the way he deals with his frustration. More masculine ways of coping now have potential physical consequences for him and so this patient reported the need to adopt a more female-oriented coping strategy:

> *"Talking is a way of taking that frustration out of your body when you can't go and thump a wall because you end up with a flare so, and you can't go and kick a football around or anything like that you know, so you need to find an outlet and talking is the outlet I suppose"* (James, 47)

However, James still finds current offered support unhelpful due to the focus on emotional support:

> *"The self help groups don't confront it enough, it might be all lovey-dovey but sometimes you have got to be quite hard about it"* (James, 47)

Some patients explained that they experience more than mere frustration due to their RA and the way it impacts on their lives. A small number of patients reported feelings of anger, which seem to arise from their frustration and is exacerbated by their symptoms such as pain and fatigue:

> *"It, I don't know, it just makes you snap sometimes, it just makes you, I think it's the frustration because you want to do it and you can't do it and the frustration and the tiredness and everything"* (Chloe, 42)

> *"No room for self pity at all or anything, no, just anger really"* (Michael, 48)

As well as frustration and anger, the impact of RA on their lives can cause patients to worry. One source of worry for patients in employment is how their employer will react, particularly when they are unwell or need time off work due to their RA:

> *"I'm quite worried about how work are going to react to that [operation]. Um, because I just see it as er, it'll be an opportunity for them to fill my position while I'm away and, and I'm not so sure it'll still be there when I get back"* (Linda, 52)

Patients also worry about their RA causing them embarrassment in public. It is possible that the prospect of having to depend on others, particularly strangers, makes patients feel vulnerable:

> *"I worry a lot about falling over um, because with my knee being replaced, I find it hard if I'm down on the floor, I cannot get up on my own, I cannot get, I have to literally physically have someone help me up. If I fall over somewhere and there's no-one I know, I'm so embarrassed, I'm like 'Oh my God', you know, 'Open the floor up and let me in', because I just can't get up"* (Chloe, 42)

Some patients experience feelings of guilt when they believe that they are holding people back or letting them down, particularly friends and family. This can be due to cancelling plans or being unable to keep up with them:

> *"I do sometimes feel that when we go on holiday I'm holding them [husband and teenage children] back from doing things that they'd enjoy doing"* (Linda, 52)

> *"We do manage to take holidays don't we [to husband]? But I can't carry cases or bags, so it's all left to him, and he ain't getting no younger [laugh]. It's like carting a nuisance about isn't it? But he's ever so good though. Without him mind, I'd be lost"* (Amelia, 67)

Amelia seemed to be aware of a certain level of dependence on her husband, which may challenge her sense of worth, thus causing her to feel like a burden.

Patients use a number of strategies to minimise and rationalise the impact that RA has on their daily life and to keep their illness firmly in the background. A number of patients reported using supportive family and friends in order to cope with difficult periods, such as exacerbated symptoms or low mood:

> *"I think you're able to have a much more positive attitude if you've got a lot of support behind you"* (Linda, 52)

> *"I find sometimes um if you go out and you socialise it does take your mind off of it a bit"* (Jane, 65)

Some patients also find it helpful to talk to other patients about their experiences. However, they feel it is important to speak to someone who is of a similar age and who has a similar outlook. In contrast, other patients reported being reluctant to speak to other patients due to previous bad experiences:

> *"I didn't realise how, you know, useful that was, or how nice that was to speak to other people sort of in the same age group"* (Emma, 42)

> *"She's [friend with RA] put me off talking to patients or other sufferers I will say that and the fact that every time I talk to her and say how is this 'Oh yeah, yeah I am really down'"* (James, 47)

Patients also reported using the clinical rheumatology team for support. Those who receive good support feel grateful for it, whilst those who don't feel supported are impacted by its absence:

> *"You just feel safe I can't explain it, it just feels like a safety net. You are not on your own, so it's massive your relationship [with the medical team]"* (Isabelle, 45)

> *"The problem is, is that I've never really had anybody support me with this at all. Even at rheumatology, it just, it's been an absolute mess, the support that I've been offered"* (Kate, 35)

Another way in which patients attempt to minimise the impact of their RA is by using humour to discuss it:

> *"Because I do a lot of typing at work, recently I have been given some gloves to put on my hands that seem to support the hands when you are typing, although I look a little bit like Michael Jackson [laughs]. It's not a good look but you know I get all sorts of yeah people taking the p**s out of me for that"* (Charlotte, 37)

> *"I mean I get called 'an old crip' you know but I [laughs] because my toe has gone funny and my friend calls me a 3-toed sloth and all that but it's all in fun, you know"* (Jane, 65)

Using humour to talk about RA may be a way for patients to avoid addressing their underlying concerns. However, it is of note that the jokes have originated from people other than the patients. Thus the humour may be an attempt to help others cope with the reality of RA.

6.7.2 Re-defining 'me'

Due to the restrictions it imposes on valued and daily activities, RA has the potential to pose a severe threat to patients' identities. In order to deal with this, patients begin to accept changes and report the need to *"learn about your own body again"* (Charlotte, 37). They also re-evaluate their abilities, the way others see them, and how they see themselves, redefining themselves as someone with RA.

6.7.2.1 “I am really fiercely independent”: Retaining independence

Patients discussed the importance of independence and reported that they will fight to be as independent as possible. This can sometimes mean standing up to friends or family who are trying to help and who may not realise that they are posing a threat to the patient’s independence:

> *“I am quite independent so I tend to sort of do things by myself and doing things by myself I get a bit you know ‘no, no, I will do it’ yeah a little bit bolshie about it”* (Charlotte, 37)

> *“He [Husband] says ‘You won’t listen!’ I says ‘Well I do listen but I’ve always been active and independent and then all of a sudden that’s taken away isn’t it?’ You know, that I think that’s a big issue for people that um, have never wanted people to do things for them”* (Amelia, 67)

Some patients feel as though the choice to be independent has been taken away due to their RA. One patient (Isabelle) explained that she has decided to get a wheelchair to be able to go out more and therefore increase her independence. Isabelle seems to be choosing to compromise one aspect of her identity, where she portrays herself as a young, healthy woman in order to retain another aspect of her identity; an independent woman:

> *“I don’t wanna be in it [wheelchair] trust me I really don’t because I’m too vain, but I have got to, I’m just too restricted now and I wanna do things, I wanna see places and go places you know and now these places are so much more accessible, I need to just get over myself and get on with it, you know?”* (Isabelle, 45)

6.7.2.2 “You just accept it as normal”: Adapting normalities

Patients find the need to accept and adjust to a new level of ‘normal’ in terms of a body that has fluctuating levels of symptoms on a daily basis. Some patients explained that the pain is always there and you have to learn to push through the pain and accept it, whilst others say that they don’t always notice the pain as they are so used to it being there. The latter patients have incorporated this background level of pain into what is ‘normal’ for them:

> *“It’s just the way of life now, you are just used to it”* (Roger, 56)

> *“Sometimes you’ve gotta kind of work through the pain, but you know, it doesn’t tend to sort of intrude, you know, sort of too much, you just sort of accept it as normal really”* (Michael, 48)

In terms of altered abilities, some patients do not find it so easy to accept a ‘new normal’. One patient describes a change in her abilities that challenges her identity as she is no longer able to make a favourable comparison between herself and her friend:

> *”There was um something that I just couldn’t carry that was too heavy for me, and my friend just picked it up and I know I’ve always been much stronger than her”* (Emma, 42)

Emma used this single event to create a negative belief about her physical abilities as it challenged her identity as a strong, capable woman. This demonstrates how one event that highlights a decline in abilities can have a negative impact on a person’s identity:

> *“That’s something that I find quite hard to deal with really, that I’m a weakling”* (Emma, 42)

Other patients are able to be more pragmatic and rationalise their declining abilities. One patient compares her change in activities to the general population who change as they get older, thus normalising the changes that she is adjusting to:

> *“What I do in sort of my personal life has changed because I can’t do what I used to do ten years ago. I mean that’s normal for people as they get older anyway”* (Kate, 35)

It is important to note that it is also possible that Kate is attempting to minimise the impact of her symptoms by trying to convince herself that it is normal to have reduced abilities at 35 years old.

6.7.2.3 “It’s just part of me”: Incorporating RA into identity

The majority of patients in this study spoke about their RA as though they have incorporated it into their identity:

> *“It’s just part of me”* (Debbie, 44)

> *“It’s just like, you know, it’s kind of that’s who you are. You just, it’s just, it’s that you have it [RA] and you just deal with it”* (Charlotte, 37)

Whether they have incorporated RA into their identity or not, patients are determined not to be defined by their RA or to be treated any differently because of it. It is possible that if they allowed themselves to be treated as an ‘RA patient’ they may feel that they are losing their identity. It seems that RA can become part of patients’ identities whilst still allowing them to retain their sense of self:

> *“Yeah, it doesn’t define me”* (Charlotte, 37)

> *“So they are trying to sympathise and empathise, but when you’re young you don’t want that, you just want to be treated like everyone else”* (Isabelle, 45)

In contrast, one patient (Kate) discussed RA as separate from her personal identity, she makes a clear distinction between 'the body' and 'me'. Kate previously resisted taking her medication due to worries about side effects, although she is aware that medication is the most effective way to keep on top of her RA. In order to reconcile this difference and accept taking her medication, Kate thinks of her 'RA body' as separate to her personal identity:

> *"I just think actually my body's been pretty s**t to me so if I can get my own back on it a little bit by filling it full of toxins, then so be it, if it don't behave that's what it gets...If it chooses to behave then I'll be a bit nicer to it and I'll come off some of the drugs"* (Kate, 35)

6.7.2.4 "You need to be positive": Cognitive adjustment

Patients in this study seemed to be trying to minimise the effect that RA has on them by trying not to acknowledge it:

> *"On the whole I tend to convince myself that actually everything's fine and I'm completely normal"* (Kate, 35)

> *"Well I could still say it doesn't really affect me that much, but you know, I know that's not really true but it does seem right to say that"* (Emma, 42)

Patients also attempt to minimise the impact of their RA by having a positive attitude towards it, although not all patients find it easy to stay consistently positive:

> *"You need to be positive the whole time and think well no, the pain's there, yes, but the pain will go eventually"* (Chloe, 42)

> *"You have to just try and stay positive because for me it is really, and I get really tired of trying to be positive"* (Isabelle, 45)

Some patients tried to see the best of their situation by making comparisons to how they used to be or thought they would be. Patients also made downward comparisons between themselves and other patients, and with people with life-threatening illnesses. Such downward comparisons enabled them to feel better about their own situation, even though they are unable to change it:

> *"I'm in a much better position than I thought I probably would be"* (Michael, 48)

> *"I see some people that can hardly walk, you know and I am thinking 'No, I'm not going to let it get to that stage'"* (Liz, 59)

> *"This is an inconvenience, it's not life threatening, there's lots and lots of life threatening diseases out there you know, put you in perspective where you are"* (James, 47)

> *“ I mean there’s so much going on in the world isn’t there at the moment, and like I say, you know, these poor soldiers coming back from Afghanistan and you know, and you think well you’ve got so much to be grateful for haven’t you?”* (Linda, 52)

Occasionally patients made comparisons with someone who is less disabled than they are such as friends or family who do not have RA. However, upward comparisons such as these were unhelpful and largely negative:

> *“I should think even my Mum can touch her toes and she’s 75”* (Emma, 42)

6.7.3 Theme 1: Summary

In normal everyday life, patients’ RA is in the background, while their wellness is in the foreground. This simple explanation may indicate that patients do not have any concerns about daily life with RA. However, even when patients’ RA is in the background, there is a complex set of beliefs, expectations, impact and management surrounding the patient, which they have to learn to balance. All of the sub-themes discussed above have an impact not only on the patient but also on each other (Fig 6.17), for example the physical impact of RA can reduce a patient’s independence, which in turn reduces how close they feel to ‘normal’ for them. The physical impact can be mediated with self-management, which would in turn increase a patient’s independence and sense of normality (Fig 6.17). Theme 1 has been used as the beginnings of a conceptual model to explain life with RA (Fig 6.18).

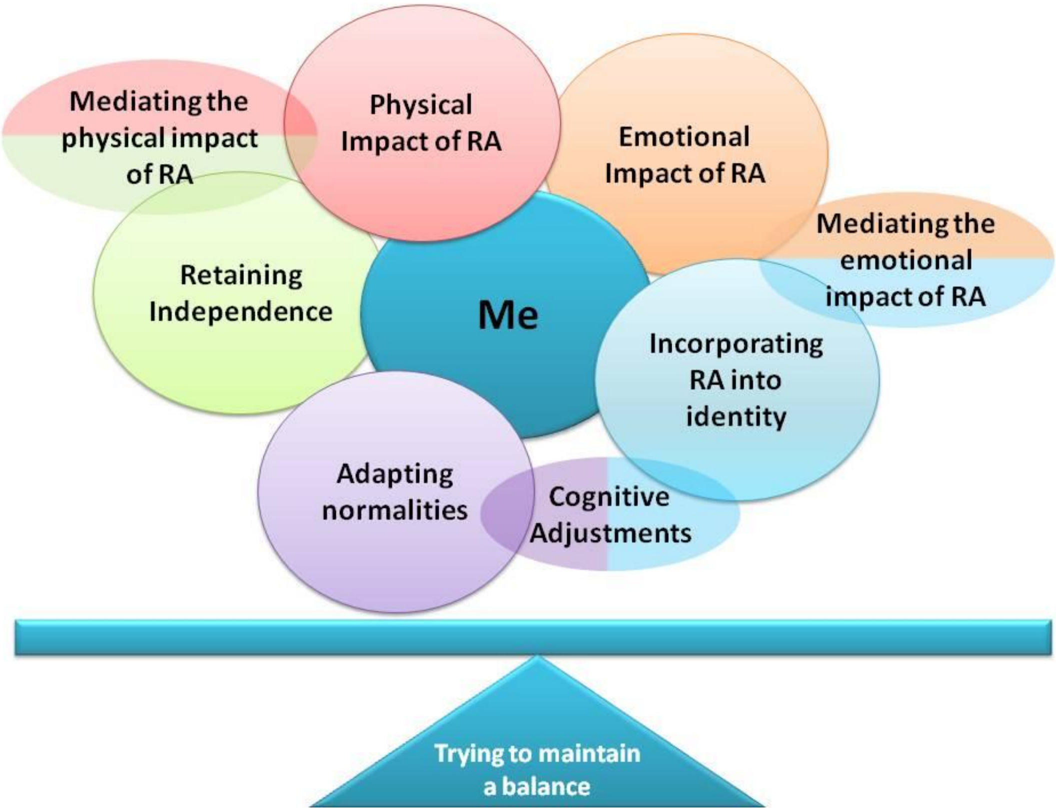


Figure 6.17: Living with RA in the background

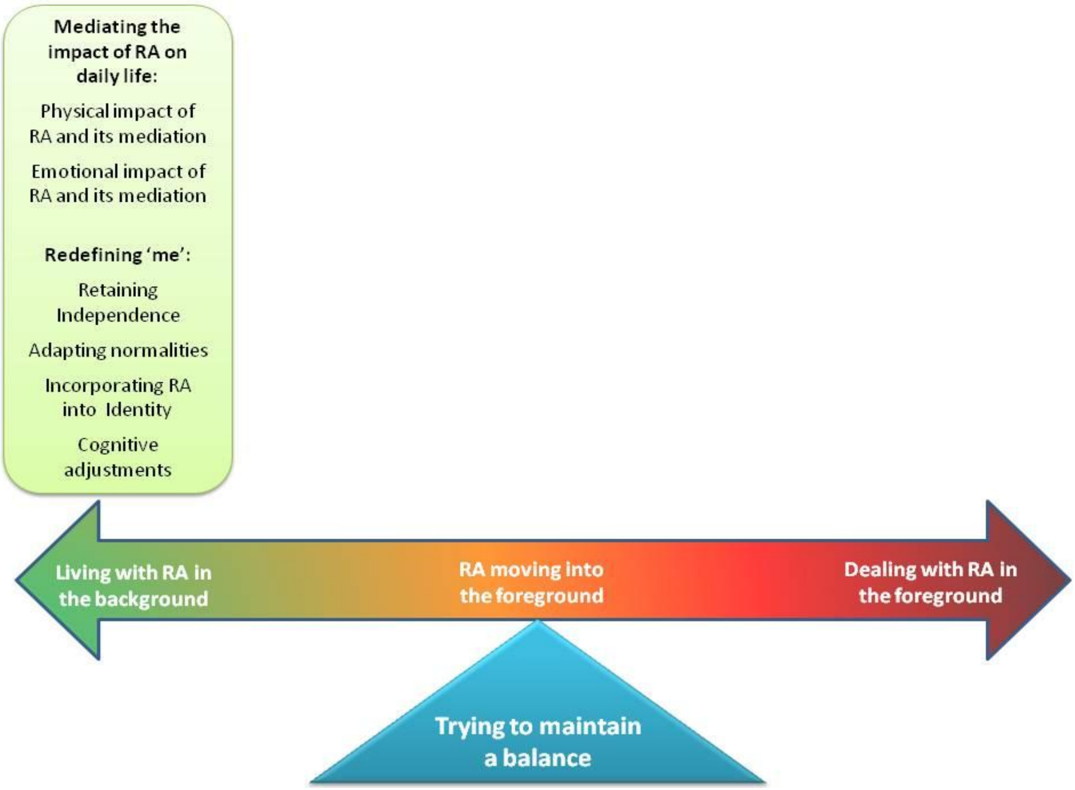


Figure 6.18: Beginning of a conceptual model to explain life with RA

6.8 Theme 2: RA moving into the foreground

Patients have strong coping and self-management strategies that allow them to keep their RA in the background most of the time. However, the unpredictable and uncertain nature of life with RA can mean that despite their best efforts, RA can move into the foreground and begin to intrude on patients' lives.

6.8.1 Unwelcome reminders

Living with RA, patients can experience unwelcome reminders about their condition. This can be due to changes in RA disease activity leading to exacerbated symptoms, due to the clash between life and RA making people more aware of their limitations, or due to other people's reactions to the person with RA.

6.8.1.1 "I forgot that I've got this arthritis": The unpredictable nature of RA

Life with RA can be unpredictable as symptoms can fluctuate on a daily basis and patients are often unable to predict what each day might be like, which can mean they may need to cancel or change their plans. Several patients discussed the fluctuating nature of their symptoms on a daily basis, the peaks referred to by Charlotte are not RA flares but a high level of daily symptoms:

> *"You do sort of have peaks and troughs, yeah definitely"* (Charlotte, 37)

> *"There doesn't feel like there's been any pattern to it"* (Kate, 35)

Patients also discussed their inability to predict what the next day holds as there is no consistency between the way they feel in the morning and the way they felt the night before:

> *"Um, God it's really difficult, it's so different, I never know what I'm going to feel like when I wake up"* (Isabelle, 45)

> *"Some days I can get up in the morning, and they're [swollen joints] gone, that is gone, you know, down like this one [finger] that's got a bit there and then another day it's just up like that for nothing innit? I don't know why it is really. I mean to me, if you've been resting all night, why should it go like that?"* (Amelia, 67)

Patients are also sometimes unable to predict or they forget what exacerbates their symptoms. This causes an unwelcome reminder that their RA is a part of their life:

> *"You might do something if you're feeling good, you might do something then just go 'Ooh I shouldn't have done that, I forgot that you know, I've got this arthritis kind of thing'"* (Charlotte, 37)

Due to unpredictable symptoms many patients find it difficult to make plans as these may have to be cancelled or altered depending on how they feel on the day. This can be because of being physically unable to do something due to pain or stiffness, but it can also be due to the wipe-out feeling caused by fatigue.

> *"I do suffer quite a lot from fatigue, so it really depends how much energy I have to do that and then also if something's quite sore I might not want to, you know, I might cancel a shopping trip if I've got a very sore knee or ankle or something, knowing that it's going to aggravate it"* (Debbie, 44)

> *"There's been a couple of times when we've been going to go somewhere and I just say I don't feel like going, you know, I'd rather stay at home"* (Mary, 77)

Some patients felt it is better to keep plans vague and wait to see how they feel, becoming flexible around their RA, whilst others felt that the lack of ability to plan means they are unable to work:

> *"Some days I can't be bothered to go out at all and that's that and I just sit with my feet up. Another day I'll think 'Well I can go out today'"* (Amelia, 67)

> *"I did think if I could do that [charity work] maybe I could do a part-time job, but then that just confirmed that I just couldn't sustain it, you couldn't go in so many days a week or, because you never know what you're going to be like"* (Isabelle, 45)

One patient suggested that cancelling plans does not have a big effect on her. However, it's possible that cancelling or rearranging plans, particularly holidays as mentioned, does have an effect, but that she is choosing to minimise the impact it has on her:

> *"Plans are plans you know, and if I phone up and say 'Oh, I'm sorry I've got a bad day' 90% of my friends say 'that's fine, we'll leave it' or you know, we will go on holiday a day later or whatever, no it doesn't affect my life that much to be quite honest"* (Liz, 59)

RA is not only unpredictable in terms of symptoms on a daily basis, but also in terms of RA flares, with patients never knowing when their flare will come. The phrase "out of the blue" was used numerous times by patients talking about their flares, indicating their unpredictable nature. The majority of patients interviewed therefore experience no warning signs that they are about to have a flare:

> *"It comes out of the blue"* (Sophie, 51)

> *"They just come from nowhere"* (Roger, 56)

6.8.1.2 "It's hard for other people to understand": Perceptions

Patients reported the ways in which they felt others perceived them due to their RA. First, patients felt that arthritis is an 'old person's' condition and they therefore worry that they might be seen as 'old' due to having RA. They also find other people are less sympathetic to a young person with RA as they can't understand why they might be slow or tired:

> *"It is hard, the tiredness is the worst part of it. People say 'Oh you shouldn't be tired you're young'"* (Chloe, 42)
>
> *"It's hard for people to understand, especially if you are quite young, why you can't do things, why you can't walk so fast and all that sort of stuff"* (Charlotte, 37)

One patient compared RA to multiple sclerosis (MS) in terms of the differences in public understanding. The following quote indicates that RA has a large impact on this patient's self-identity as she now thinks of herself as someone with an 'old person's' condition. It is possible that she is projecting these feelings onto other people as she is presuming that this is what they are thinking, rather that anyone having said anything to her specifically:

> *"I wish I had MS, because you could say to somebody 'I've got MS' and they automatically think of a younger person and how difficult that is to manage work and relationships and everyday life because it's a younger person's disease. I have to say 'I've got arthritis' and straight away they think 'Oh she don't look eighty, I wonder if she's incontinent'"* (Kate, 35)

Patients also felt that other people do not always believe that they are as unwell as they say. The unpredictable and fluctuating nature of RA means that patients can have periods of feeling ill and of feeling well within the same day. As the full impact of RA on patients is not visible to others (fatigue and pain are invisible symptoms), it may be hard for other people to legitimise these symptoms and thus believe the patient. Patients may therefore feel as though their symptoms are not validated by others. It is particularly important in a work situation for an employer to understand the fluctuating nature of RA and to believe patients, but also for other colleagues to understand in order to prevent resentment:

> *"I mean, just sitting down for long periods at work, I then, you know, get up and then I sort of find it difficult to get going again, which I'm sure people find really funny, that you know, I'm limping one minute and then I'm not the next"* (Emma, 42)

Linda felt that she should not have to educate her employer about what is wrong with her and that she deserves to be believed. Kate on the other hand will seize opportunities to show colleagues the visible aspect of her RA in order to increase their understanding:

> *"I don't want to educate, do you know what I mean, really. I mean I suppose I just want them to accept me as I am, and if I say I can't do something, then I'm not trying to sort of opt out of doing it. It really is because, you know, I can't do it"* (Linda, 52)

> *"I'll actually show her [colleague] all the bits that are swollen, because that actually helps. Because it's something that people can see that is easy to identify and for me that is actually better because it can be seen"* (Kate, 35)

Patients' perceptions of a disbelieving attitude held by others are not confined to the work-place. As Isabelle described, the general public can be just as doubting, making patients feel uncomfortable, which is a further reminder that RA is a part of their life:

> *"It's hard work when you are not, when you don't look like there is anything wrong with you and especially like when I get out of the car, even though I might be limping a little bit, I get out of the car and the looks and the people I've had come up and say to me, 'Why have you got a blue badge then?' even the wardens and that, they'll lean and I'm sat in my car with the badge up just about to get out or get in and they're literally leaning across looking and they'll sort of look me up and down and they'll look at my badge"* (Isabelle, 45)

Some patients also find that their family and friends are not particularly understanding. As Jane mentioned this is possibly because patients are good at hiding their symptoms and do not complain:

> *"You know they [friends] all say 'Don't you look... oh you do look well' [laughs] I think they think you are swinging the lead but they don't really understand how bad you feel because I am good at hiding it you know, I don't want to give in to it do you know what I mean?"* (Jane, 65)

Life with RA therefore may not always be what it seems. Patients often put on a brave face and appear to manage well despite the daily impact of RA. This, coupled with invisible symptoms can make it difficult for friends, relatives or employers to tell whether patients are really affected by their RA or not. In order to live with RA in the background and to protect their personal identities, patients would choose to think and talk about their RA as little as possible. However, this may not be an option for patients for whom it's important that other people understand their situation and believe them:

> *"You either have it one way or the other I suppose; that you're constantly going on about it and you let it rule your life; or you don't let it rule your life and then people don't really understand"* (Emma, 42)

6.8.2 Trying to make sense of fluctuation

Patients discussed feelings of uncertainty surrounding various aspects of their life with RA, often due to its unpredictability, which can leave people wondering whether there is anything they can do to make a difference. Patients try a variety of self-management techniques, but they are unsure as to whether any of these methods are working as at times there seems to be inconsistency between the self-management technique and the way the disease responds. Patients are often unsure as to whether they are experiencing a flare or not, which may lead to a delay in help-seeking behaviours.

6.8.2.1 "It's always playing it by ear": Uncertainty

Patients reported that despite the uncertainty surrounding whether a self-management technique is working, they are reluctant to avoid trying or continuing something in case it does work. Thus they feel it is better to do something that doesn't work, than not do it and later regret that decision:

> *"I mean I do think that whatever you do, it [RA] does what it wants, I still think that. 'Cos I used to do hand exercises, I wouldn't have not liked to have done them because they might have been so much worse, you know. I mean, it's something you will never know, but you do wonder how much good they've done, because your hands still end up, you know, becoming inflamed and fusing and all these things happening to them."* (Linda, 52)

Some patients monitor their food in order to manage their RA. This can be for two reasons, the first is that they worry about gaining weight and therefore putting extra stress on their joints, therefore these patients eat as healthily as they can. In contrast, other patients believe that certain foods have the potential to cause a flare, they therefore cut these foods out of their diet. Patients still seem to remain uncertain about whether this is truly making a difference or not:

> *"And things like oranges, where there's acid in it. Anything with um...a big amount...if I have an orange I only have about three slices of the orange"* (Amelia, 67)

> *"But I can't say that it [special diet] made any difference, but it's really hard sometimes to know whether something is making a difference"* (Emma, 42)

Some techniques for self-management have their pros and cons and this can lead to patients feeling uncertain regards their priorities:

> *"Figure out whether drinking more helps because it deadens the pain or actually not drinking is going to help because it won't make me so ill, that tends to be a bit of a judgement call"* (Kate, 35)

This uncertainty about whether a particular technique for managing symptoms does more harm than good in the long term affects patients' concerns about medication. Some patients are unsure whether the medication is causing side-effects, or whether those symptoms are part of the RA, whether it's due to them overdoing things, or whether they have had a bad day due to an external factor such as the weather:

> *"I was wondering sometimes if it's because of the tablets you are taking that makes you tired"* (Jane, 65)

> *"I do feel, when it's damp, I do feel it sort of, it does get a little bit worse I would definitely say that, um but it's hard to sort of work out because you are in Bristol and it rains quite a lot"* (Charlotte, 37)

The unpredictable nature of RA makes it difficult to isolate a cause to patients' symptoms as the disease may respond differently at different times:

> *"I mean I feel that sometimes I am tired, but then I do get active and do lots of, you know, things and, you know, I might be doing something every night, but then other times I might not be doing something every night and I don't think I necessarily notice that it gets any worse"* (Emma, 42)

Other patients are concerned about the long-term effects of medication, while for others there is an uncertainty about whether their body will get used to the medication and therefore lose its effectiveness. In contrast Sophie has concerns that the medication is working so well, it might be masking symptoms that should be warning her to take things more gently:

> *"He [doctor] said 'You 50 now' and I said 'Yeah', he said 'You could live 'til you 80 but tablets probably kill you first'"* (Jane, 65)

> *"It's like a lot of tablets isn't it? Once you get used to them they don't do you no good, but, so I'm hoping you know"* (Mary, 77)

> *"If I'm taking Diclofenac and it's making me not hurt, am I going to be damaging something by thinking it's not hurting when really it should be hurting and I should be not using it, you know?"* (Sophie, 51)

Patients try to make sense of how their disease might progress, they wonder about whether the disease will get any worse and what the long term damage to their joints will be. This is an unknown quantity to both patients and professionals and so patients report that all they can do is *'wait and see'* (Roger, 56). Some patients such as Linda see the positive side of this:

> *"When they do me feet I can probably get some flat sandals and stuff like that hopefully, unless something else crops up. The other hip goes or the other knee goes. That's the only trouble, you don't know where it's gonna go"* (Amelia, 67)

> *"You don't ever know what's round the corner with it really. It's just unpredictable but I mean it's no use worrying about it is it? It's just, I mean I'm not the bravest of people and um, I don't think I'd want to know what was round the corner anyway, do you know what I mean?"* (Linda, 52)

As discussed in Section 6.8.1.1, flares are unpredictable, coming with very little notice, there are no certainties with a flare and so *"it's always playing it by ear"* (Chloe, 42). However, a few patients do report getting an early warning of their flare developing, although this is shrouded in uncertainty. One patient explained how she experiences tiredness prior to a flare, although she was uncertain as to whether it is a flare developing or a cold coming on. Early warnings seem to be unusual and even if they are experienced, they seem to be only recognised with hindsight:

> *"[Before a Flare] I tend to get a bit tireder. Especially I might even be a bit tireder the day before sort of like some things, you know, like am I coming down with a cold, or am I? You know, that type of thing"* (Debbie, 44)

Another patient who experiences early warnings before her flares is Isabelle:

> *"Believe it or not I tend to feel really well before a flare-up, it's almost like euphoric"* (Isabelle, 45)

It is possible that the euphoric feeling is not necessarily an early warning sign of a flare, but rather a period of respite from the disease activity. In the face of this improvement, the patient may overdo things due to feeling so well, and therefore trigger a self-induced flare, leading to the perception of the calm before the storm:

> *"I realise the warning signs now is when I feel like that it's time to just 'Whoa' just not, it's always when you feel really good you wanna do more because you physically feel you can do more but then when you do that, it bites you in the backside"* (Isabelle, 45)

Whilst the flare is developing, patients experience a period of uncertainty as to whether they are experiencing a flare or not. Sophie made the distinction between symptoms from a flare (which she defines as the immune system being attacked), and from having overdone things (which she does not class as a flare). This reinforces the difficulties (see Chapter 2) in gaining consensus as to what a flare is and what causes it:

> *"It's not clear enough to actually determine for me whether it, I'm fighting something off, an infection, or I'm, or my body's fighting itself, basically. So it's hard to tell*" (Debbie, 44)

> *"Whether that's my immune system being attacked or a, I don't know, or whether I've done too much with that arm in the day or walked too far on the previous day, I don't know"* (Sophie, 51)

Patients are unsure as to what has caused the flare, how long it will last and even whether it definitely is a flare or not. They therefore try to make sense of what they are experiencing:

> *"It's a human thing isn't it, to try and connect it with something, like if you're sick you think 'Oh, that must have been some food that I ate'"* (Sophie, 51)

In trying to make sense of the cause or length of their flares there doesn't seem to be much consensus between patients, or much certainty in their explanations. Flares can be attributed to eating particular foods, to the weather, to stress or to overdoing things, which can include repetitive actions. However, there is often confusion surrounding these causes due to lack of consistency or, as Amelia mentions, because the rheumatologist has not validated the patient's opinion:

> *"I mean they say food don't give you flare-ups, I believe it do. It don't matter which doctor you speak to, they say it's a load of rubbish, there's research have found there's nothing, but if they, I don't think it's a load of rubbish"* (Amelia, 67)

> *"Cold damp weather seems to bring out all the aches and pains and you feel absolutely dreadful"* (Roger, 56)

> *"Stress can cause it, you know something that's worrying. I mean, when my son's marriage broke up that caused a flare-up"* (Jane, 65)

The following quote demonstrates how patients try to make sense of the cause of a flare, but however strong their conviction, they are still not certain:

> *"This time I am fairly convinced, this is possibly the clearest I've ever been, that I'm fairly convinced it's weather orientated"* (Emma, 35)

6.8.2.2 "It might go away": Avoiding seeking medical help

Although some patients will contact the medical team almost immediately for help with their RA flare, many more will try everything they can first. Due to the uncertainty about whether they are in a flare (Section 6.8.2.1), patients experience a period of wishful thinking and hope that the flare might go away on its own.

> *"I am just one of those that thinks it might go away, you know"* (Jane, 65)

Some patients have beliefs that cause them to avoid seeking medical help. These include the idea that the medical team would be unable to help them; that there is a limit on the number of steroid injections that they can have in a year and so they try to 'save' them up; or they feel like a fraud when making a downward comparison (Section 6.7.2.4) between themselves and other patients:

> *"I couldn't get out of bed, yeah I had the doctor then, not that she could do much because, just because I knew what it was all about you know"* (Mary, 77)
>
> *"They can give me a depo [Depomedrone injection] and I can have up to 4 but I really try not to, I only try and have them when I'm going on holiday um, which is about twice a year"* (Isabelle, 45)
>
> *"I am just conscious that, you know, you go to sit in a waiting room and there's loads of people with walking sticks and all sorts in all sorts of trouble so I just want to, I don't feel like I am that bad"* (Charlotte, 37)

There is a point at which some patients are aware that they need to seek help from the medical team, but continue to avoid help-seeking. This can be due to feeling as though the flare has been self-induced, not wishing to see other patients in clinic, or not wishing to take drugs:

> *"If I'd done something stupid or you know been dancing 'til 5am in the morning and wondering why my knees were hurting the next day, I wouldn't go in, I would feel embarrassed"* (Charlotte, 37)
>
> *"Not wanting to come in here as well, to be fair, 'cos whenever you come in, you look around and you just think, I'm a generation below, if not two. Everybody's sat in this room, you know, and it's just like, you just don't want to see it"* (Kate, 35)
>
> *"I wouldn't get on the phone straight away because I'm a bit of a, I don't really want to take drugs to be honest"* (Emma, 42)

In general, patients see seeking medical help as a last resort and they will wait until they are really desperate before contacting the medical team:

> *"I'm the type of person that I would do it [ask for help] as a last resort and I don't like feeling like I am wasting anyone's time"* (Charlotte, 37)
>
> *"Dr X [rheumatologist] knows I'll wait until I am sort of pretty desperate really"* (Isabelle, 45)

6.8.3 Theme 2: Summary

Fluctuating symptoms mean life with RA is unpredictable, which can cause patients to question how other people perceive them. The unpredictable nature of RA also leaves patients uncertain as to what is causing their symptoms and how long they will last, which is one of the reasons that patients will avoid help-seeking at this point. The impact of these fluctuating symptoms cause the delicate balance that patients maintain in daily life, to begin to tip towards RA being in the foreground of their lives (Fig 6.19). Theme 2 has been incorporated into the developing conceptual model of life with RA (Fig 6.20).

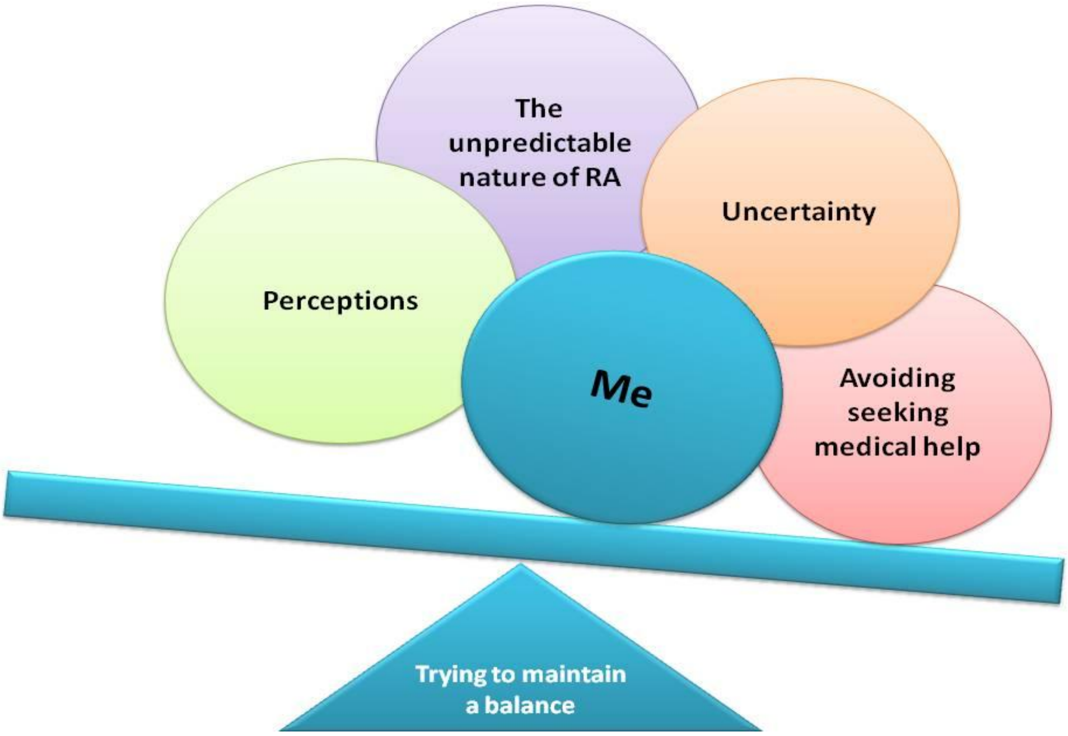


Figure 6.19: RA moving into the foreground

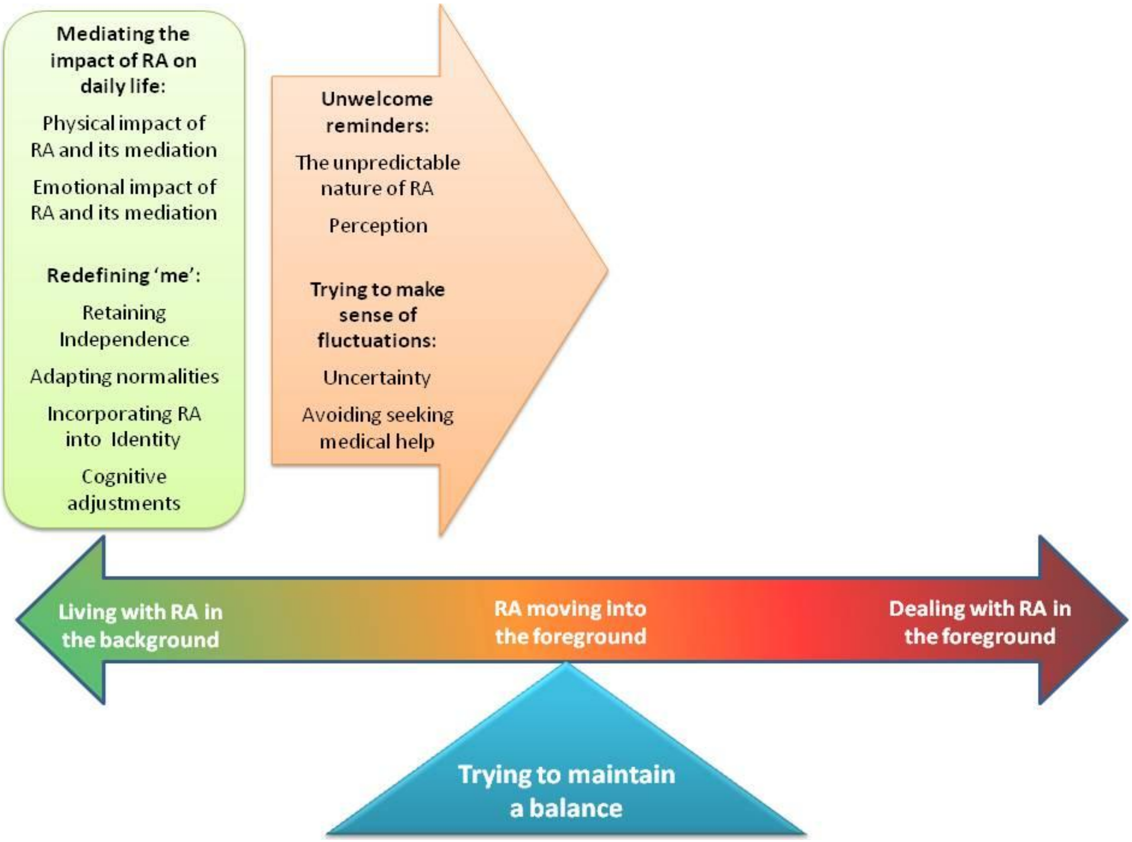


Figure 6.20: Developing conceptual model to explain life with RA

6.9 Theme 3: Dealing with RA in the foreground

When patients experience an RA flare, their RA can no longer be ignored or pushed into the background. Patients attempt to regain control of their RA and their lives, but once their self-management strategies can no longer contain their increasing symptoms, patients decide that they have no choice but to seek medical help. At this point, patients are experiencing their RA in the foreground as an unwelcome reality and have to deal with their wellness disappearing into the background.

6.9.1 Trying to regain control

When patients are in a flare, they can feel like they are losing control of their lives and will employ a number of strategies in an attempt to regain that control. Patients increase their self-management strategies to try and control the flare symptoms. Some patients withdraw socially to control the effect that their symptoms and emotions might have on others, whilst others withdraw in order to control the amount that they have to acknowledge the effect the flare is having on them. All patients involve luck when talking about their RA, which seems to be an attempt to manage the loss of control they experience.

6.9.1.1 "I just try anything": Crisis management of a flare

When in a flare patients are more likely to use crisis management techniques. This differs from patients' day-to-day management of their symptoms as they are no longer using preventative measures and have moved into damage control in an attempt to reduce their symptoms and the impact those are having on their lives. When the situation and their emotions become overwhelming, patients experience desperation and report being prepared to try anything:

> *"I mean I just try anything to, you know, try and defeat it really"* (Emma, 42)

In terms of trying anything, some patients resort to extreme measures in an attempt to control their symptoms, such as fasting:

> *"If I feel really bad, I do fast for a day. I'll drink [fluids] but I do fast and that does help"* (Isabelle, 45)

Patients use tried and tested techniques such as using hot and cold packs on their swollen or aching joints in an attempt to alleviate symptoms:

> *"If I got really achy joints I tend to use sort of like heat therapy on those and it just kind of relaxes you a bit more and I have also got gel packs that you can put in the freezer and then if they are really swollen I will use those"* (Charlotte, 37)

> *"I would actually sit down and see if I can either rest it or get some ice on it depending on you know, which joint it was and how easy that was to do"* (Debbie, 44)

Patients recognised the importance of resting and relaxing whilst they are in a flare. They also discussed the need to slow down and pace themselves and may therefore either leave a task unfinished or delegate to others:

> *"When I have had them [flares] I've always gone and sat down and tried to rest to see and very often I do feel a lot, feel a lot better after I've rested"* (Mary, 77)

> *"So I had to make sure that I had enough 'sick time' and that, that when I had a flare-up I could take it [sick-leave] rather than just overdoing it"* (Kate, 35)

Some patients like to keep themselves busy when they are in a flare in an attempt to distract themselves from their symptoms, or possibly in an attempt to deny to themselves that they are in a flare. However, this cannot be sustained and patients find themselves needing to rest and relax:

> *"That's what I found is when I'm, because you are on almost automatic pilot and you've got something else to think about but it's as soon as you relax it's like it's, you know 'Remember, remember me?' and it [RA] raises its ugly head"* (Isabelle, 45)

Patients also use medication to control their flare symptoms by increasing the frequency and amount of their analgesics:

> *“I get out of bed and walk around and I think ‘I’ll go and take Diclofenac, or whatever, an aspirin’, whatever I can take”* (Sophie, 51)

> *“I’ve got Tramadol which is another strong pain killer that I take sometimes and um it gets rid of the pain”* (Chloe, 42)

6.9.1.2 “You just go into hibernation mode”: Social Withdrawal

When they are in a flare, some patients retreat into themselves, choosing to close themselves off from friends and family. This seems to be due to patients either trying to protect themselves from the reality of their flare or to protect other people from their frustrations. Isabelle says *“You just go into ‘hibernation mode’”*. She explained the reasons for not wishing to see anyone as not wanting them to see her struggling, she also does not seem to want any sympathy. This could be part of keeping up a public identity as a ‘well person’ and letting herself be seen in a flare would challenge her sense of self:

> *“I can’t stand being around my friends thinking that I’m, not that they would but think that I’m like ‘Ooh’ or moaning or when I get up it’s like hobbling and they go ‘Are you all right?’ and they are so good and I am like ‘Ooh just’, so I just retreat I do, I don’t want to see anybody”* (Isabelle, 45)

Kate also discussed why she avoids seeing other people when she’s in a flare. She explains how in previous flares, her denial that RA was affecting her, could not continue if other people saw her. There is a need for other people to validate the way we feel about ourselves, if they are unable to do this our beliefs about ourselves are challenged. In order to protect herself from this, Kate chose to keep friends and family away as a defence mechanism:

> *“I don’t think it’s necessarily the denial, it’s the fact that I couldn’t carry on my denial when I was in those flare-ups, because if people had come round they would actually see how bad it was and I couldn’t process that at that point”* (Kate, 35)

As well as not wanting to see anyone, patients can also experience apathy and a loss of motivation to do any of the activities they would normally do. Patients often don’t want to leave the house and many need their bed either due to tiredness or low mood:

> *“I just feel that I’m not interested in anything really”* (Mary, 77)

> *“I don’t know really but I mean when you’re feeling, when you are in a flare-up then you do, it’s just everything is an effort”* (Jane, 65)

> *"I just feel so tired I just want to sit down and go asleep, you know it feels like you want to hibernate as well, you know"* (Emma, 42)

Kate described how she would stay in bed during her flares due to tiredness and pain, but this became a problem as her low mood caused her to remain in bed:

> *"I would then just get stuck in bed and I think the cycle would just feed into itself that on the days that I possibly was feeling a bit better physically, mentally I wouldn't be so then that would bring it all down. Because not getting out of bed and not moving makes everything hurt more because you're not using anything"* (Kate, 35)

6.9.1.3 "Just keeping my fingers crossed": Attributing fluctuations to luck

The unpredictable and fluctuating nature of RA means that despite expert self-management strategies, patients are not always able to control their own outcomes. Thus in order to manage the release of this control, patients attribute the fluctuating nature of RA to luck. Every patient mentioned luck in some form:

> *"I've been* ***lucky [he touches wood]*** *that it's usually a couple of days, two or three days it's settled and I just come up to a stable point again"* (James, 47)
>
> *"So a normal day is pretty normal life really, I'm quite* ***lucky****, you know, I've only got it mildly"* (Roger, 56)

Patients use lucky actions such as keeping their fingers crossed and touching wood when they talk about future outcomes with their RA. This may be an attempt to maintain an illusion of control over their outcomes:

> *"They upped the Methotrexate, which I do have to say,* ***touch wood****, um, has actually begun to settle things down"* (Linda, 56)
>
> *"I'm just keeping my* ***fingers crossed****"* (Mary, 77)

6.9.2 Losing control

When patients are in a flare, their RA is firmly in the foreground, and they seem to be fighting a losing battle; they are severely restricted, start to lose control of their symptoms and eventually have to ask for help.

6.9.2.1 "It's like a 'Game Over'": Unmanageable Impact

When they are in a flare, patients experience further restrictions on their day-to-day abilities. This level of impact of RA is more than patients have learnt to adapt and adjust to in their daily lives. Thus even patients who have accepted a new normality in their lives are unable to tolerate this new level of restriction. Whilst patients experience a slower pace of daily life due to RA limiting their mobility, in a flare this restriction is dramatically increased with some patients reporting that they lose their mobility completely and with some even finding themselves confined to their bed:

> *"It isn't the pain really it's the immobility, what it makes you feel is, it's just on top of the restriction you've got, it's like a 'Game Over'"* (Isabelle, 45)

> *"At times I could not get out of bed"* (Mary, 77)

Other patients find that a flare means having to deal with restrictions on practical tasks, which can cause frustration or embarrassment. The flare draws attention to patients, meaning they are unable to preserve their public identity as a 'normal' person:

> *"If I've got a flare and my hands hurt, I find that I drop things easily um and it's difficult to open things and sort of like anything that's fiddly"* (Debbie, 44)

> *"Awkward things and things more embarrassing than um, than uncomfortable or painful just in a social way, in a shop when you're like picking stuff up and you drop it. Like, I'm trying to get my credit card out and she's giving me a receipt and then she says 'Have you got a Nectar card?' and I throw it at her"* (Sophie, 51)

Patients describe feelings of frustration and irritation due to the extreme limitations that an RA flare can impose on them. This can be made worse by the flare symptoms such as pain and fatigue causing patients to have a shorter temper than usual:

> *"You just put up with it, it's very very frustrating, extremely frustrating"* (James, 47)

> *"I do tend to get irritable when I'm tired and in pain"* (Debbie, 44)

Chloe described how she was unable to pick up her new born baby, showing the impact a flare can have on even her most valued role. She went on to describe how the intense effort needed to overcome these restrictions is reserved for truly extreme circumstances. This demonstrates how an RA flare can cause patients to lose control of their situation and they may be unable to fulfil even the most important of their responsibilities, through no choice of their own:

> *"I'd just had my second child and she was only six weeks old and I couldn't even lift her out of the cot. I just could not lift her up, I just couldn't physically, I was so bad with a flare-up that I just couldn't move. I couldn't even get out the chair, I couldn't walk, I couldn't do anything"* (Chloe, 42)

> *"The little one's just about to go out the door and you're thinking 'who left the stair gate open?' and he's gone and you're thinking 'oh I can't run after him', I just, you know. I do if I have to, I will have to put my head on and say 'Right, you have got*

> *to do it', it might hurt, but you've got to get to him before he gets to the gate and he tries to go out into the road"* (Chloe, 42)

When they are in a flare, patients often feel that they have no choice but to ask for help from friends or family. Independence is important to patients with RA (Section 6.7.2.1) and having to ask for help may not only cause them to feel dependent on others, but may also challenge their self-identity as capable, independent people:

> *"I have to [ask for help] when, I really have to when it's a flare-up because I can't pick things up, I can't even dress myself um, so then I do have to ask for help"* (Liz, 59)

The feeling of having no control over their flare is also expressed by patients in terms of when it comes, or how long it lasts. Patients attempt to regain control over their symptoms through their normal self-management and coping strategies (section 6.7.1). However, when these strategies are no longer sufficient, patients become even more aware of their loss of control as they are unable to help themselves:

> *"Don't know what to do about it [flare]. Don't know how to alleviate it"* (Sophie, 51)

> *"There are times when, it just seems whatever you do, um it doesn't prevent the flare going any further"* (Linda, 52)

During an RA flare, patients not only experience restrictions on their lives, but they can also lose both their control and independence. Due to this, many patients report experiencing low mood during a flare, which some patients say is harder to deal with than the physical RA symptoms:

> *"It's not so much the pain because you can take tablets for that but, you know, you can't take tablets for what's in your brain [negative thoughts], I don't think"* (Isabelle, 45)

> *"It affects you in other ways, you know I think it does get you down and things like that, so it's more than just the wrist pain"* (Emma, 42)

6.9.2.2 "I was in agony and I couldn't do anything": Seeking medical help

Patients will eventually seek help from the medical team for their flare. An important tipping point for this seems to be when a patient feels they are no longer in control. This can include a combination of: being unable to cope with the pain; being unable to control their symptoms; or the RA affecting their quality of life.

> *"I went into one [flare] and I was in agony and I couldn't do anything and um, I contacted them"* (Chloe, 42)

> *"It depends whether it's really affecting what I'm able to do"* (Debbie, 44)

Another tipping point for seeking help is when patients feel that the flare is severe enough and it's more than normal symptom fluctuation or when it has lasted longer than expected:

> *"I think you get a feeling as to what is just general activity and what is the medicine starting not to work and it's getting a bit more out of control"* (Debbie, 44)

> *"If I do have a flare, yeah I would contact them if it's prolonged"* (Charlotte, 37)

When patients' flare symptoms and the impact of these on their lives become noticeable, friends and family will often recognise that the patient needs to seek help. Being prompted by friends or family is the tipping point for many patients when they are seeking help. This may be because patients are able to maintain their stoic, self-sufficient identity by being able to claim that they were pushed into seeking help:

> *"I do leave it quite a long time. My daughter and my husband always say 'You ought to go and see somebody' and I think, 'Oh, just give it a little bit longer, it'll probably be ok', but usually when it gets as bad as that I do need to um, see somebody"* (Linda, 52)

Previous experiences also encourage patients to seek help. This can include knowing how bad the disease can get and not wishing to let it get that bad again, knowing that the medical team can help and knowing that there is easy access to the medical team.

> *"I'm having a flare-up now, and it's ok because I'm still managing, and that's why I won't ever let it get to the point that I can't get out of bed again"* (Kate, 35)

> *"At which point then you have got to come in and have injections and I wouldn't want anybody to have fluid drained off your knees because it's one of the most painful things I have ever had done in my life"* (James, 47)

> *"I think that's a huge, a massive thing for me is the accessibility to them [medical team]"* (Isabelle, 45)

Although patients will eventually seek help from the medical team when they are unable to manage their symptoms themselves, this is seen as a last resort for some patients, which they will only use when they feel desperate and unable to cope alone:

> *"I know last time I did everything I could to sort of prevent it, but it's always the last port of call coming to see the rheumatologist. I go through absolutely everything at home before I come and see them"* (Linda, 52)

6.9.3 Theme 3: Summary

The unmanageable impact of RA that patients experience when they are in a flare, and the social withdrawal that this can lead to, tip the balance of life to RA being firmly in the foreground. Patients try to balance the release of control over their symptoms with crisis management and attributing the flare to luck. In daily life, patients will try to maintain a balance between asking for help and remaining independent, but when they are sure they are in a flare, patients will restore the balance to their lives by seeking medical help (Fig 6.21). This behaviour completes the model that describes daily life with RA; the Fluctuating Balances Model (Fig 6.22).

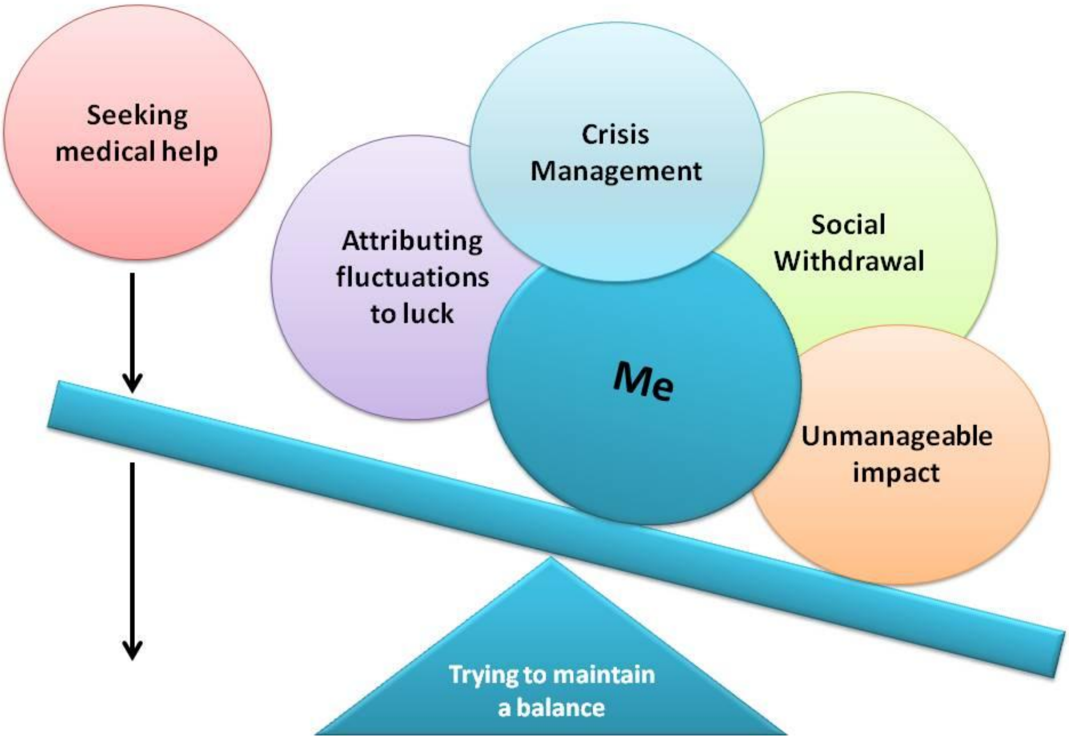


Figure 6.21: Dealing with RA in the foreground

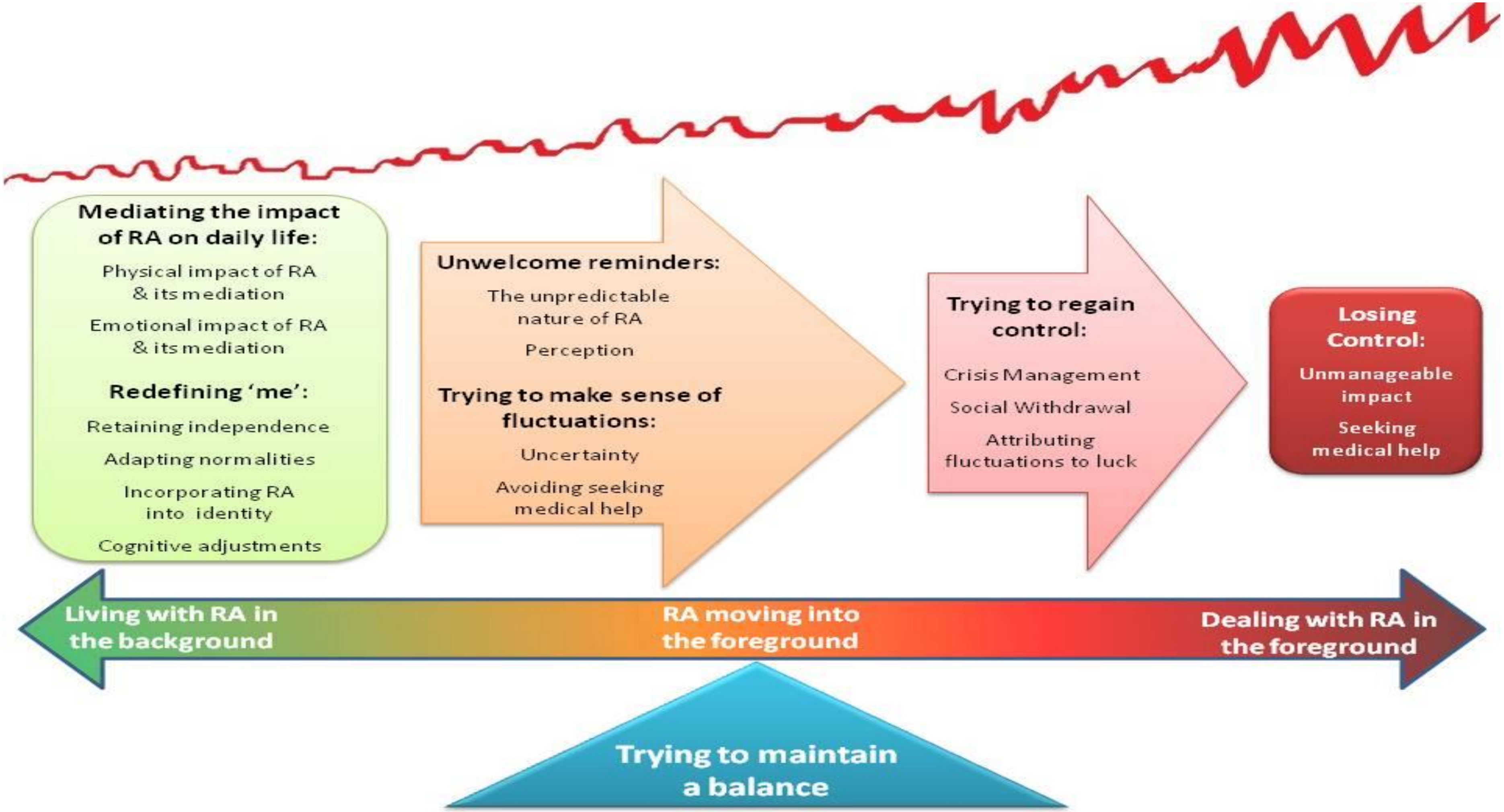


Figure 6.22: Fluctuating Balances Model

6.10 Discussion

This study has enabled the development of the Fluctuating Balances Model of living with RA (Fig 6.22), which centres around the need for patients to balance their fluctuating condition, in order to retain a sense of normality, identity, independence and control in their lives. The model depicts life with RA as the illness shifting between the background and foreground of patients' lives depending on the impact on their lives, their self-management techniques and the severity of their symptoms. The red line at the top of the model represents the fluctuating symptoms experienced by patients, whilst the triangle at the bottom represents patients' ability to balance every aspect of their lives.

In daily life, patients were aware of the need to balance self-management strategies, as neither extreme of rest nor exercise is beneficial. Patients also try to maintain a healthy balance between asking for help and remaining independent. However, this balance can be tipped when patients avoid seeking medical help for an RA flare. Thus the impact of RA is mediated by the patient's ability to maintain a delicate balance in their lives.

The current study identified that life with RA is characterised by a fluctuation of the condition between the background and foreground of patients' lives. This supports the Shifting Perspectives Model (Patterson, 2001), which depicted the experience of chronic illness as continually changing perspectives about the disease to enable people to make sense of their experience. The illness-in-the-foreground perspective is characterised by a focus on the sickness, suffering, loss and burden of the disease, whereas the wellness-in-the-foreground perspective includes attempts to reconcile self-identity and the identity shaped by the disease. However, the data from this study suggest that people with RA differ from this model in that the fluctuating nature of RA means that patients' symptoms as well as their attitudes drive this shift in perspective.

The individual graphs indicate that patients are never symptom free in daily life and following a flare they return to a baseline level of symptoms rather than an absence of symptoms. Patients mediate the impact that physical and emotional symptoms have on their lives through a variety of self-management strategies and coping techniques. A finding of particular note is that patients develop a strategy of micromanaging their symptoms, putting small adjustments in place throughout their day to reduce the potential future impact of their symptoms. Through self-managing their physical symptoms, patients are also able to reduce the impact that their RA has on their independence. However, when patients' symptoms begin to move into the foreground, they step up their self-management techniques in an attempt to reduce the chance of them turning into a flare. Once patients' symptoms have developed into a flare, they step their self-management up yet again from preventative management to crisis management, or damage control, but when their flare becomes unmanageable the final step is to seek medical help. Thus patients appear to employ a stepped approach to managing their RA, depending on their symptoms. In this way, patients move between the various steps on a 'Mediation Ladder' (Figure 6.23), which has been developed from these study findings.

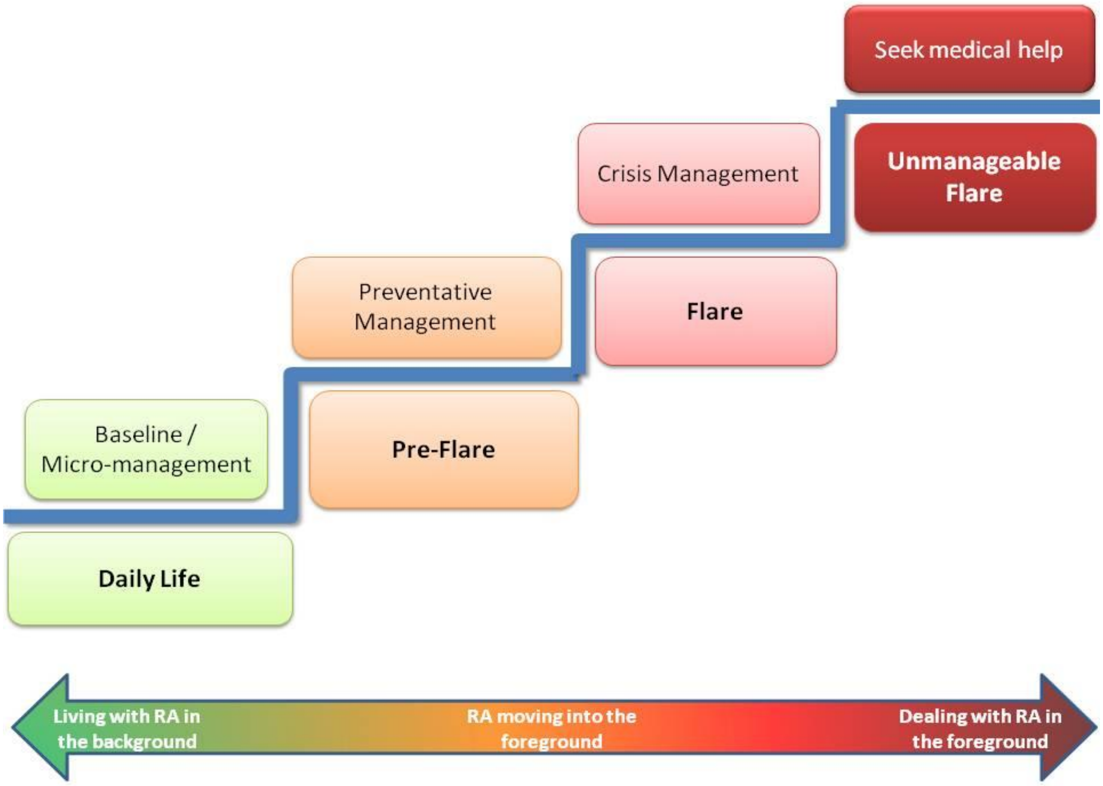


Figure 6.23: Mediation Ladder: Increasing steps of self-management

Further, the findings in this study suggest that the components comprising impact of RA on daily life are severity of symptoms, self-management/coping strategies and symptom importance. This supports the proposed Impact Triad (Sanderson *et al,* 2011b) in which symptom severity, coping and importance interact to create a sense of impact. Thus whilst patients' symptom severity impacts on their lives, this can be mediated by their self-management and coping strategies. However, when patients are unable to participate in valued activities, which are important to them in terms of maintaining their sense of normality and identity, this increases the impact of RA on their lives.

The importance of retaining normality was raised, which supports previous findings (Sanderson *et al,* 2011a) in which six different typologies of normality were highlighted. The current study identified some but not all of the normality typologies in the patients' stories. Patients seemed to reconcile their personal identity with their identity as an RA patient, either by acknowledging and defining the two identities as separate or by incorporating RA into their identity. Patients that reconcile their identities fit into Sanderson's 'resetting normality' typology (normal life includes my illness). However, patients trying to keep the two identities separate seem to be trying to reconcile 'disrupted normality' (overwhelming symptoms, normal life impossible) with 'struggling normality' (presenting a normal life whatever the cost). Sanderson's 'fluctuating normality' (life isn't normal when I'm in a flare) is supported by the Fluctuating Balances Model (Fig 6.22) in which patients struggle to maintain a balance of control, independence, identity and normality in their lives when they are in flare.

Patients use cognitive adjustments in order to mediate the impact that RA has on their identity and normality. This includes adjusting their expectations of themselves and their abilities and making social comparisons. Social comparison is a coping strategy that is particularly useful when a person is unable to change their situation (Wills, 1981; 1987). Downward comparisons, which the majority of the patients in this study use, involve comparing oneself to a less advantaged person, often another less fortunate, patient (DeVillis *et al,* 1990). One patient in the study displayed upward comparison, but this is not a positive coping strategy as patients are comparing abilities with someone who does not have the same restrictions (Wills, 1981; 1987).

All patients in this study referred to the involvement of luck on their RA outcomes. Locus of Control Theory (Rotter, 1966) proposed that individuals with a strong internal locus of control believe that they control their own outcomes through their own abilities and efforts, whilst people with a strong external locus of control believe that outcomes are due to external causes, such as luck. This may indicate that patients with RA apply cognitions of an external locus of control to their RA. However, there are two dimensions to the external locus of control; chance and powerful others, and people who subscribe to one belief, do not necessarily hold the other. Thus a multidimensional health locus of control typology was proposed (Wallston and Wallston, 1982) in which patients could score high or low on each of the three dimensions of internal health locus of control (IHLC), powerful others health locus of control (PHLC) and chance health locus of control (CHLC), meaning 6 different locus of control typologies are possible. Four typologies include high CHLC, three of which seem unlikely to apply to the study population. These are 'pure chance' (IHLC and PHLC scored low); 'double health external' (IHLC scored low, PHLC scored high) and ‘Yea-sayer’ (IHLC and PHLC both scored high, indicating participant scored yes to every question). The yea-sayer typology does not apply in this case as patients were not asked to complete a locus of control questionnaire. Further, the other two CHLC options do not apply to the RA patients in this study as they all discussed self-management techniques and controlling their RA themselves. Thus RA patients seem to fall into typology VI (high IHLC and CHLC, low PHLC), which has been left unnamed due to rarely being relevant. This typology states that the individual has learnt that there are certain aspects of their health that they can control and other aspects that are totally unpredictable (Wallston and Wallston, 1982). This describes the experience of living with RA and thus chance is used as a tool to enable the individual to manage relinquishing control when they no longer have a choice.

The current study found that unpredictability and uncertainty are central to patients’ experiences of RA, which supports previous qualitative research (Stenström, Bergman and Dahlgren, 1993; Hewlett *et al,* 2005a). Patients try to make sense of their symptoms in terms of cause, how long they will last, and whether they can be defined as a flare. This supports the Self-Regulatory Model (Leventhal, Nerenz and Steele, 1984; Leventhal and Diefenbach, 1991), which proposed that patients’ illness representations are based around distinct components which, in turn, determine coping. Thus according to the revised Self-Regulatory Model (Leventhal *et al,* 1997) patients will base their coping strategies on their own beliefs about the identity, cause, time-line and consequences and curability/controllability of their illness. This model is supported by a previous study in which patients managed their RA flare according to its perceived cause (Kett *et al*, 2010) and by the current study, which found that patients use different types of management depending on how they define their symptoms (identity) (Fig 6.23). Further patients will seek medical help for an RA flare based on how long they perceive their symptoms will last (time-line), worrying about long-term joint damage (consequences) and whether they feel able to self-manage their symptoms (controllability).

Previous research (Hewlett *et al,* 2012) suggested that patients will wait to seek help for their RA flare, but as their self-management increases and their uncertainty as to whether they are in a flare decreases, they will seek medical help. Although the current study supports these findings, it also highlights an additional stage that patients go through before seeking help. When patients decide they are in a flare, they will continue to delay help-seeking, whilst employing crisis management techniques, and withdrawing socially. The majority of patients report leaving help-seeking until their self-management strategies no longer control their symptoms.

6.10.1 Strengths and Limitations

This study included 15 participants and therefore could be criticised for not being representative. However, this study sampled for a range of age, disease duration and disability, and recruited from 6 different consultants across 2 NHS trusts, thereby accessing a range of different disease experiences and care pathways. Although the aim was to sample for a range of gender, only 3 male patients were recruited (20%), which is slightly less than the percentage of men in the general RA population (30%: Crowson *et al*, 2011). The research did not ask patients about the impact of RA on intimacy and this imformation was not freely offered by patients, thus this issue has been overlooked in this study.

This study involved one to one interviews with RA patients rather than focus groups, which enabled patients' individual experiences to be understood without the risk of conformity bias (Asch, 1958). The researcher introduced herself as a researcher, separating herself from the clinical team, which allowed patients to speak openly about their experiences. A proportion of the data were independently analysed by two researchers and a patient partner to ensure rigour and reduce the chance of researcher bias (Cohen and Crabtree, 2008).

6.11 Summary

Patients' experiences of RA shift between RA being in the background and wellness being in the foreground and vice versa. In daily life with RA, even on current treatment regimes, patients experience a complex mixture of symptoms, emotions and beliefs, which they mediate through self-management, coping strategies and cognitive adjustments in order for the patient to maintain a balance in their life. Patients experience life with RA as full of uncertainty and unpredictability due to the fluctuating nature of the disease. When patients are uncertain as to whether they are in a flare, they will avoid help-seeking, whilst hoping for the best. However, even when patients realise they are in a flare, they will often continue to put off seeking help, whilst engaging in crisis management and withdrawing socially. It is only when they can no longer control their symptoms, as a last resort, that patients will accept that they need to seek help from the medical team.

It can be very difficult to articulate abstract illness concepts when patients have incorporated illness into everyday life and their sense of personal identity. Given that metaphors have been used in healthcare before, the issue of metaphors to communicate the experience of living with RA was explored in depth, and will be presented in Chapter 7.

Chapter 7: Study 1b: Eliciting meanings from words (Metaphor analysis)

At the end of the Study 1 interviews patients were asked 'If your RA were an animal what would it be?' The current chapter describes the rationale for asking this and presents the results for this question along with other metaphors used by participants.

7.1 Literature Review: Metaphors

The term metaphor has two different uses, both originating with Aristotle in 4c BC. A metaphor is a literary figure of speech that uses an image, story or tangible thing to represent a less tangible or intangible concept or quality. The term metaphor can also be used for any rhetorical figures of speech that achieve their effects through association, comparison or resemblance. Thus antithesis, hyperbole, metonymy and simile would all be considered types of metaphor (McArthur, 1992). In this study, the latter meaning will be used, employing the broader definition of the term metaphor.

7.1.1 Metaphors and the construction of reality

It is suggested that a person's conceptual system, which governs their thoughts and structures their perception of the world, is largely metaphorical (Lakoff and Johnson, 1980). Since communication is based on the same conceptual system used in thinking and acting, language provides evidence for what that conceptual system is. One example of a concept being a metaphor and that concept structuring everyday activity is the concept *argument* and the metaphor *argument is war*. This metaphor is used in everyday language for example *'that claim is indefensible'* or *'my argument was shot down'*. Argument is not only talked about in terms of *war*, but arguments can also be *won* or *lost* and the person being argued with is considered an *opponent* (Lakoff and Johnson, 1980). Thus metaphors may create social realities, and can be a guide for future actions that fit the metaphor reinforcing its power and making the experience coherent. Lakoff and Johnson (1980) provide an example of this in the form of President Carter's declaration that the energy crisis was *"the moral equivalent of war".* A more modern example of this is President Bush declaring *'"War on Terror",* a metaphor that generated an *'enemy'*, and a *'threat to national security'*. The acceptance of the metaphor forces one to focus only on those aspects of the experience that it highlights. Thus the metaphor begins to define its own reality (Lakoff and Johnson, 1980), in the example of President Bush this reality included the concept that terror could be personified as an enemy. *"War on Terror"* was not merely a way of viewing reality, but led to policy change and political action.

Metaphors therefore are conceptual in nature and can play a central role in the construction of social and political reality. Exploring the way in which RA patients use metaphors may provide powerful insight into how they perceive their RA flares, daily life with RA and its daily management, how they experience the world within their wider life with RA and their socially constructed reality, including how they communicate this to health care professionals.

7.1.2 Metaphors and the unconscious

A child needs to understand what is going on within his conscious self so that he can cope with what is going on in his unconscious. This can be achieved through daydreaming, fantasizing and story-telling (Bettelheim, 2010). It is therefore possible that adults may also be able to uncover their unconscious concerns through the use of metaphors. In fact, it is suggested that metaphor functions unconsciously as the interpreter of emotional memory (Modell, 2005).

Metaphors have been part of psychotherapy since Freud (1900) referred to symbols in dreams and noted the metaphoric equivalent meanings that children may attribute to the sensations that arise from bodily openings, such as the mouth (Freud, 1933). This ability of the infant to transfer perceptual experience from one sensory modality to another, indicates that abstract representations of perception are formed and acted upon from the earliest days of life (Stern, 1985). Metaphorical process is an inborn readiness, independent of language and thus metaphors may lead directly to what is unconscious (Wurmser, 2011). If metaphors are the *"language of the soul [and] the discourse of the inner world"* (Wurmser, 2011: 123) then looking at the metaphors used by RA patients has the potential to uncover a deeper, more meaningful understanding of patients' individual experiences and perceptions of living with RA.

7.1.3 Metaphors in the cancer discourse

Metaphors are used in health and illness, and an example of this is the cancer discourse, where patients and physicians use metaphors to describe the experience of cancer. In addition, cancer itself is used as a metaphor in daily life.

For both physicians and patients, war is a dominant metaphor for cancer (Reisfield and Wilson, 2004). It is talked of in terms of a fight, which can be won or lost. This war metaphor can be seen throughout the cancer literature including cancer charities and the media such as *"Join the biggest **fight** against cancer"* (Cancer Research UK, 2012); *"**Stamp out** male cancer"* (The Institute of Cancer

Research, 2012); and a story about an 11 year old boy describes him as *“**brave**”* during his *“four-year **battle**”* and reports that he *“**lost** his **fight** against brain cancer*” (Daily Mail *online,* 2011). However, the use of war as a metaphor has its limitations. Firstly, it is inherently masculine, power-based, paternalistic and violent (Mitchell, Ferguson-Pare and Richards, 2003) and for some patients conflict and fighting are not the preferred ways of coping with illness (Bowker, 1996; Hawkins, 1999). Further, there is the suggestion that winning the war (defeating the cancer) is only a matter of fighting hard enough (Hawkins, 1999), and thus one is personally responsible for one’s death by failing to fight.

Cancer is also used as a metaphor in daily life. Cancer is associated with slow, agonising and disfiguring death (Fye, 1996), and regarded with dread as ‘loathsome’, thus it is logical that cancer has emerged as an evocative metaphor (Clow, 2001). Sontag (1979) provides the example of the Nazis likening the Jewish community to a *‘cancerous lesion’.* She argues against the use of illness as metaphor, claiming that metaphors warp illness experiences by heightening the social and psychological anguish experienced by a cancer diagnosis, because metaphors insinuate that the disease is disgraceful and shameful. Sontag wished to eliminate metaphors from the cancer discourse, believing that removing the symbolic associations would enable patients to see cancer as a biological phenomenon rather than a social or moral one. However, neither shame nor silence have been found to be features of the experience of cancer (Clow, 2001).

7.1.4 Metaphors in healthcare

In a health care setting, metaphors can assist both the physician and the patient. For the physician, metaphors can be time-efficient tools for helping patients understand biologic processes (Arroliga *et al,* 2002). For patients, metaphors can increase empowerment (Harpham, 2010) and improve comprehension of health explanations and retention of illness explanation (Whaley, 2000). Metaphors can also be used by family members to help make sense of their loved one’s experience (Mastergeorge, 1999). The shared language of metaphors can therefore aid the therapeutic relationship by providing a shared understanding of clinical reality (Reisfield and Wilson, 2004).

Metaphors have helped health researchers gain insight into a range of understandings and experiences including patients’ and caregivers’ experiences of palliative care (Richardson and Grose, 2009) and men’s experiences of fibromyalgia (Paulson *et al,* 2001). Caregivers’ of dementia patients use the metaphor of a journey to describe their situation (Golden, Whaley and Stone, 2011). They describe themselves as *"drifting* along" and trying to *"find a course"*, whilst they describe the person with dementia as *"going downhill"*. These caregivers also describe life using other metaphors such as a machine (*"system is beginning to shut down"*) or harm (they're *"falling apart"; "beating [themselves] up"* and *"banging [their heads] against a wall"*).

Children with asthma (Peterson and Sterling, 2009) describe their condition as *"a boa constrictor squeezing the life out of you"*; a *"troll [that] sleeps all day in the dark…until I wake him up by the activities I do, [then] he climbs up the ladder to tell the air it has to pay to come into my chest"* or *"[a] guardian angel [that] helps me to be good. However, if I mess up, I will get into trouble. My guardian angel does not protect me and can even take the air away"*. These metaphors provide a powerful insight into the way in which these children perceive the cause and experience of asthma.

Metaphors are currently used in both family therapy and cognitive behavioural therapy (CBT). Family therapy uses a technique called the animal attribution story telling technique (AASTT), which is used with children with behavioural disorders. AASTT involves asking children to assign animals to each of their family members and tell a story that includes all the animals. This technique is fun, non-threatening and encourages participation. It provides the clinician with material that begins to explain the relationships within the family and provides a 'safe' way of discussing this (Arad, 2004). Metaphors have been used in CBT as a tool to assist with information processing or to provide a model for the change that a patient is trying to undertake (Otto, 2000).

The use of metaphors has therefore been shown to be used in many health conditions as a way of grasping emotionally difficult concepts and of finding meaning in intangible thoughts and ideas (Lakoff and Johnson, 1980). However, the use of metaphors to understand patients' experiences of RA has not yet been explored.

7.1.5 Animals as metaphors

Although it can be argued that metaphors are culturally specific and may therefore not be universally comprehended, it is precisely this culturally specific nature that makes them valuable in emphasising the degree of emotion in a situation (Richardson and Grose, 2009). Thus in prompting RA patients to describe their experience in terms of metaphors it would be necessary to choose a prompt that could be universally relevant.

The metaphor *"humans are naked apes"* (Morris, 2005) indicates that what humans share with animals is more important than what they don't share (Goatly, 2006). Animals as symbols exist in all cultures, they are in sayings such as *'the early bird gets the worm'* and in myths, fairy tales and fables. By relating to an image of an animal, one relates to its specific characteristics and symbolic meaning. This allows for a range of experiences, emotions and perceptions to be acknowledged in a single animal image. The externalisation of thoughts and feelings through animal imagery can facilitate dialogue, inspire change and increase the sense of personal power (Arad, 2004).

7.2 Methods

In an attempt to capture either the most important aspects of living with RA or those concepts that patients may find difficult to express in a general conversation, patients in Study 1 were asked a question that allowed them to think in a more abstract way about their RA. The two questions considered for this were *"if your RA were an animal, what animal would it be?"* and *"if your RA were a person, what relationship would you have with them?" as* both questions include universally relevant metaphors. Following discussions with PRPs it was decided that the animal question would be the most appropriate. The PRPs felt that trying to compare their RA to a person would be uncomfortable for them as the question felt too personal to answer. The animal question was therefore chosen as it was a concept that could be universally understood, whilst allowing patients to think abstractly about their RA in a way that was removed from their personal relationships.

Interviews were conducted with 15 RA patients as described in Chapter 5.4. At the end of each interview, participants were asked *"If your rheumatoid arthritis were an animal, what animal would it be?"* The interviewer acknowledged that the question was unusual and that it was alright for them to think for a little about their answer. The interviewer was also ready with examples to give in case patients struggled with the concept, but this was not needed.

7.2.1 Analysis

The use of animals as a metaphor caused the researcher to be sensitive to other unprompted metaphors used during the interviews, as patients explained their experiences of daily life. There is no agreement on the best method for identifying metaphors and the boundary between literal and metaphorical can be ambiguous (Gibbs and Franks, 2002). For the purpose of this study, as mentioned in Section 7.1, metaphors included any rhetorical figures of speech that achieve their effects through association, comparison or resemblance. Deductive Thematic Analysis

(Braun and Clarke, 2006) was used to search the data for both prompted and unprompted metaphors.

7.3 Results

This was the same participant sample as described in Chapter 6.4.1 and Table 6.1. Patients used a range of metaphors to describe living with RA without being prompted. The animal question was asked at the end of the interview, therefore patients had not already been primed to think in abstract ways. Three main themes were identified, underpinned by a sense of identity:

7.3.1 Theme 1: Zombies and dragons: Experiencing rheumatoid arthritis

Patients used metaphors to describe the wide range of physical symptoms of RA that they experience on a day to day basis. One patient said *"I walked around like a Zombie for half the day"* (Liz, 59), describing her experience of fatigue. This indicates that fatigue can make patients feel as though they are not themselves; they may be unable to think straight or function as normal. Fatigue is a concept that patients found particularly difficult to describe as it is not a visual symptom and cannot truly be understood by people who have never experienced it themselves. Metaphors used to describe this symptom involve large objects creating a barrier for patients:

> *"I can wake up sometimes and feel like I've got a lead weight on me...It's just like walking into a brick wall"* (Roger, 56)

The swelling in their hands and feet were compared to *"sausages"* (Mary, 77) and *"great big plates of swollen meat"* (Chloe, 42). Using everyday objects makes it easy to visualise the symptoms being described as it puts it into a context that a lay-person can understand. Their descriptions make their hands and feet sound unattractive, the comparison to pieces of meat may indicate that patients see the swollen parts of their body as objects rather than a part of them.

RA pain was likened to common types of pain that other people will have experienced and will understand. The use of a familiar sensation enables friends and family to have a better understanding of patients' symptoms:

> *"I was constantly in toothache in my knee"* (Chloe, 42)

One patient described the pain she has experienced as *"a lot of knives going into you"* (Mary, 77). Although unlikely that friends and family have experienced this, it is still a concept that can be recognised as painful and traumatic. It conjures up a powerful mental image, providing insight into this patient's experience, which may not have been achieved without the analogy. Patients described pain and discomfort in their feet, again using sensations that most people will be able to relate to. Whilst these are less disturbing than the knife metaphor, they provide a clear picture of the discomfort:

> *"If you walk on gravel in bare feet, it's like that all the time even when you've got shoes on"* (Linda, 52)

> *"Like walking on pebbles on a pebbly beach, that's how it feels, that you can do it and it's not gonna do you any harm but it's not comfortable"* (Sophie, 51)

The periodic flares of RA characterised by hot, swollen joints, were likened to a fiery dragon or other examples of heat:

> *"A Dragon comes to mind because it's breathing my heat...that nasty fire that keeps attacking"* (Liz, 59)

> *"a burning knotted flame"* (Liz, 59)

> *"as though you're boiling, like it's [blood] bubbling"* (Amelia, 67)

Living with RA can also be an emotional experience, patients reported feelings of anger and frustration (Chapter 6.7.1.2). One patient described this as:

> *"Being in a pressure cooker, it bubbles and bubbles and bubbles and then it just goes"* (Chloe, 42)

Patients with RA have many symptoms that are difficult to describe, particularly those that are invisible such as pain and fatigue. Using metaphors, patients are able to paint vivid pictures of concepts that would not otherwise be understood. As a tool for communication, they enable patients to explain to friends and family how they experience life as a person with RA.

7.3.2 Theme 2: Snakes and tigers: Unpredictable and uncertain

Patients chose animals that attack from out of the blue, that are sneaky and that stalk their prey. One patient compares his RA to a snake, highlighting its unpredictable nature:

> *"Snakes, because they are horrible and sinister and sneaky and you know you don't know when they are going to come and attack you"* (James, 47)

Another described a Tiger: an animal that is potentially dangerous due to its speed and sharp teeth. However this patient describes her RA in terms of a tiger because of its unpredictability, rather than its ferocity:

> *"I just envision a tiger creeping up through the undergrowth and you don't know when it's going to hit and then it does"* (Charlotte, 37)

Another patient chose a Hyena, again highlighting the unpredictable aspect of this animal's nature:

> *"Snarly and laughing at you one minute and then snapping at your heels the next"* (Isabelle, 45)

When asked to think of an animal that represents their RA, many patients were drawn to vicious animals:

> *"I'm thinking about the deadly 60 now"* (James, 47)

This quote refers to a children's television programme in which a wildlife presenter attempts to find 60 of the world's deadliest animals (CBBC, 2012). These animals represent not only the aggressive nature of RA, but also its unpredictable nature. In contrast, other patients chose tamer animals to describe the unpredictable and uncertain nature of living with RA. One patient compared his RA to a domestic cat, indicating the lack of control that patients can feel due to unpredictability:

> *"It [Cat] can be friendly when it wants to be but when it doesn't want to be, you know, you can talk to the tail, as they say"* (James, 47)

Another patient used an unprompted metaphor to describe how her symptoms change daily:

> *"You're sort of up and down like the Weston donkeys"* (Jane, 65)

This refers to the donkeys on Weston-Super-Mare beach that walk up and down the beach giving rides to children, it is an expression used by people local to the Bristol area. It suggests fluctuation, another aspect of the unpredictable nature of RA.

One patient provided such a powerful description when asked *"If your RA were an animal, what would it be?"* that his story is highlighted in full. Michael was angry with the way his RA was handled at the point of diagnosis, and although he had been diagnosed for 10 years it does not appear that he has been able to accept his RA. He did not like the idea of comparing his RA to an animal, he came up with his own solution and provided his reasons for this:

> *"Well, comparing it to say to someone in the animal kingdom, which are natural creatures in their natural environment, doing their natural things, I am not sure that's a good analogy to be honest with you. Um, you know because an animal doesn't attack you for no reason...because you are normally threatening it you know. If it's people that would be different"* (Michael, 48)

Michael was then invited to answer the question any way he would like to. His response provides a vivid metaphor for the helplessness patients can feel due to the unpredictable and aggressive nature of RA:

> *"Someone like Hannibal Lecter [notorious fictional psychopath and cannibal: Harris 1981; 1988]... Um, it's going to attack you at your lowest point and um where it hurts and um with malice in their heart really. Whereas animals, you see, they don't do that they will just react instinctively and you know if it is attacking you, you have got a chance of defending yourself and shooting it and removing it as a threat you know. But if you have got someone that's cleverer than you are and it's on your case it's stalking you um, no you are not looking at an animal, which is just doing its own thing so no I'm sorry I am not sure I can think of any animal even the most venomous you know they are in their own element. As I say for me it's Hannibal Lector as a person...there is only one creature that does things out of malice and nastiness and that's your fellow human being really, and that is what your arthritis is really, it's attacking, it's turning your defences against you, your vulnerable points, your weak points in a way that hurts and you know catches you at your most awkward and most vulnerable and that's what your psychiatrist turned serial killer does isn't it really that's their raison d'être really that's their theme"* (Michael, 48)

Michael used metaphors throughout his interview to make sense of his situation. One modern metaphor he used highlights the uncertainty surrounding RA as he attempted to make sense of the cause of RA and went on to hypothesise a cure:

> *"It's almost like a computer virus...it's got an endless loop that won't stop. So the question then is how do you solve that on a computer? Well you can, well you pull the plug out and put it back in. So maybe with that analogy...the logical sort of follow-on from that maybe is um you know whether the body would redo that, you know, reboot its immune system, would it default back to the original factory setting?"* (Michael, 48)

Patients often chose unpleasant metaphors to describe their RA, concentrating on the unpredictability and aggression. Patients were also uncertain about how bad their symptoms will be from day to day, about the cause of their symptoms and many patients spoke of the hope for a cure.

7.3.3 Theme 3: My ugly sister: Living together

Many patients develop the skills to adapt to and cope with their RA (Chapter 6.7) and are therefore used to living with their condition, although it remains an unwelcome presence in their lives:

> *"It's almost like an ugly sister [laughs] it's like almost, not the devil, but it lives with me"* (Isabelle, 45)

> *"An angry cat [laughs], it's sort of like a, it's my companion, but it can be quite vicious sometimes"* (Debbie, 44)

Patients also used metaphors to describe the restrictions they experience due to their RA, this includes having to adjust to a slower pace of life and dealing with the barriers that RA can create:

> *"It [elephant] can't really run as fast as it used to, it can't pick anything up, it could with its trunk but not with its hands, um, yeah an elephant"* (Sophie, 51)

> *"You're there trying to fight your way through it and it [spider] keeps putting its web up to keep tracking you and stop you doing things that you want to do"* (James, 47)

There is also an awareness of the background reality that RA is gradually causing further joint damage, coupled with the fear of disease progression:

> *"I thought of a rat...it's just gnawing away quietly*" (Linda, 52)

Patients used less aggressive metaphors to explain what it is like to live with RA in general, as opposed to metaphors that specifically encompassed their symptoms or RA flares. Despite the softer metaphors, patients still discussed living with their RA in terms of a battle. A pathetic fallacy (McArthur, 1992) is similar to personification but more abstract, referring to the inclination to attribute human qualities to nature. The term pathetic refers to 'pathos' or 'empathy', the capability of feeling and is therefore not intended as a derogatory term. Thus by describing RA as something/someone capable of winning, these patients employed the 'pathetic fallacy' that RA has the human capacity of wanting to beat them:

> *"I have to feel really really, that it's beaten me to [have to] go to bed"* (Linda, 52)

> *"Then obviously when it's a flare-up it feels like it's won"* (Isabelle, 45)

Although patients learn to adapt to their RA and to self-manage their symptoms on a daily basis, it is possible that patients never truly accept their RA. Through the metaphors in this theme patients indicate that whilst RA is part of their lives, it is an unwelcome inconvenience.

7.3.4 Underpinning Theme: My yellow brick road: Identity

Retaining identity is important to patients; some tackle this by incorporating RA into their identity, whilst others are determined to keep their pre-RA identity in spite of their RA. One patient, Kate, explained that she feels other people have negative perceptions of her as an RA patient (Chapter 6.8.1.2). Kate went on to highlight this issue when she was asked to describe an animal:

> *"It's [Sloth] big, it's cumbersome, it looks horrible, it looks like it can't do anything, but it actually is still able to get up and down a tree... even though it might look quite bad, on a good day you can actually be completely normal and you are completely normal ...but they can still climb up trees, and there's nothing in nature that says they should be able to climb up trees, because they're great big hairy mammals, but they can"* (Kate, 35)

The metaphor of the sloth shows the need for patients to defy the negative perceptions that others may have of them. It is of note that Kate slipped between talking about the sloth and herself in the above quote, indicating how personal the metaphor is to her. It is important to Kate that despite having RA, she is able to retain her identity of being a strong, self-sufficient woman.

As discussed in Section 7.3.2 patients often chose aggressive, unpleasant animals as metaphors for their RA. However, many patients mentioned softer options for the animals. It is possible that the fluffier choice of animal is because these patients have incorporated their RA into their identity. These patients may find it difficult to think of themselves and their RA as truly separate, and thus not wish to associate themselves with an ugly or unpleasant animal:

> *"I suppose you could equally say a shark but no something furry would be better [Tiger], nice and furry at least it's a little bit furry and cuter"* (Charlotte, 37)

> *"I think anyone would say that they'd rather be a sloth than a snail, less likely to get squashed under-foot"* (Emma, 42)

Many patients also felt it was important to note that they were only able to give their own account of living with RA and that patients all experience very different journeys:

> *"This is the path I took, this is my yellow brick road"* (James, 47)

7.4 Discussion

The secondary analysis of these data indicates that patients use metaphors in a descriptive way, to improve their explanations of their symptoms to others. Patients used these descriptive metaphors throughout the interviews without any prompting, which indicates that this is a technique that they use with their friends or family. One of the descriptive metaphors used by patients is that their fingers are like sausages. This is a comparison that is also made by professionals in relation to psoriatic arthritis, with "*sausage fingers"* being an accepted term used in the diagnostic literature (Mease and Goffe, 2005; Taylor *et al,* 2006) and in patient information leaflets (Arthritis Research UK, 2011c). It is possible that patients recognise this term from hearing professionals use it, although it is also plausible that patients have come up with the term themselves due to the appearance of their fingers when swollen. In slang, ‘sausage fingers’ is a derogatory term to describe a person with fat fingers and it is therefore also possible that this is the root of patients’ use of the term.

A further explanation is that patients are using pieces of meat to describe parts of their body as this may allow them to think of their body parts as objects that they are able to dissociate themselves from. This idea resonates with the psychic defence mechanism of ‘splitting’ (Klein, 1952), which is the separation of one item into two, such that they can be handled separately. When a person holds two thoughts in their mind that are contradictory or uncomfortable, the person will cognitively separate them, not thinking of the separate thoughts at the same time. This is a process of 'psychic economy' whereby a complex situation is simplified by separation rather than resolution. This can be in the form of visual appearance, concepts or ideas, commonly split into ‘good’ and ‘bad’. In this way people can split ‘whole objects’ (a whole person) into ‘part objects’ (part of a person), which can be ‘good’ or ‘bad’. The ‘good part objects’ can then be retained, loved and admired whilst the ‘bad part object’ is externalised and attacked or repressed. This allows people to like themselves, while still recognising some unlikeable qualities. Thus patients may be unconsciously separating the ‘part objects’ of their body that they consider ‘bad’ (due to visible RA e.g. sausage fingers) from their ‘self’.

Patients also used a battle or war metaphor when discussing their RA, which can be compared to the use of this metaphor in the cancer discourse (Hawkins, 1999) and may indicate that patients attempt to counter-act the powerlessness they feel due to their RA with a power-based metaphor. Whilst the media use the battle metaphor in reference to cancer, the same cannot be found in the public literature for RA. However, similar terms have been found in the media in relation to the common cold (NHS Choices, 2010; Daily Mail, 2010). As the common cold does not have a long-term impact on people’s lives, it is possible that the battle metaphor now exists in society as a metaphor for illness in general, which may have removed some of the power that these fighting terms once carried.

The machine metaphor that was used by RA patients has been seen in both the cancer and dementia literature (Gibbs and Franks, 2002; Golden, Whaley and Stone, 2011). One patient compared his RA to a *“computer virus”* and hopes it will *“default back to factory settings”*. It is possible that through using a metaphor of a machine, patients or care-givers are able to dissociate themselves from the body or mind, thus making it easier to cope with an altered body or mind. The concept of dissociation was also mentioned in relation to patients describing their bodies as pieces of meat. It is possible that patients use metaphors as a way of explaining their disease, whilst still being able to emotionally distance themselves.

Very few studies include comparisons of health conditions to animals. In a previous qualitative study one young patient compares his asthma to a boa-constrictor (Peterson and Sterling, 2009). This enables comparisons to be drawn with the current study as one patient used a snake as a metaphor for his RA. However, the reasons that the snakes were chosen for the two conditions differ; in asthma the snake metaphor represents the crushing, restricting feeling of being unable to breathe; whereas in RA the snake metaphor represents the sneaky, unpredictable nature of the disease. This demonstrates that the same animal can be used to typify two different concepts and therefore the reason that patients are using particular metaphors should be listened to and assumptions should not be made. One similarity between the asthma metaphor of the boa constrictor and the RA metaphor of the snake is that both types of attack result in the patient losing control. The feeling of losing control is exemplified by a number of the animal metaphors chosen by RA patients in terms of not being able to control or predict when a flare will come (e.g. tiger), loss of control over everyday symptoms (e.g. domestic cat) and loss of control over the pace of life (e.g. elephant).

When patients were asked to describe their RA in terms of an animal, some found it a strange or abstract concept and asked the researcher why she was asking them, whilst other patients immediately took to the question and gave an instant answer. Those patients who thought the question slightly strange were satisfied with the answer that the question was there to add some light relief to the end of the interviews and that it may uncover issues that they had not previously thought of. All participants were able to give an answer to the question without any difficulty, in fact many enjoyed this task, reporting that it allowed them to think about their RA in a different way. Some patients even expressed intentions to ask friends who have RA the same question.

The majority of patients seemed to choose animals that reflected the overall tone of the interview and the concepts that were emerging as most salient to them. The most pertinent of these was Kate, who focussed in her interview on how other people have negative perceptions of her due to her RA. Kate wanted to show that she is still a strong young woman and thus used the metaphor of the sloth as it is able to do more than its appearance suggests. Other examples include; Michael, who was angry about his RA and the lack of control he felt and compared his RA to Hannibal Lecter; and James who was unhappy at having had to give up playing Rugby due to his RA and described his RA as a spider's web putting up obstacles to stop him doing what he wants to. It is possible that these issues are only what was most important to patients at the time of the interview rather than in general about their RA. However, the use of metaphors to illustrate the most important aspects of RA, even if only at that moment, would enable clinicians to gain more insight into the issues that matter most to RA patients. The large use of metaphors to highlight the unpredictable nature of RA indicates that this is an aspect of RA that is highly salient to patients.

7.4.1 Strengths and limitations

Secondary analysis can be criticised on epistemological grounds (Mauthner, Parry and Milburn, 1998; Blommaert, 2001) suggesting that only through a personal involvement in data collection and the reflexive relationship between the researcher and the researched, can the researcher interpret the interviews and recommending that secondary analysis is limited to 'methodological exploration'. However, this secondary analysis was done shortly after the initial analysis. The researcher conducted the interviews herself and had audio versions of the interviews as well as the transcripts in order to give the patients as much of a voice in the secondary analysis as in the first.

Whilst metaphors have been used in a number of other health conditions to explore the patient experience, the use of metaphors in RA is still a novel concept. Patients in this study were asked to describe their RA in terms of an animal at the end of the interviews, and therefore patients were not primed to think in terms of metaphors for the duration of the interview. This demonstrates that the metaphors used by patients prior to the animal question were all naturally occurring. Further, patients were asked to expand on their reasons for choosing these animals, so that no assumptions could be made as to the reasons patients chose a particular animal.

7.5 Summary

Patients used a range of metaphors to explain their experiences of living with RA, which seems to be a method of communication familiar to them. Patients use aggressive, unpleasant metaphors to describe fluctuating symptoms or flares, but gentler metaphors to describe daily living. The use of metaphors to explain life with RA is underpinned by patients' sense of identity. Further, when asked to summarise their RA under one metaphor, patients will pick the aspect of their RA that is most important to them, thus providing a valuable insight into their experience.

Chapters 6 and 7 have presented the patients' experiences of RA as a balancing act between living with it in the background, seeing it creeping back into the picture, and then dealing with flare in the foreground, vividly encapsulated by the use of metaphors. The variation in these experiences and decisions on seeking help will now be explored for clusters or patterns, using Q-Methodology on data from these 15 patients, presented to a fresh cohort of patients.

Chapter 8: Study 2: Elucidating clusters of experience (Q-Methodology)

Chapters 6 and 7 highlight that life with RA comprises a diverse range of experiences, which patients can find difficult to express. The current chapter therefore presents the results for the Q-methodology study (Study 2), which aims to obtain consensus of these diverse experiences, using statements generated in Study 1.

8.1 Objectives for Study 2

1. To obtain consensus on the experience of living with RA from day-to-day
2. To obtain consensus on patients' decision-making surrounding help-seeking behaviours when in a flare

8.2 Summary of Study 2 methods

Q-methodology is the scientific study of subjectivity and aims to explore the subjective dimension of any issue towards which different points of view can be expressed (Brown, 1996). First, the range of opinions, or concourse (Brown, 1993) on both daily life with RA and help-seeking for RA flares needed to be sampled. This was done through interviews with 15 RA patients (Study 1, Chapter 6) and a literature review. The statements taken from this wide concourse were refined through discussions with a PRP and put onto cards. The statements were divided into two Q-sorts, one for daily life and one for flare help-seeking. Prior to the Q-sorts patients were asked to complete a questionnaire (Appendix C) comprising demographic questions and the HAQ (Fries *et al,* 1980). Then, each patient sorted (ranked) all of the Q-statements across a normal distribution grid into the order that they agreed with them (daily life; +5 to -5 and flare help-seeking +4 to -4). Patients were invited to complete comments booklets about why they decided to sort the statements in this way and any other thoughts and feelings they had about individual statements (Appendices O1 and O2). Patients were particularly encouraged to comment on the three top and three bottom sorted statements. Q-analysis was used to analyse these data using PCQ for Windows software (Stricklin and Almeida, 2010). For the full study methods see Chapter 5.5.

8.3 Deciding on the Q-set

The statements (Q-set) used in the daily life Q-sort were gathered from Study 1 (Chapter 6), which produced 68 statements (Appendix P1). 21 of these statements were removed due to being related to a long-term rather than daily consequence of RA (e.g. "I have had to give up something important to me because of my RA") and 12 statements were removed due to being duplicates or polar opposites of the remaining statements. Four individual statements were added based on patients' experience of their symptoms in the qualitative interviews (statements D35 to D38). This produced 39 daily life statements.

The flare help-seeking Q-set were gathered from Study 1, which produced 50 flare statements (Appendix P2), 30 of which were removed due to being related to the experience of flare rather than specifically to help-seeking (e.g. "A flare affects your entire body"). Further, a literature review produced three flare statements that had not already been raised in the interviews, and were included to ensure a full range of beliefs (Table 8.1), producing 23 flare help-seeking Q-statements.

Table 8.1: Sources of statements taken from the literature review

Statement	Source
F13: I am reluctant to seek medical help as I don't get on well with my rheumatology team	Kett *et al* (2010)
F18: I am reluctant to seek medical help as I don't want to waste my own time	Sheppard *et al* (2008)
F23: I wait until I have more than one flare symptom before seeking medical help	Hewlett *et al* (2012)

8.4 Factor extraction

In Q-methodology it is necessary for the researcher to decide how many factors to extract for interpretation, and there are a range of criteria that can be used to decide this. For the purpose of this study Watts and Stenner's (2012) method was used, which combines the Kaiser-Guttman criteria (Guttman, 1954; Kaiser, 1960; 1970), Brown's (1980) 'magic number seven' (Chapter 5.5.9.2) and the ability of the researcher to override these criterion when experience, logic and the data dictate otherwise.

As discussed previously (Chapter 5.5.9.1) the percentage variance accounts for a certain percent of the common variance present in the study. For example, daily life Factor A accounts for 11% of the study variance and therefore accounts for 11% of everything that the Q-sorts have in common (Watts and Stenner, 2012). An Eigenvalue (EV) is indicative of a factor's statistical strength and explanatory power. Low factor EVs, specifically those less than 1.00 are generally disregarded in Q due to the factor accounting for less study variance than a single Q-sort (Watts and Stenner, 2005a). This is known as the Kaiser-Guttman criteria (Guttman, 1954;

Kaiser, 1960; 1970). Thus high EVs and variances are considered worthy of attention (Kline, 1994).

The statements were analysed using PCQ for Windows software (Stricklin and Almeida, 2010). The factors were extracted and rotated using the orthogonal varimax procedure. The researcher began with the daily life Q-study, by extracting five factors, based on Watts and Stenner's (2012) rule of thumb of starting with one factor for every 6-8 participants, a variation of Brown's (1980) 'magic number seven'. This five-factor solution (Appendix Q1) explained 45% of the study variance and the EVs on all five factors exceeded 1.00, which complied with the Kaiser-Guttman criteria (Guttman, 1954; Kaiser, 1960; 1970). However, three of the factors had no statements that distinguished them from the other factors and thus this solution was rejected due to not providing sufficiently diverse experiences of living with RA to justify a five factor solution. Four factors were then extracted (Appendix Q2), which explained 40% of the study variance and the EVs on all four factors again complied with the Kaiser-Guttman criteria. However, with the four-factor solution, two of the Q-sorts were confounded (i.e. significantly loading on more than one of the presented factors) and one factor contained no statements that distinguished it from the other factors and thus this solution was rejected and a three-factor solution was extracted. The three-factor solution (Appendix Q3) explained 33% of the study variance and the EVs of all factors complied with the Kaiser-Guttman criteria. Further, none of the Q-sorts were confounded and all factors contained distinguishing statements. In order to ensure that the three-factor solution was the most appropriate the researcher extracted a two-factor solution (Appendix Q4). This explained 26% of the study variance, the EVs of both factors far exceeded 1.00 and both factors contained distinguishing statements. However, with a two-factor solution 12 of the individual Q-sorts did not significantly load onto either of the factors, in comparison to only 7 that did not significantly load onto the three-factor solution. Thus the three-factor solution was chosen as presenting sufficiently diverse experiences of living with RA, which included the greatest number of individual Q-sorts. Table 8.2 summarises the findings from the various factor extractions.

Table 8.2: Results from factor extraction of the Daily Life Q-sorts

Factor Solution	Factor	Eigenvalue	Study variance	Confounded sorts	Non-significant sorts	Distinguishing statements
5-factor	Factor A	2.97	10			3
	Factor B	3.39	11			0
	Factor C	2.59	9			0
	Factor D	1.98	7			0
	Factor E	2.47	8			2
	Total	**13.40**	**45**	**1**	**6**	
4-factor	Factor A	3.01	10			3
	Factor B	3.25	11			3
	Factor C	2.58	9			2
	Factor D	3.05	10			0
	Total	**11.89**	**40**	**2**	**5**	
3-factor	Factor A	3.29	11			7
	Factor B	3.97	13			4
	Factor C	2.67	9			5
	Total	**9.92**	**33**	**0**	**7**	
2-factor	Factor A	3.83	13			11
	Factor B	3.97	13			11
	Total	**7.80**	**26**	**0**	**12**	

Then, based on the findings from the daily life Q-sort, the researcher extracted a four-factor solution for the flare help-seeking Q-sort. This solution (Appendix R1) explained 63% of the study variance and the EVs on all four factors exceeded 1.00, which complied with the Kaiser-Guttman criteria, but three of the factors had no statements that distinguished them from the other factors and thus this solution was rejected due to not providing sufficiently diverse explanations of seeking help for RA flares to require a four-factor solution. Three factors were then extracted (Appendix R2), which explained 57% of the study variance and the EVs on all three factors again exceeded 1.00. However, there were no statements that distinguished Factor A from the other two factors and thus a two-factor solution was extracted. The two-factor solution (Appendix R3) explained 51% of the study variance and the EVs far exceeded 1.00. Further, none of the Q-sorts were confounded and all factors contained distinguishing statements. Thus the two-factor solution was chosen as presenting sufficiently diverse explanations for help-seeking, which included the greatest number of individual Q-sorts. Table 8.3 summarises the findings from the various factor extractions.

Table 8.3: Results from factor extraction of the Flare Help-Seeking Q-sorts

Factor Solution	Factor	Eigenvalue	Study variance	Confounded sorts	Non-significant sorts	Distinguishing statements
4-factor	Factor A	9.29	32			0
	Factor B	4.01	14			1
	Factor C	2.95	10			0
	Factor D	1.93	7			0
	Total	**18.19**	**63**	**1**	**8**	
3-factor	Factor A	8.83	30			0
	Factor B	3.30	11			3
	Factor C	4.63	16			1
	Total	**16.77**	**57**	**2**	**9**	
2-factor	Factor A	10.18	35			7
	Factor B	4.58	16			7
	Total	**14.76**	**51**	**0**	**7**	

8.5 Presentation of results for individual Q-studies

The daily life and flare help-seeking Q-sort results will be presented in sections 8.6 and 8.7 respectively. The participant demographics for the two Q-sorts differs slightly, therefore each section begins with a table of participant characteristics. Q-methodology is a quasi-quantitative method (Stenner and Stainton-Rogers, 2004), thus the quantitative analyses are presented first. This will include the Q-study description, including the level of significance and the study variation. First a table displaying the statements included in the Q-sort and the ranking assigned to each statement by each factor will be presented, followed by the statements that achieved consensus for all of the factors produced.

Each factor will then be presented individually, describing the percentage variance and the EV. An exemplifying Q-sort will be displayed for each factor that is produced by averaging the participant Q-sorts that loaded significantly on that factor alone. This will be contextualised by a table displaying the demographic information of each participant loading on to the given factor. In addition, a narrative or qualitative account will also be presented for each factor. The qualitative explanation will treat these configurations as Gestalt entities (Watts and Stenner, 2005b), they are constructed by considering the relative rankings and overall configuration or distribution of the statements in each factor exemplifying Q-sort. The rankings (daily life: +5 most agree to -5 most disagree; flare help-seeking +4 most agree to -4 most disagree), which inform the construction of the account at each point are included in the text: (D6: +4) for example, indicates that statement D6 was ranked in the +4 position and that this ranking is relevant to the account being offered. This account is further enriched by the comments of participants whose individual Q-sorts have loaded significantly on the relevant factor.

8.6 Results: Q-methodology: “Living with RA day-by-day means….”

8.6.1 Daily life Q-sort: Participants

72 people with RA were invited to participate from UHBT, NBT and ASPH and 32 (44%) agreed to take part. Data from two participants were excluded: a 73 year old man was unable to understand the task and a 68 year old man asked his wife to make the decisions regarding the sorting of the cards. The majority of the participants (n=30) were female (73%) and participants’ ages ranged from 30 to 79 years (Table 8.4). The majority were not currently working, these were either retired or unemployed. There was a range of treatment regimes including one patient taking no medication. There was also a range of disease duration (1-40 years), self-reported disease activity (using the DAS global) and disability (HAQ score). Six participants reported being in a flare at the time of the study.

Table 8.4: Characteristics of participants in the Daily Life Q-study

		Frequency	Percentage
Gender	Female	22	73.3
	Male	8	26.7
Age (years)	Under 40	4	13.3
	40 – 49	4	13.3
	50 – 59	8	26.7
	60 – 69	11	36.7
	70+	3	10.0
Employment	Employed	12	40.0
	Unemployed	9	30.0
	Retired	9	30.0
Medication	Anti-TNF	13	43.3
	DMARD	12	40.0
	Steroids	4	13.3
	No Medication	1	3.3
Disease Duration	> 2yrs < 5 yrs	8	26.7
	> 5 yrs	3	10.0
	> 10 yrs	9	30.0
	> 20 yrs	9	30.0
	Unknown	1	3.3
Pt Global	0 ≤ 4 (mild)	19	63.4
	> 4 ≤ 7	10	33.3
	> 7 ≤ 10 (severe)	1	3.3
Disability Score	0 ≤ 1	13	43.3
	>1 ≤ 2	8	26.7
	> 2 ≤ 3	9	30.0

8.6.2 Daily life Q-sort: Quantitative results

Three factors were extracted and rotated using the orthogonal varimax procedure, which explained 33% of the variance and accounted for 23 of the 30 participants. Factor A comprised all positive loadings (A+), Factor B had both positive and negative loadings (B+, B-) and Factor C comprised only negative loadings (C-). None of the sorts were confounded (i.e. significantly loading on more than one of the presented factors). A participant loading of 0.41 reached significance at $p < .01$ in this study.

Table 8.5 shows the ranking assigned to each of the 39 statements in each of the factor-exemplifying Q-sorts (Section 8.5). Reading the table first by column shows the comparative ranking of statements that characterise a particular factor, for example Factor A+ scored statement **D3: "Struggling to do certain things"** at +1 and statement **D13: "Not letting my RA get me down"** at +3. Then, reading the table by row shows the comparative ranking of a particular statement across factors, for example statement **D1: "I sometimes have to cancel plans due to my RA"** was scored at 0 by Factor A+, Factor B+ and Factor B-, and was scored at -1 by Factor C-. The highest and lowest rankings assigned to each of the statements are indicated, for example statement **D16: "Using alternative medicines/therapies to manage my RA symptoms"** received the highest score from Factor B+ (+3) and the lowest score from Factor A+ (-4).

Table 8.5: By-Factor rankings of statements given in the Daily Life Q-Sort

	Factor Scores			
Statement	**Factor A+**	**Factor B+**	**Factor B-**	**Factor C-**
D1: I sometimes have to cancel plans due to my RA	**0**	**0**	**0**	**-1**
D2: Being more spontaneous with life	-1	**+3**	**-3**	+1
D3: Struggling to do certain things	+1	**-2**	**+2**	0
D4: Choosing my clothes according to how easy they will be to put on and take off	+1	**+2**	**-2**	**-4**
D5: I am unable to predict how bad my symptoms will be each day	-1	**-3**	**+3**	+1
D6: Taking longer to get things done than I think it should	**+2**	**-2**	**+2**	**-2**
D7: Finding different ways of doing the things I want to	**+4**	**0**	**0**	+2
D8: Giving myself permission to leave a task half finished	**+1**	0	0	**-1**
D9: Using tools or devices to aid me in daily tasks	**+3**	+1	-1	**-5**
D10: Finding a balance between asking for help and remaining independent	**+2**	**-1**	+1	0
D11: Doing what I want to do regardless of the consequences	**-3**	**+2**	-2	-1
D12: Choosing to prioritise pleasurable activities against chores	0	**+2**	**-2**	**-2**
D13: Not letting my RA get me down	+3	+3	**-3**	**+4**
D14: Relying on support from my family/friends/others	**0**	**0**	**0**	**-3**
D15: Talking to other people with RA who are similar to me helps	**-1**	**+1**	**-1**	**-1**
D16: Using alternative medicines/therapies to manage my RA symptoms	**-4**	**+3**	-3	0
D17: Distracting myself from my symptoms	**+2**	**+1**	**-1**	0
D18: Trying not to eat certain foods	**-4**	**+4**	**-4**	-3
D19: I am cautious of gaining weight and putting extra stress on my joints	**-1**	0	0	**+3**
D20: Exercising as much as I can	+1	**+5**	**-5**	+2

Table 8.5 continued overleaf

D21: Making small adjustments to my day or activities constantly because of my RA	+5	-1	+1	0
D22: Taking my medication exactly as prescribed	**+3**	+1	**-1**	+2
D23: Planning rest time into my week	**+2**	+1	-1	**-3**
D24: Feeling lucky in comparison to other people	-1	+2	**-2**	**+5**
D25: I have periods of being completely symptom free	-3	**+4**	**-4**	-2
D26: Dealing with the severity of my symptoms going up and down	**+1**	**0**	**0**	**+1**
D27: Getting frustrated due to my RA	-2	**-3**	**+3**	+2
D28: Feeling guilty about holding others back due to my RA	-2	-1	**+1**	**-4**
D29: Feeling that my body has let me down	**-2**	-1	**+1**	**0**
D30: Trying to forget that I have RA	0	+1	**-1**	**+3**
D31: Worrying because of my RA	-2	**-3**	**+3**	0
D32: Repetitive tasks make my RA symptoms worse	0	**-2**	**+2**	-1
D33: Being determined not to allow my RA to interfere with my responsibilities	**+4**	**0**	**0**	**+4**

All statements include the prefix “Living with Rheumatoid Arthritis day-by-day means...” Text highlighted in blue indicates the highest ranking assigned to each statement. Text highlighted in yellow indicates the lowest ranking.

8.6.3 Daily life Q-sort: Qualitative results: Consensus items

There are three consensus items in the daily life Q-study, meaning that all three factors sorted the statements into a similar place on the grid (Table 8.6).

Table 8.6: Consensus items from Daily Life Q-sort

Statement	**Factor Score**			
	A+	**B+**	**B-**	**C-**
D1: I sometimes have to cancel plans due to my RA	0	0	0	-1
D8: Giving myself permission to leave a task half finished	+1	0	0	-1
D15: Talking to other people with RA who are similar to me helps	-1	+1	-1	-1

The consensus items are all sorted close to the neutral zero score placement on the grid, which could be due to participants considering them as less important. However, the comments booklets provide more information regarding the positioning of the statements.

The comments indicate that the statement **"I sometimes have to cancel plans due to my RA"** may be placed in a neutral position as patients are reluctant to cancel their plans, but know that this is something that they *should* do. They therefore do not feel that they are able to place this statement more negatively:

> *"I don't but probably should, as I often end up in more pain the next day"* (P15)

The statement **"I give myself permission to leave a task half-finished"** received one comment, which suggests it has been sorted neutrally as patients don't feel that they need to give themselves permission:

> *"I don't give myself permission, I do it anyway"* (P12)

The comments associated with the statement **"Talking to people with RA who are similar to me helps"** suggest their lack of experience of talking to other patients may have forced a neutral stance. Others have had both positive and negative experiences of interacting with other patients and still sorted the statements neutrally:

> *"I haven't really had chance, I think it would help though"* (P12)

> *"I've never done it, RA is not a big enough part of my life for me to go to a support group"* (P20)

> *"I've got a friend with RA who's younger than me and working. It really helps to talk to her and hear something positive. I went to a support group at the hospital when I was newly diagnosed. It was full of people moaning and made me more depressed, so I never went back"* (P21)

Each factor will now be explored in depth, contextualising the quantitative data with demographic and qualitative data.

8.6.4 Factor A+: Taking active control: "Just a fact of life"

Factor A+ has seven significantly loading participants, it has an eigenvalue of 3.29 and it explains 11% of the Q-study variance. The exemplifying Q-sort for this factor (Table 8.7) shows how each statement (1-39) loads across negative to positive opinion (-5 to +5). Summaries of the statements, as well as the statement numbers have been included to aid interpretation. For example, the average score for patients loading onto Factor A for statement D21: **"Making small adjustments to my day or activities constantly because of my RA"** is **+5**, therefore these patients strongly agree with this statement.

Table 8.7: Exemplifying Q-sort for Daily Life Factor A: Taking active control: “Just a fact of life”

Negative					Neutral					Positive
-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
34: Being angry because of my RA	16: Using alt medicines /therapies to manage my RA	11: Doing what I want regardless of the consequences	27: Getting frustrated due to my RA	2: Being more spontaneous with life	1: I sometimes have to cancel plans due to my RA	3: Struggling to do certain things	6: Taking longer to do things than I think it should	9: Using tools/devices to aid me in daily tasks	7: Finding different ways of doing the things I want to	21: Making small adjustments to my day or activities constantly
	18: Trying not to eat certain foods	25: I have periods of being completely symptom free	28: Feeling guilty about holding others back due to my RA	5: I am unable to predict how bad my symptoms will be	12: Choosing to prioritise pleasurable activities against chores	4: Choosing Clothes according to how easy they will be to put on	10: Finding a balance between asking for help and remaining independent	13: Not letting my RA get me down	33: Being determined not to allow RA to interfere with responsibilities	
		39: Struggling to explain to family and friends what life is like	29: Feeling that my body has let me down	15: Talking to other people with RA who are similar to me helps	14: Relying on support from family/friends/others	8: Giving myself permission to leave a task half finished	17: Distracting myself from my symptoms	22: Taking my medication exactly as prescribed		
			31: Worrying because of my RA	19: Cautious of gaining weight and putting extra stress on joints	30: Trying to forget that I have RA	20: Exercising as much as I can	23: Planning rest time into my week			
				24: Feeling lucky in comparison to other people	32: Repetitive tasks make my RA symptoms worse	26: Dealing with severity of symptoms going up and down				
				37: Experiencing swelling daily	36: Experiencing pain daily	35: Experiencing unexplainable fatigue / exhaustion daily				
					38: Experiencing stiffness daily					

8.6.4.1 Daily Life Factor A+: Taking active control: “Just a fact of life”: Demographic information:

Of the seven participants loading onto this factor, six were female (Table 8.8). They had an age range of 46 to 72 years with a mean average age of 61.7 years (SD 10.3). The disease duration ranged from 7 to 36 years with a mean average of 22.7 years (SD 10.8). The mean disability (HAQ) score was 2.0 (SD 0.6) and mean disease activity (Pt Global) was 3.1 (SD 1.7). Five patients were on anti-TNF therapies, one used steroids and two used NSAIDs. One participant was in a self-defined RA flare at the time of completing the Q-sort. None of the participants had dependent children.

Table 8.8: Demographic information for patients loading onto Daily Life Factor A+

ID	Gender	Age (yrs)	Dis Dur (yrs)	HAQ	Pt Global	Med	NHS Trust*	In Flare?	Work status	Help at home	Dependents	Factor Load
P1	F	67	7	1.38	2.2	Anti-TNF	2	No	Retired	Husband**	Husband**	0.48
P2	F	72	36	2.38	6.7	NSAIDs	3	No	Retired	Husband	None	0.70
P3	F	46	23	2.63	2.6	Anti-TNF	3	Yes	Incapacity	Husband	None	0.55
P4	F	65	16	2.63	2.3	Anti-TNF	3	No	Retired	None	None	0.52
P5	M	72	32	2.25	2.6	Steroids	3	No	Retired	Wife	None	0.51
P6	F	50	31	1.50	4.0	Anti-TNF	2	No	Employed	Husband	None	0.59
P7	F	60	14	1.38	1.5	Anti-TNF	2	No	Retired	Grown-up child	None	0.52
Mean		**61.7**	**22.7**	**2.0**	**3.1**							
SD		**10.3**	**10.8**	**0.6**	**1.7**							
Range		**26**	**29**	**1.3**	**5.2**							

*Nb NHS Trusts have been distinguished by numbers due to concerns about retaining patients' anonymity

****Nb patient and husband both care for and depend on each other

Key:

Dis Dur = Disease Duration

HAQ = Health Assessment Questionnaire score 0-3, high bad

Pt Global = Disease activity score patient global measure 0-10, high bad

Medication: Anti-TNF = Anti-Tumour Necrosis Factor, NSAIDs = Non-steroidal anti-inflammatory

8.6.4.2 Factor A+: Taking active control *"Just a fact of life"*: Interpretation

The patients loading onto this factor are predominantly female, of retirement age and have been diagnosed with RA longer, on average, than the patients loading onto the other two daily life factors. These patients also have more disability in comparison to the other factors. However, their rating of the statements suggests that they reduce the impact that RA has on them by "taking active control" through effective self-management techniques.

The statements in this factor indicate that patients make small adjustments to their day or activities constantly because of their RA (Table 8.7, statement D21: opinion +5), and the patient comments clarified this ranking further; *"this is important as you need to be able to do this to manage your RA effectively"* (P1). The discourse suggests that patients find different ways of doing the things they want to (D7: +4) and are determined not to let their RA interfere with their responsibilities (D33: +4). However, they will acknowledge that they struggle to do certain things (D3: +1) and that it can sometimes take longer to get things done than they think it should (D6: +2).

In this factor patients take responsibility for managing their disease within their daily lives; they take their medication exactly as prescribed (D22: +3) as *"it's important and part of my routine"* (P5) and will not do what they like regardless of the consequences (D11: -3):

> *"You can't just do this, people that do this make me angry. You can't expect the doctors to help you if you don't help yourself"* (P4)

They adopt a practical approach to dealing with their RA, which includes using tools and devices to aid with daily tasks (D9: +3). They also find a balance between asking for help and remaining independent (D10 +2) and will use pleasurable activities to distract them from their symptoms: *"paint and draw, anything relaxing takes my mind off of it"* (P5).

These patients will not avoid foods that have the potential to trigger a flare (D18: -4) as they *"don't find they make a difference"* (P2), and are also unlikely to try alternative medicines or therapies (D16: -4) as they generally *"don't believe in them"* (P5). One patient explains how she might be more inclined to use something if she felt desperate:

> *"I tried acupuncture, but it didn't work and was too expensive. I do think some alternative medicines may help, but I'm well enough controlled not to need to try them. If my back was against the wall I might try"* (P7)

They do not feel guilty about holding others back due to their RA (D28: -2) as *"they should understand by now"* (P1). They also do not struggle to explain to family and friends what daily life is like for them (D39: -3). This seems to apply to experienced RA patients; they either no longer need to explain as their friends and family understand or alternatively they have given up trying to explain:

> *"They're understanding as I've had it a while now"* (P2)

> *"I don't bother trying any more, other people just don't understand. I don't think they should call it arthritis – people with osteoarthritis in one finger think they know how you feel"* (P4)

The discourse suggests that patients never experience periods of being symptom free (D25: -3), *"you get used to your symptoms, but because of the disability you're never symptom free"* (P7). However, the daily experience of pain (D36: 0), joint swelling (D37: -1), joint stiffness (D38: 0) and dealing with the severity of their symptoms going up and down (D26: +1) have all been sorted in the more neutral placements. The comments suggest this is because patients are so used to dealing with these symptoms that they are no longer salient to them:

> *"Just a fact of life, they're sorted lower as they're not as interesting as the other statements"* (P2)

This even includes the experience of fatigue (D35: +1), of which one patient says:

> *"This is a biggy. People assume that it's just because I'm getting older, but there's a big difference between that and fatigue"* (P4)

These patients don't worry (D31: -2) or get angry (D34: -5) because of their RA. They do not feel as though their body has let them down (D29: -2) as "*that's a negative way of thinking"* (P7) and they are determined not to let their RA get them down (D13: +3).

In summary, patients in this factor 'take active control', they use effective self-management strategies, which they have developed through experience, they have become experts in managing their RA and they know what works for them. They take a practical approach to managing their RA, using preventative rather than crisis management techniques.

8.6.5 Factor B: Feeling good: "Anti-TNF has kept me working" (B+) versus Constant struggle: "It gets me down every single day" (B-)

Factor B is a 'bipolar' factor, meaning that two opposed viewpoints are being expressed by the participants who load on to this factor, each viewpoint having a factor exemplifying Q-sort that is the 'mirror-image' of the other. It is therefore necessary to present two narrative accounts for Factor B.

Factor B has nine significantly loading participants (one on Factor B+, eight on Factor B-), it has an eigenvalue of 3.97 and it explains 13% of the Q-study variance. The exemplifying Q-Sorts for both the positive and negative loadings of this factor are displayed in Tables 8.9 and 8.10, respectively.

Table 8.9: Exemplifying Q-sort for Factor B+: Feeling good: “Anti-TNF has kept me working”

Negative					Neutral					Positive
-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
34: Being angry because of my RA	35: Experiencing unexplainable fatigue / exhaustion daily	5: I am unable to predict how bad my symptoms will be	3: Struggling to do certain things	10: Finding a balance between asking for help and remaining independent	1: I sometimes have to cancel plans due to my RA	9: Using tools/devices to aid me in daily tasks	4: Choosing clothes according to how easy they will be to put on	2: Being more spontaneous with life	18: Trying not to eat certain foods	20: Exercising as much as I can
	36: Experiencing pain daily	27: Getting frustrated due to my RA	6: Taking longer to do things than I think it should	21: Making small adjustments to my day or activities constantly	7: Finding different ways of doing the things I want to	15: Talking to other people with RA who are similar to me helps	11: Doing what I want regardless of the consequences	13: Not letting my RA get me down	25: I have periods of being completely symptom free	
		31: Worrying because of my RA	32: Repetitive tasks make my RA symptoms worse	28: Feeling guilty about holding others back due to my RA	8: Giving myself permission to leave a task half finished	17: Distracting myself from my symptoms	12: Choosing to prioritise pleasurable activities against chores	16: Using alt medicines /therapies to manage my RA		
			38: Experiencing stiffness daily	29: Feeling that my body has let me down	14: Relying on support from family/friends/others	22: Taking my medication exactly as prescribed	24: Feeling lucky in comparison to other people			
				37: Experiencing swelling daily	19: Cautious of gaining weight and putting extra stress on joints	23: Planning rest time into my week				
				39: Struggling to explain to family and friends what life is like	26: Dealing with severity of symptoms going up and down	30: Trying to forget that I have RA				
					33: Being determined not to allow RA to interfere with responsibilities					

Table 8.10: Exemplifying Q-sort for Factor B-: Constant struggle: "It gets me down every single day"

Negative **Neutral** **Positive**

-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
20: Exercising as much as I can	18: Trying not to eat certain foods	2: Being more spontaneous with life	4: Choosing Clothes according to how easy they will be to put on	9: Using tools/devices to aid me in daily tasks	1: I sometimes have to cancel plans due to my RA	10: Finding a balance between asking for help and remaining independent	3: Struggling to do certain things	5: I am unable to predict how bad my symptoms will be	35: Experiencing unexplainable fatigue / exhaustion daily	34: Being angry because of my RA
	25: I have periods of being completely symptom free	13: Not letting my RA get me down	11: Doing what I want regardless of the consequences	15: Talking to other people with RA who are similar to me helps	7: Finding different ways of doing the things I want to	21: Making small adjustments to my day or activities constantly	6: Taking longer to do things than I think it should	27: Getting frustrated due to my RA	36: Experiencing pain daily	
		16: Using alt medicines/ therapies to manage my RA	12: Choosing to prioritise pleasurable activities against chores	17: Distracting myself from my symptoms	8: Giving myself permission to leave a task half finished	28: Feeling guilty about holding others back due to my RA	32: Repetitive tasks make my RA symptoms worse	31: Worrying because of my RA		
			24: Feeling lucky in comparison to other people	22: Taking my medication exactly as prescribed	14: Relying on support from family/friends/others	29: Feeling that my body has let me down	38: Experiencing stiffness daily			
				23: Planning rest time into my week	19: Cautious of gaining weight and putting extra stress on joints	37: Experiencing swelling daily				
				30: Trying to forget that I have RA	26: Dealing with severity of symptoms going up and down	39: Struggling to explain to family and friends what life is like				
					33: Being determined not to allow RA to interfere with responsibilities					

8.6.5.1 Factor B: Demographic information

Of the eight participants loading negatively onto this factor five were male (Table 8.11). Patients in Factor B- had an age range of 41 to 63 years with a mean average of 55.5 years (SD 7.4). Disease duration ranged from 2 to 40 years with a mean average of 15.3 years (SD 14.3). The mean disability (HAQ) score was 1.5 (SD 0.8) and mean disease activity (Pt Global) was 5.3 (SD 2.1). Three participants were on anti-TNF therapies, four were taking DMARDs and one was taking only steroids due to trying for a baby. One patient was in a self-defined RA flare at the time of completing the Q-sort and one participant had one dependent child. The patient who loaded positively onto this factor was a 50 year old man. His disease duration is unknown but he had a disability score of 0, disease activity of 0.5 and was on anti-TNF therapy.

Table 8.11: Demographic information for patients loading onto Daily Life Factor B

ID	Gender	Age (yrs)	Dis Dur (yrs)	HAQ	Pt Global	Med	NHS Trust*	In Flare?	Work status	Help at home	Dependents	Factor Load
P8	M	50	Unknown	0.00	0.5	Anti-TNF DMARDs	3	No	Self-employed	Wife	Wife	0.70
P9	M	61	40	2.25	6.9	DMARDs	2	No	Retired	Wife	None	-0.50
P10	F	63	27	0.50	4.3	DMARDs	3	No	Retired	None	None	-0.46
P11	F	51	4	1.63	4.7	DMARDs Steroids	1	No	Employed	Grown-up child	1 child	-0.70
P12	M	55	2	2.00	5.4	Anti TNF DMARDs	2	No	Incapacity	Wife & Grown-up child	None	-0.54
P13	M	52	5	0.63	6.7	DMARDs	2	Yes	Self-employed	None	None	-0.46
P14	M	61	25	2.13	5.5	Anti-TNF Steroids	3	No	Incapacity	Wife	Mother	-0.54
P15	F	41	2	0.75	7.9	Steroids	2	No	Employed	Partner	1 child	-0.85
P16	M	60	17	2.14	1.0	Anti-TNF DMARDs	2	No	Unemployed	Wife	None	-0.42
Mean		**54.9**	**15.3**	**1.3**	**4.8**							
Stan Dev		**7.1**	**14.3**	**0.9**	**2.5**							
Range		**22.0**	**38.0**	**2.3**	**7.4**							

*Nb NHS Trusts have been distinguished by numbers due to concerns about retaining patients' anonymity

Key:
Dis Dur = Disease Duration
HAQ = Health Assessment Questionnaire score
Pt Global = Disease activity score patient global measure
Medication: Anti-TNF = Anti-Tumour Necrosis Factor, DMARDs = Disease Modifying Anti-Rheumatic Drugs

8.6.5.2 Factor B- : Constant struggle: "It gets me down every single day": Interpretation

The majority of participants loaded negatively onto this factor and will therefore be presented first. These patients are predominantly male (5: 71%), which is of particular note when compared to the other two factors and to the study population (26% male), which reflects the RA population. These participants appear to struggle with their RA, reporting negative experiences and thoughts associated with their RA.

This factor describes patients who never experience periods of being completely symptom free (D25: -4). They experience daily pain (D36: +4), fatigue (35: +4), swelling (D37: +1) and stiffness (D38: +2). Patients describe fatigue as *"the worst symptom"* (P11):

> *"This is worse than pain. I have lost my enthusiasm and 'get up and go'. It's like feeling ill all the time"* (P15)

However, despite the daily symptoms, the statements indicate that they are unable to predict how bad their symptoms will be each day (D5: +3).

The discourse in this factor suggests that patients get frustrated (D27: +3) and angry (D34: +5) because of their daily life with RA. They also worry because of it (D31: +3) and it gets them down (D13: -3):

> *"I get very frustrated with it, the problem is then I get irritated and take it out on the wife"* (P9)

> *"It [RA] gets me down every single day"* (P15)

These patients feel unlucky in comparison to other people (D24: -2), the thought of being lucky is *"ridiculous"* (P16).

These patients are unable to exercise (D20: -5) or to be spontaneous (D2: -3). They will not prioritise pleasurable activities against chores (D12: -2) and find that repetitive tasks make their RA symptoms worse (D32: +2). They also struggle to do certain things (D3: +2) and find it takes longer to get things done than they think it should (D6: +2), which they find frustrating:

> *"Very frustrating for me as I used to do things quickly"* (P11)

> *"I always did things quickly, I didn't ever sit around. I find the less I do, the less I want to do and I don't want that. I find it very frustrating"* (P14)

These patients would not do what they like regardless of the consequences (D11: -2). They will not try to avoid certain foods (D18: -4) as they *"don't know what* *to avoid"* (P12) nor will they will try alternative medicines (D16: -3): *"they're a waste of time and money"* (P14):

> *"None of it works. People often suggest things to me, but I just tell them I've already tried it – it shuts them up"* (P16)

In summary, these patients seem to prioritise the physical symptoms they experience, reporting negative thoughts and emotions associated with their RA, and they do not seem to have found self-management or coping strategies that work for them. They may therefore be experiencing a sense of hopelessness about their lives with RA. Despite having less disability than patients in Factor A+, these patients seem to be in a 'constant struggle' with their RA.

8.6.5.3 Factor B+: Feeling good: "Anti-TNF has kept me working": Interpretation

Factor B+ represents a direct reversal of the configuration of statements that was characteristic of Factor B-. This single patient, loading positively onto this factor, appears to have little or no disability or disease activity (patient global 0) and may even be considered to be in remission, he is therefore feeling good, which he attributes to anti-TNF therapy.

This factor describes periods of being completely symptom free (D25: +4) and not experiencing pain (D36: -4), fatigue (D35: -4), swelling (D37: -1) nor stiffness (D38: -2) daily. This patient suggests this has improved *"since I've been on anti-TNF"* (P8). It is hard for him to predict the severity of symptoms (D5: -3), perhaps because they no longer occur daily.

The discourse in this factor suggests that this patient does not get frustrated by his RA (D27: -3) or worry because of it (D31: -3). He definitely does not get angry due to his RA (D34: -5) as this is a *"negative emotion"* (P8) nor does he allow his RA to get him down (D13: +3). In fact, he feels reasonably lucky in comparison to other patients (D24: +2):

> *"I know I'm lucky in comparison to others, especially people with young children or who are trying to carry on working – anti-TNF has kept me working"* (P8)

This patient exercises as much as he can (D20: +5) and tries to be more spontaneous (D2: +3) as *"being diagnosed was a wake-up call"* (P8) and will prioritise pleasurable activities against chores (D12: +2). He does not find that repetitive tasks make his RA symptoms worse (D32: -2), does not take longer to get things done than he thinks it should (D6: -2) nor does he struggle to do things (D3: -2). To manage his RA, this patient will try to avoid certain foods that have the potential to trigger a flare (D18: +4) and will try alternative medicines (D16: +3). However, he will still do what he likes regardless of the consequences (D11: +2).

In summary, this patient is ‘feeling good’ and RA does not have a great impact on his life. It is possible that this is due to effective management through anti-TNF therapy.

8.6.6 Factor C- : Keeping RA in its place: “It’s a very small part of you”

Factor C- has seven significantly loading participants, it has an eigenvalue of 2.67 and it explains 9% of the study variance. All seven participants load negatively onto this factor, therefore the negative viewpoint will be presented. The exemplifying Q-sort for the negative loading of this factor is displayed in Table 8.12

Table 8.12: Exemplifying Q-sort for Daily Life Factor C-: Keeping RA in its Place: “It’s a very small part of you”

Negative					Neutral					Positive
-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
24: Feeling lucky in comparison to other people	13: Not letting my RA get me down	19: Cautious of gaining weight and putting extra stress on joints	7: Finding different ways of doing the things I want to	2: Being more spontaneous with life	3: Struggling to do certain things	1: I sometimes have to cancel plans due to my RA	6: Taking longer to do things	14: Relying on support from family/friend/others	4: Choosing Clothes according to how easy they will be to put on	9: Using tools/devices to aid me in daily tasks
	33: Being determined not to allow RA to interfere with responsibilities	30: Trying to forget that I have RA	20: Exercising as much as I can	5: I am unable to predict how bad my symptoms will be	10: Finding a balance between asking for help and remaining independent	8: Giving myself permission to leave a task half finished	12: Choosing pleasurable activities over chores	18: Trying not to eat certain foods	28: Feeling guilty about holding others back due to my RA	
		35: Experiencing unexplainable fatigue / exhaustion daily	22: Taking my medication exactly as prescribed	11: Doing what I want regardless of the consequences	16: Using alt medicines/therapies to manage my RA	15: Talking to other people with RA who are similar to me helps	25: Periods of being symptom free	23: Planning rest time into my week		
			27: Getting frustrated due to my RA	26: Dealing with symptoms going up and down	17: Distracting myself from my symptoms	32: Repetitive tasks make my RA symptoms worse	34: Being angry because of my RA			
				36: Experiencing pain daily	21: Making small adjustments to my day or activities constantly	37: Experiencing swelling daily				
				38: Experiencing stiffness daily	29: Feeling that my body has let me down	39: Explaining to friends and family				
					31: Worrying because of my RA					

8.6.6.1 Factor C-: Keeping RA in its place: “It’s a very small part of you”:

Demographic information:

All seven of the loading participants are female (Table 8.13). They had an age range of 30 to 63 years with a mean average of 42.4 years (SD 11.2). The disease duration ranged from 1 year to 30 years with an average of 9.9 years (SD 10.2). The mean disability (HAQ) score was 0.5 (SD 0.5) and mean disease activity (Pt Global) was 1.7 (SD 1.0). Three patients were on anti-TNF therapies, two were taking DMARDs, one was taking only steroids due to being pregnant and one was taking no medication due to having recently had a baby. One patient was in a self-defined RA flare at the time of completing the Q-sort. Three participants had three dependent children, one participant had two dependent children and another was pregnant with her second child, two participants did not have dependent children.

Table 8.13: Demographic information for patients loading onto Daily Life Factor C-

ID	Gender	Age (yrs)	Dis Dur (yrs)	HAQ	Pt Global	Med	NHS Trust*	In Flare?	Work status	Help at home	Dependents	Factor Load
P17	F	63	9	0.38	1.2	Anti-TNF	2	Yes	Employed	None	None	-0.52
P18	F	30	6	0.00	0.3	Steroids	1	No	Maternity leave	Husband	1 child	-0.42
P19	F	50	1	0.13	1.3	DMARDs	3	No	Employed	Husband & Grown-up child	None	-0.67
P20	F	39	16	0.88	3.4	Anti-TNF	3	No	Employed	Husband	2 children	-0.44
P21	F	33	30	0.63	2.3	No medication	1	No	House-wife	Husband	3 children	-0.63
P22	F	39	3	0.00	1.9	DMARDs	1	No	Employed	Husband & Grown-up child	3 children	-0.48
P23	F	43	4	1.25	1.5	Anti-TNF	3	No	Housewife	Husband	3 children	-0.59
Mean		**42.4**	**9.9**	**0.5**	**1.7**							
St Dev		**11.2**	**10.2**	**0.5**	**1.0**							
Range		**33.0**	**29.0**	**1.3**	**3.1**							

*Nb NHS Trusts have been distinguished by numbers due to concerns about retaining patients' anonymity

Key:
Dis Dur = Disease Duration
HAQ = Health Assessment Questionnaire score
Pt Global = Disease activity score patient global measure
Medication: Anti-TNF = Anti-Tumour Necrosis Factor, DMARDs = Disease Modifying Anti-Rheumatic Drugs

8.6.6.2 Factor C- : Keeping RA in its place: “It’s a very small part of you”: Interpretation:

This factor comprises all female patients, younger on average than those loading onto the other two daily life factors. These patients are all either working, have young children or both. These patients seem to have responsibilities that they place above their own well-being and therefore find it necessary to keep RA in its place. The discourse in this factor suggests that patients are determined not to let their RA interfere with their responsibilities (D33: +4):

> *“I’ve lived with it for a long time now, I’m not going to allow it to ruin my life, it’s not fair on the children. I’ll do what I can for the children, even if I suffer for it”* (P20)

They find different ways of doing the things they want to (D7: +2) and they will prioritise chores over pleasurable activities (D12: -2). They also do not find that it takes longer to get things done than they think it should (D6: -2). These patients therefore do not feel guilty about holding others back (D28: -4) as they *“don’t hold others back”* (P23) and they are often able to forget that they have RA (D30: +3):

> *“This works. I am able to forget about it a lot of the time. My Consultant said to me ‘This is you [draws a circle] and this is your RA [draws a much smaller circle]’. It’s a very small part of you, and I believe that”* (P22)

The discourse also indicates that patients do not plan rest time into the week (D23: -3) as they consider themselves too busy for this:

> *“Not going to happen. I run my own business and have two small children”* (P20)

These patients are cautious of gaining weight and putting extra stress on their joints (D19: +3); it’s *“a constant worry”* (P19). They therefore try to exercise as much as they can (D20: +2):

> *“Staying active is important to me, I’ve got a dog for this reason”* (P22)

They do not struggle to explain what life is like for them to family and friends (D39: -1), and they do not rely on support from family and friends (D14: -3) as they *“don’t ask for help”* (P19). They do not find the need to use tools or devices to aid with daily tasks (D9: -5), they do not avoid certain foods that have the potential to trigger a flare (D18: -3) and nor do they worry about choosing clothes according to how easy they are to put on and take off (D4: -4):

> *“I never think of my RA when I’m shopping for clothes, I just wear what I like”* (P18)

These patients will take their medication as prescribed (22: +2) as *"this is really important"* (P22).

The discourse suggests that patients do not get angry due to their RA (D34: -2) and will not allow their RA to get them down (D13: +4). They feel particularly lucky in comparison to other people (D24: +5):

> *"Definitely – most important [statement]. RA runs in the family, so I've seen relatives in wheelchairs and very unwell with it and you see other people in clinic. I look and feel so well with it."* (P17)

In summary, the female patients loading onto this factor do not allow RA to impact on their lives, which may be due to their lower disability and disease activity, but also seems to be due to them putting other people first. Either way, these patients 'keep RA in its place' and carry on with their lives despite the presence of their RA.

8.6.7 Daily life summary

This Q-study indicates that daily life with RA can be experienced in at least 4 ways (Fig 8.1). Some patients (Factor B+) may have such well-controlled RA that they feel good and experience little impact of RA, whilst other patients lessen the impact that RA has on their lives through taking active control of their RA with self-management strategies perfected through experience (Factor A+) or by putting RA in its place and putting responsibilities first (Factor C-). However, some patients, the majority of whom appear to be male, struggle through, they seem unable to identify effective self-management or coping strategies and experience negative thoughts and beliefs about their RA.

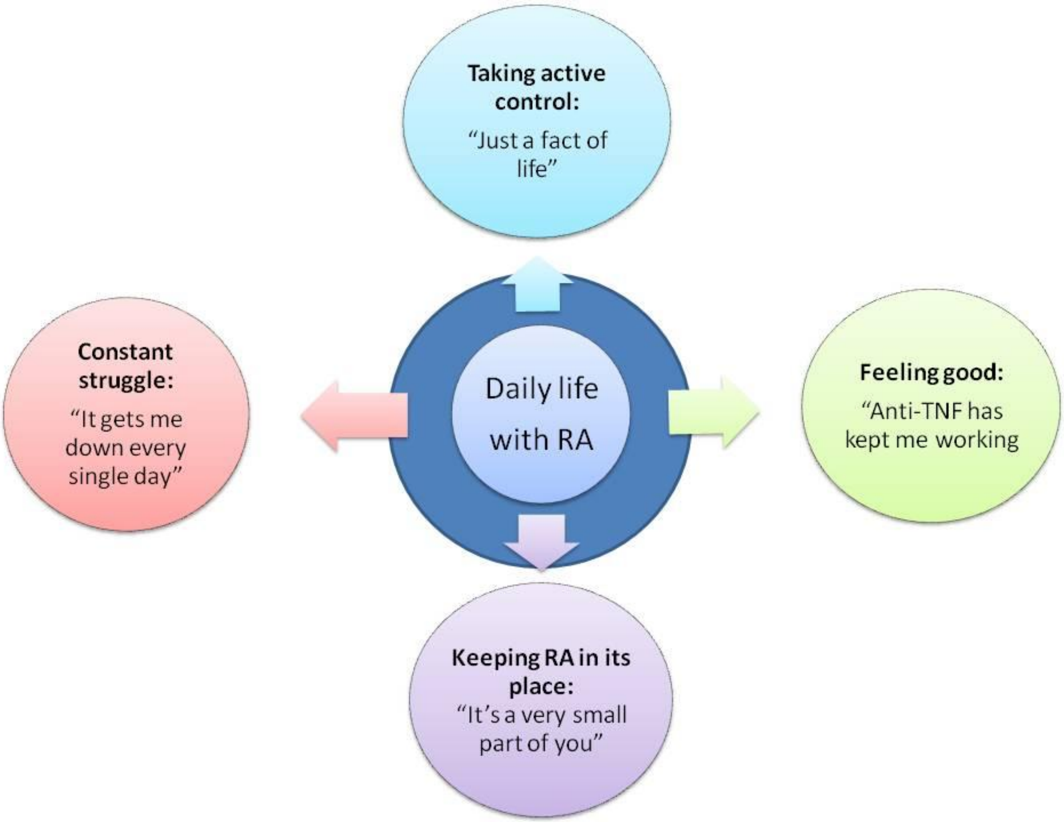


Figure 8.1: Different ways of experiencing daily life with RA

Having explored patients' views on daily life with RA, their views on help-seeking when in an RA flare will now be presented.

8.7 Results: Q-methodology: "When I am in a flare…"

8.7.1 Flare help-seeking Q-sort: Participants

The same 72 patients were invited to participate and 30 (42%) agreed to take part. Two participants who completed the daily-life Q-sort did not complete this flare help-seeking Q-sort: a 72 year old man (daily life patient P5) who did not have time to complete it and a 60 year old woman (daily life patient P7) who explained she had not experienced an RA flare since starting anti-TNF therapy and therefore felt she could not comment on her help-seeking behaviour. Data from a 73 year old man who was unable to understand the task was excluded. Data from the man who was excluded from the daily life study due to help from his wife was included in this flare help-seeking Q-study as this Q-sort was conducted whilst his wife was not in the room. The majority of the participants (n=29) were female (72%) and participants' ages ranged from 30 to 79 years (Table 8.14). The majority were not currently working, these were either retired or unemployed. There was a range of treatment regimes including one patient taking no medication. There was also a range of disease duration (1-40 years), self-reported disease activity (using the DAS global) and disability (HAQ score). Six participants reported being in a flare at the time of the study.

Table 8.14: Characteristics of participants in the Flare Help-Seeking Q-methodology study

		Frequency	Percentage
Gender	Female	21	72.4
	Male	8	27.6
Age (years)	Under 40	4	13.8
	40 – 49	4	13.8
	50 – 59	8	27.6
	60 – 69	11	37.9
	70+	2	6.9
Employment	Employed	12	41.4
	Unemployed	9	31.0
	Retired	8	27.6
Medication	Anti-TNF	12	41.4
	DMARD	13	44.8
	Steroids	3	10.3
	No Medication	1	3.5
Disease Duration	> 2yrs < 5 yrs	8	27.6
	> 5 yrs	3	10.3
	> 10 yrs	8	27.6
	> 20 yrs	9	31.0
	Unknown	1	3.5
DAS Global	0 ≤ 4 (mild)	17	58.6
	> 4 ≤ 7	11	37.9
	> 7 ≤ 10 (severe)	1	3.5
Disability Score	0 ≤ 1	13	44.8
	>1 ≤ 2	7	24.2
	> 2 ≤ 3	9	31.0

8.7.2 Flare help-seeking Q-sort: Quantitative results

Two factors were extracted and rotated using the orthogonal varimax procedure, which explained 51% of the variance and accounted for 22 of the 29 participants. None of the sorts were confounded (i.e. significantly loading on more than one of the presented factors). A participant loading of 0.54 reached significance at $p < .01$ in this study.

Table 8.15 shows the ranking assigned to each of the 23 statements in each of the factor exemplifying Q-sorts. Reading the table by column shows the comparative ranking of statements which characterise a particular factor. Reading the table by row shows the comparative ranking of a particular statement across factors. The highest and lowest rankings assigned to each of the statements are indicated.

Table 8.15: By-Factor rankings of statements given in the Flare Help-Seeking Q-Sort

	Factor Scores	
Statement	**Factor A**	**Factor B-**
F1: I feel the flare will last until I seek medical help	0	-3
F2: I will contact the medical team as soon as possible	+1	-3
F3: I am reluctant to seek medical help as I worry about wasting the rheumatology team's time	-3	0
F4: I am more reluctant to seek medical help when I think I've caused the flare	-1	-2
F5: I am reluctant to seek medical help as I don't think the Dr can do anything to help	-3	-1
F6: I am reluctant to seek medical help as I hope it'll go away on its own	-1	+4
F7: I avoid seeking medical help as I don't like taking drugs	-2	-2
F8: I seek help from the medical team once flare starts to affect my quality of life too much	+4	+1
F9: I know I don't have to manage my flare alone	+2	+1
F10: Easy access to the medical team is part of my decision to seek help for my flare	+1	0
F11: A loved one tells me I ought to seek medical help	0	+2
F12: I don't like admitting that I need to ask for help	-1	+2
F13: I am reluctant to seek medical help as I don't get on well with my rheumatology team	-4	-4
F14: I manage my symptoms until the flare stops	0	+1
F15: I seek help from the medical team as I worry about long term damage to my joints	+1	-1
F16: I seek help from the medical team when the pain becomes too intense	+3	+3
F17: I wait until my next scheduled appointment with the rheumatologist before seeking help	-2	-1
F18: I am reluctant to seek medical help as I don't want to waste my own time	-2	0
F19: I seek help from the medical team when I know my flare needs to be controlled by new medication	+2	-2
F20: I control my flare symptoms with medication before contacting the medical team	0	0
F21: I seek help from the medical team when my symptoms become uncontrollable	+3	+3
F22: I seek help from the medical team when the flare has gone on longer than I expected	+2	+2
F23: I wait until I have more than one flare symptom before seeking medical help	0	0

All statements include the prefix "When I am in a flare..." Text highlighted in blue indicates the highest ranking assigned to each statement.
Text highlighted in yellow indicates the lowest ranking.

8.7.3 Flare help-seeking consensus items

There are nine consensus items in this study, meaning that both factors sorted the statements into a similar place on the grid (Table 8.16).

Table 8.16: Consensus items from Flare Help-Seeking Q-sort

	Factor Score	
Statement	**A**	**B-**
F4: I am more reluctant to seek medical help when I think I've caused the flare	-1	-2
F7: I avoid seeking medical help as I don't like taking drugs	-2	-2
F9: I know I don't have to manage my flare alone	+2	+1
F13: I am reluctant to seek medical help as I don't get on well with my rheumatology team	-4	-4
F16: I seek help from the medical team when the pain becomes too intense	+3	+3
F20: I control my flare symptoms with medication before contacting the medical team	0	0
F21: I seek help from the medical team when my symptoms become uncontrollable	+3	+3
F22: I seek help from the medical team when the flare has gone on longer than I expected	+2	+2
F23: I wait until I have more than one flare symptom before seeking medical help	0	0

There is a large amount of consensus in terms of patients' decision-making and help-seeking behaviours. There is agreement that patients know they don't have to manage their flare alone due to *"supportive family and friends"* (P8). The discourse also suggests agreement that patients do get on well with their rheumatology team and would not avoid seeking help due to the team:

> *"They know my name and say 'Hi' to me, even when they haven't seen me in months. Completely different experience to [another department]"* (P17)

There is also consensus that patients would not avoid seeking help due to having caused the flare themselves. However, the two justifications provided for this are very different to each other:

> *"No, how would I have caused a flare? It's the disease that causes it"* (P13)

> *"Most flares are self-inflicted, so you can't avoid coming in just for that reason"* (P14)

Patients also disagree that they avoid seeking help due to not wanting to take medication, explaining that if they are bad enough they will *"do what I need to"* (P26). Both Factors score the statement **"I control my flare symptoms with**

medication before contacting the medical team" in the neutral zero space. The comments made by the patients suggest that they try to control their symptoms with medication, but it does not always work:

"I try steroids first, it usually doesn't work, but it's worth trying" (P20)

Both Factors also score the statement **"I wait until I have more than one flare symptom before seeking medical help"** in the neutral zero position. The comments suggest that this can depend on the type of flare that is being experienced:

"No, sometimes just my thumb or just my knee hurts" (P1)

Of particular note are the tipping points for help-seeking that received consensus. These are the flare going on longer than expected, the pain becoming too intense and when patients are no longer able to control their symptoms:

"When I just don't know what to do anymore" (P25)

8.7.4 Factor A: Definite decisions: "It won't go away, so I won't wait"

Factor A has sixteen patients significantly loading, it has an eigenvalue of 10.18 and it explains 35% of the study variance. The exemplifying Q-sort for this factor is displayed in Table 8.17.

Table 8.17: Exemplifying Q-sort for Flare Help-Seeking Factor A: Definite decisions: “It won’t go away, so I won’t wait”

Negative				**Neutral**				**Positive**
-4	-3	-2	-1	0	+1	+2	+3	+4
13: I don’t get on with my Rheumatology team	3: I worry about wasting the Rheumatology team’s time	7: I don’t like taking drugs	4: More reluctant to seek help when I think I’ve caused the flare	1: I feel the flare will last until I seek medical help	2: I will contact the medical team as soon as possible	9: I know I don’t have to manage my flare alone	16: I seek help when the pain becomes too intense	8: I seek help when flare affects my quality of life
	5: I don’t think the doctor can do anything to help	17: I wait until my next scheduled appointment	6: I hope it’ll go away on its own	11: A loved one tells me I ought to seek medical help	10: Easy access to the team is part of my decision	19 I seek help when my flare needs to be controlled by new medication	21: I seek help when my symptoms become uncontrollable	
		18: I don’t want to waste my own time	12: I don’t like admitting that I need to ask for help	14: I manage my symptoms until the flare stops	15: I worry about long term damage to my joints	22: I seek help when the flare has gone on longer than expected		
				20: Control flare symptoms with medication				
				23: I wait until I have more than one flare symptom				

8.7.4.1 Factor A: Definite decisions: “It won’t go away, so I won’t wait”: Demographic information

Of the sixteen participants loading onto this factor eleven were female (Table 8.18). They had an age range of 39 to 68 years with an average age of 54.8 years (SD 10.7). The disease duration ranged from 2 to 31 years with an average of 15.2 years (SD 10.9). The mean disability (HAQ) score was 1.2 (SD 0.8) and mean disease activity (Pt Global) was 3.3 (SD 2.5). Eleven patients were on anti-TNF therapies, one used NSAIDs and four used DMARDs. Three participants were in a self-defined RA flare at the time of completing the Q-sort. Four participants had dependent children, one had a parent who depended on them and two patients had spouses who depended on them for care.

Table 8.18: Demographic information for patients loading onto Flare Help-Seeking Factor A

ID	Sex	Age (yrs)	Dis Dur (yrs)	HAQ	Pt Global	Med	NHS Trust*	In Flare?	Work status	Help at home	Dependents	Factor Load
P17	F	63	9	0.38	1.2	Anti-TNF	2	Yes	Employed	None	None	0.90
P8	M	50	Unknown	0.00	0.5	Anti-TNF	3	Yes	Self-employed	Wife	Wife	0.86
P20	F	39	16	0.88	3.4	Anti-TNF	3	No	Employed	Husband	2 children	0.78
P14	M	61	25	2.13	5.5	Anti-TNF	3	No	Incapacity	Wife	Mother	0.60
P1	F	67	7	1.38	2.2	Anti-TNF	2	No	Retired	Husband	Husband	0.86
P15	F	41	2	0.75	7.9	NSAIDs	1	No	Employed	Partner	1 child	0.76
P6	F	50	31	1.50	4.0	Anti-TNF	2	No	Employed	Husband	None	0.62
P24	M	68	20	2.50	5.0	DMARDs	2	No	Retired	Wife	Wife	0.81
P25	F	53	30	0.88	0.3	Anti-TNF	3	No	Employed	Husband & Grown-up child	None	0.55
P23	F	43	4	1.25	1.5	Anti-TNF	3	No	Housewife	Husband	3 children	0.67
P10	F	63	27	0.50	4.3	DMARDs	3	No	Retired	None	None	0.78
P26	M	62	12	0.75	2.0	DMARDs	1	No	Retired	None	None	0.76
P11	F	51	4	1.62	4.7	DMARDs	1	No	Employed	Grown-up child	1 child	0.58
P12	M	55	2	2.00	5.4	Anti-TNF	2	No	Incapacity	Wife & Grown-up child	None	0.57
P3	F	46	23	2.63	2.6	Anti-TNF	2	Yes	Incapacity	Husband	None	0.70
P4	F	65	16	2.63	2.3	Anti-TNF	2	No	Retired	None	None	0.89
Mean		**54.8**	**15.2**	**1.4**	**3.3**							
St Dev		**9.6**	**10.4**	**0.8**	**2.1**							
Range		**29.0**	**29.0**	**2.6**	**7.6**							

*Nb: NHS Trusts have been distinguished by numbers due to concerns about retaining patients' anonymity

Key:

Dis Dur = Disease Duration

HAQ = Health Assessment Questionnaire score

Pt Global = Disease activity score patient global measure

Medication: Anti-TNF = Anti-tumour necrosis factor, DMARDs = Disease modifying anti-rheumatic drugs, NSAIDs = Non-steroidal anti-inflammatory drugs

8.7.4.2 Factor A: Definite decisions: “It won’t go away, so I won’t wait”: Interpretation

The patients in this factor, the majority of whom are using anti-TNF therapies, make a definite decision to seek help from the medical team. These patients will contact the medical team as soon as possible when they are in a flare (F2: +1). This statement only received one comment explaining how quickly these patients will seek help:

> *“I’ll contact the next day and I get seen very quickly”* (P11)

The discourse suggests that patients know from previous experience that the medical team are able to help them (F5: -3) and they don’t think that their flare will go away on its own (F6: -1):

> *“Minor aches and pains go away on their own, flare-ups don’t”* (P8)

These patients will ask for help if they need it (F12: -1) and don’t worry about wasting their own time (F18: -2) or the rheumatology team’s time (F03: -3) because *“that’s what they’re there for”* (P17). They wouldn’t wait until their next scheduled rheumatologist appointment before seeking help (F17: -2) as *“it won’t go away, so I won’t wait”* (P10) and easy access to the medical team is part of their decision to seek help (F10: +1).

Tipping points for seeking help specific to patients in this factor are worries about long term damage to their joints (F15: +1), knowing their flare needs to be controlled by new medication (F19: +2) and when flare begins to affect their quality of life (F8: +4). These patients make a definite decision that their symptoms constitute a flare and that the medical team are there to help them.

8.7.5 Factor B- : Cautious indecision: “Lying down and not moving until it goes”

Factor B- has six patients significantly loading, it has an eigenvalue of 4.58 and it explains 16% of the study variance. All six participants load negatively onto this factor therefore the negative viewpoint will be presented. The exemplifying Q-sort for the negative loading of this factor is displayed in Table 8.19.

Table 8.19: Exemplifying Q-sort for Flare Help-Seeking Factor B- : Cautious indecision: “Lying down and not moving until it goes”

Negative				Neutral				Positive
-4	-3	-2	-1	0	+1	+2	+3	+4
13: I don’t get on with my Rheumatology team	1: I feel the flare will last until I seek medical help	4: More reluctant to seek help when I think I’ve caused the flare	5: I don’t think the doctor can do anything to help	3: I worry about wasting the Rheumatology team’s time	8: I seek help when flare affects my quality of life	11: A loved one tells me I ought to seek medical help	16: I seek help when the pain becomes too intense	6: I hope it’ll go away on its own
	2: I will contact the medical team as soon as possible	7: I don’t like taking drugs	15: I worry about long term damage to my joints	10: Easy access to the team is part of my decision	9: I know I don’t have to manage my flare alone	12: I don’t like admitting that I need to ask for help	21: I seek help when my symptoms become uncontrollable	
		19 I seek help when my flare needs to be controlled by new medication	17: I wait until my next scheduled appointment	18: I don’t want to waste my own time	14: I manage my symptoms until the flare stops	22: I seek help when the flare has gone on longer than expected		
				20: Control flare symptoms with medication				
				23: I wait until I have more than one flare symptom				

8.7.5.1 Factor B- : Cautious indecision: “Lying down and not moving until it goes”: Demographic information

Of the six participants loading onto this factor four were female (Table 8.20). They had an age range of 30 to 66 years with an average age of 50.5 years (SD 15.4). The disease duration ranged from 5 to 40 years with an average of 18.7 years (SD 13.9). The mean disability (HAQ) score was 1.2 (SD 1.0) and mean disease activity (DAS Global) was 4.1 (SD 2.6). Four patients used DMARDs, one used steroids and one was on no medication. None of the participants loading onto this factor used anti-TNF therapy. Two participants were in a self-defined RA flare at the time of completing the Q-sort. Two participants had dependent children.

Table 8.20: Demographic information for patients loading onto Flare Help-Seeking Factor B-

ID	Sex	Age (yrs)	Dis Dur (yrs)	HAQ	Pt Global	Med	NHS Trust*	In Flare?	Work status	Help at home	Dependents	Factor Load
P21	F	33	30	0.63	2.3	None	1	No	House-wife	Husband	3 children	-0.60
P18	F	30	6	0.00	0.3	Steroids	1	No	Maternity leave	Husband	1 child	-0.71
P13	M	52	5	0.63	6.7	DMARDs	2	Yes	Self-employed	None	None	-0.63
P27	F	66	18	1.57	3.6	DMARDs	3	Yes	Retired	None	None	-0.70
P9	M	61	40	2.25	6.9	DMARDs	2	No	Retired	Wife	None	-0.72
P28	F	61	13	2.30	5.0	DMARDs	2	Yes	Retired	Grown-up child	None	-0.59
Mean		**50.5**	**18.7**	**1.2**	**4.1**							
St Dev		**15.4**	**13.9**	**1.0**	**2.6**							
Range		**36.0**	**35.0**	**2.3**	**6.6**							

*Nb: NHS Trusts have been distinguished by numbers due to concerns about retaining patients' anonymity

Key:
Dis Dur = Disease Duration
HAQ = Health Assessment Questionnaire score
Pt Global = Disease activity score patient global measure
Medication: DMARDs = Disease Modifying Anti-Rheumatic Drugs

8.7.5.2 Factor B- : Cautious indecision: "Lying down and not moving until it goes": Interpretation

These patients are similar to patients in Factor A in terms of both clinical and demographic data. However, in contrast to Factor A, none of the patients loading onto this factor use anti-TNF therapies. These patients appear to be both cautious and indecisive in seeking help for their flares. The statements in this factor indicate that patients will not contact the medical team as soon as possible when they are in a flare (F2: -3). These patients are reluctant to seek help as they hope the flare will go away on its own (F6: +4) and do not believe that the flare will last until they seek medical help (F1: -3). One comment suggests that this idea has been reinforced by their previous experiences:

> *"It does sometimes go away on its own after 3 or 4 days"* (P9)

These patients don't like admitting that they need to ask for help (F12: +2) and they worry about wasting the rheumatology team's time (F3: 0), which the comments suggest are due to beliefs that they should manage alone:

> *"I was brought up to be self sufficient and not run for help, I know that I should know better, but it's ingrained"* (P27)

These patients scored the statement **"I am reluctant to seek medical help as I worry about wasting the rheumatology team's time"** in the neutral '0' position, which may indicate that the statement is less important to them. However, Q-methodology looks at not only the statement relationships within each factor, but also between each factor. Thus in contrast to Factor A, which scored this statement at -3, the patients in Factor B- are more aware of wasting the rheumatology team's time, making this finding more robust that it initially appears. Patients in this factor may be scoring this statement neutrally due to cautious agreement. The comments suggest that patients do worry about wasting the rheumatology team's time, but feel they shouldn't worry about this, which may be causing a conflict in sorting the statement:

> *"I do worry about this [wasting the rheumatology team's time], even though I shouldn't. I went to the Dr and had to keep going back for help and it wasn't getting any better – but it wasn't getting any worse. So I thought, they know how bad it is, they don't need to see me unless it gets worse, so I left it"* (P9)

These patients are also more reluctant to seek help than patients in Factor A due to worries about wasting their own time (F18: 0). They may wait until their next scheduled appointment before seeking help (F17: +1) and will try and manage their symptoms until the flare stops (F14: +1). This statement received one comment, which suggests that this can involve *"just lying down and not moving until it goes"* (P9).

These patients are not prompted to seek help by the feeling that their flare needs to be controlled by new medication: (F19: -2). There were no comments made relating to this statement and so it is unclear as to whether this is because patients are unable to recognise the signs of a flare that needs to be controlled by a medication change. The tipping point for seeking help specific to patients in this factor is being prompted by a loved one (F11: +2).

In summary, these patients will wait to seek help whilst they are indecisive about whether they are in a flare, they are cautious of contacting the medical team until they are sure of this ("cautious indecision") due to worries about wasting the rheumatology team's time and beliefs that they should manage alone and often wait until prompted by someone else.

8.7.6 Flare help-seeking summary

This Q-study suggests that patients will seek help for their RA flares due to the intensity of the pain, longevity of the flare and no longer being able to control their symptoms. Although this appears to be a succinct explanation of why patients seek help, this study finds that there are at least two ways in which patients differ in how they reach the decision to seek help (Fig 8.2). Some patients will quickly define their symptoms as a flare and make a definite decision to seek help, believing that the medical team are there to help them. However, other patients are indecisive as to whether their symptoms constitute a flare, hoping that it will go away, and are cautious of seeking help due to worries about wasting the rheumatology team's time and beliefs that they should manage alone.

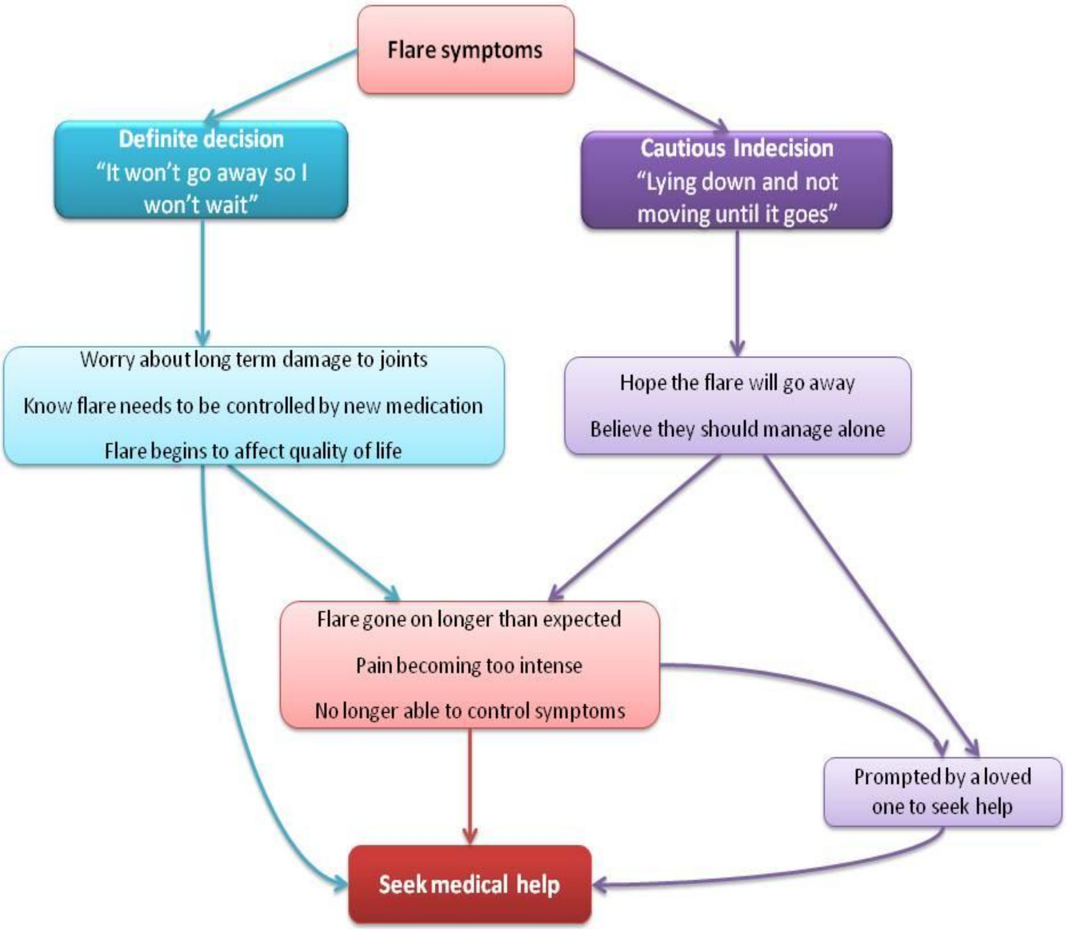


Figure 8.2: Decisions about seeking help in a flare

8.8 Comparing patients across both Q-sorts

To see whether any relationships exist between patients' experience of daily life and their help-seeking behaviours, patients have been compared according to the factors they loaded onto across the two Q-sorts (Fig 8.3). Two patients did not load onto any factors on either of the two Q-sorts (one of whom did not take part in the flare help-seeking Q-sort) 11 patients did not load onto any factors on one of the two Q-sorts and therefore cannot be compared across the two studies. Of the patients who loaded onto both Q-sorts; all the patients who loaded onto daily life Factor A+ ('taking active control') and the man who loaded onto daily life Factor B+ ('feeling good') also loaded onto flare help-seeking Factor A ('definite decision'). Patients who loaded onto one of the two flare help-seeking factors were not split evenly (Factor A: 72.7%; Factor B-: 27.3%). Thus the patients who loaded onto daily life Factor B- ('constant struggle') were divided between the flare help-seeking factors in a similar proportion to the overall study (Factor A: 71.4%; Factor B-: 28.6%). However, patients who loaded onto daily life Factor C- ('keeping RA in its place') were also divided between the flare help-seeking factors, but with a higher proportion loading onto flare help-seeking Factor B- (‘cautious indecision’) than the study proportion (Factor A: 60%; Factor B-: 40%).

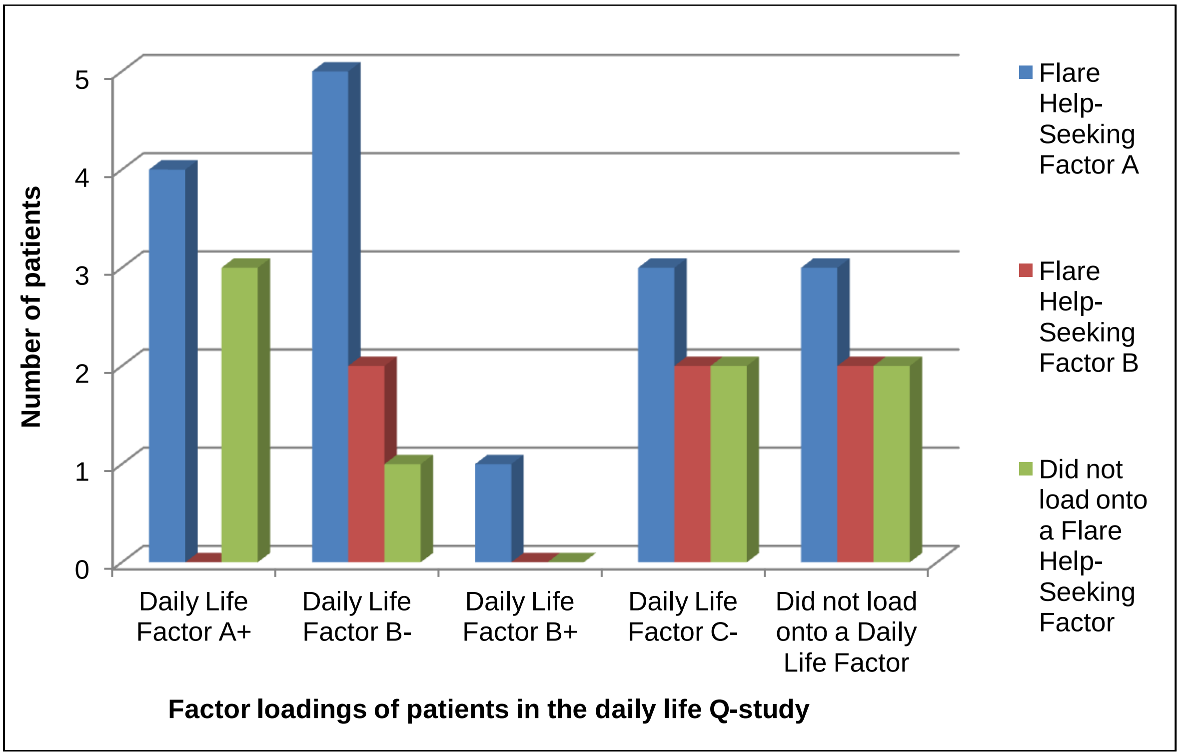


Figure 8.3: Graph showing the comparison of patient loading across both Q-studies

8.9 Discussion

The findings from both the daily life and flare help-seeking Q-methodology studies have been incorporated into the Fluctuating Balances Model (Fig 6.22, Chapter 6) to further expand and clarify the conceptual model (Fig 8.4). In terms of help-seeking, the tipping points have been incorporated into this model, along with additional arrows to indicate patients who will skip the trying to regain control stage (‘definite decision’ makers) and patients who fluctuate between trying to make sense of fluctuations and trying to regain control before finally seeking help (‘cautious indecision’). The findings from the daily life Q-sort suggest that patients experience varying degrees of impact on their lives, which they can balance with expert self-management techniques and allowing RA to have less importance in their lives. Although balance seems to be necessary to reduce the impact of RA, not all patients are able to achieve this. Thus the four experiences of daily life with RA have been incorporated into the model through their link with the underpinning theme of ‘trying to maintain a balance’.

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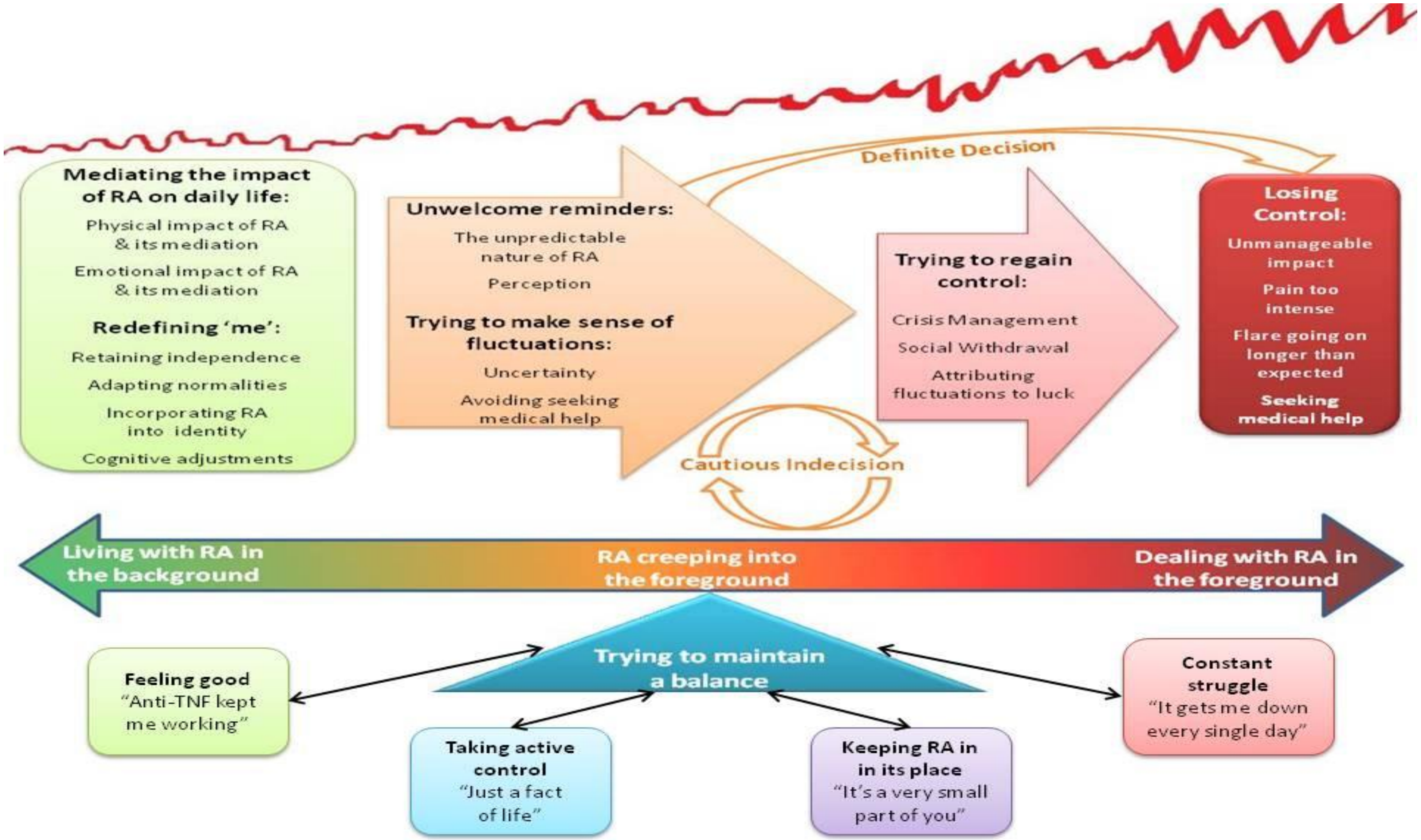

Figure 8.4: Final fluctuating balances model

This idea of patients balancing the impact that RA has on their lives supports the impact triad (Sanderson *et al,* 2011b), which claims that disease severity, importance and self-management affect the level of impact on a patient's life and these can mediate each other. An example of both the Impact Triad and Fluctuating Balances Model is daily life Factor A+ ('taking active control'), in which despite having greater disease severity, patients experience less impact on their lives due to their expertise in self-management and placing less importance on their symptoms. They have therefore balanced their fluctuating disease with self-management and attributing less importance, thus placing their RA in the background of their lives. In contrast, patients in Factor B- ('constant struggle') experience greater impact on their lives, despite having less disease severity, due to placing high importance on their symptoms and rejecting self-management techniques. These patients seem unable to maintain the balance of RA and therefore regularly experience RA in the foreground of their lives (Fig 8.4).

The factors from the two Q-studies were compared to see whether there was any relationship between the way patients experience daily life and their help-seeking behaviours. The only relationship of particular note is that none of the patients loading onto daily life Factor A+ ('taking active control') loaded onto flare help-seeking Factor B- ("cautious indecision') This clearly supports that there are two separate constructs, and that the patients in Factor A+ take a practical approach to their RA, knowing when and how to seek help.

This daily life study indicates that men may be struggling to cope with their RA and experiencing negative emotions and a greater impact on their lives because of this. This is supported by Study 1 (Chapter 6) in which James discusses having to relinquish male coping strategies and Michael reports feeling angry:

> *"You can't go and thump a wall because you end up with a flare so, and you can't go and kick a football around or anything like that"* (James, 47)
>
> *"No room for self pity at all or anything, no, just anger really"* (Michael, 48)

The finding that men struggle to cope with their RA supports a previous small qualitative study in RA (Hale *et al*, 2006), which found that men and women displayed different coping needs. It also supports the proposal that a new health strategy is needed, which takes into consideration the specific needs of men (White *et al*, 2011). The experiences of men with RA have not previously been explored in depth and this needs further investigation.

The younger women in the daily life Q-study reported not allowing RA to impact on their lives. As these women were more recently diagnosed, they had less disability than the other patients in this study, which may be why they seem to experience less impact of RA. However, the discourse also suggests that these young women will prioritize their responsibilities over their well-being, they may therefore be playing down the impact of their RA as a coping strategy. This idea is supported by Study 1 (Chapter 6) in which Emma says:

> *"Well I could still say it doesn't really affect me that much, but you know, I know that's not really true but it does seem right to say that"* (Emma, 42)

By putting their RA in its place these patients seem to be trying to maintain normality in their lives. This would support findings in Study 1 (Chapter 6) and previous research that suggested six distinct typologies of normality exist in RA, which show how patients respond differently to the challenges of RA (Sanderson *et al*, 2011a). The current study did not identify these six different typologies of normality, but the concept of normality appears to be important, particularly to younger patients.

The flare help-seeking Q-study suggests that patients will be prompted to seek help for an RA flare due to pain intensity, longevity of the flare and no longer being able to control their symptoms (statements which achieved consensus). This supports previous research (Hewlett *et al*, 2012), which found that patients will seek help from the medical team once they are certain they are in a flare and have increased their self-management. Patients in this study reached consensus that they will not avoid help-seeking due to not getting on with their rheumatology team. This contrasts to the study from which this statement originated (Kett *et al*, 2010), which was carried out with an ethnically diverse population, whilst the current study was conducted with White British patients. Thus White British patients may have a very different experience of care in comparison to patients from different cultural and ethnic backgrounds.

Whilst some patients will seek help quickly for their RA flare, others will wait, potentially causing further joint damage, due to beliefs that they should manage alone. The only difference that could be identified between these patients is that the majority of the patients who would seek help quickly were taking anti-TNF therapies, whereas those patients who will wait were not. This difference could be attributed to a number of reasons. It is possible that patients on anti-TNF therapies have a different experience of care due to regular contact with the team because of repeated medication reviews. Patients who have not been prescribed anti-TNF therapies may feel as though their symptoms are not validated, due to not having been offered this desirable, expensive treatment, which would support previous qualitative research that found patients perceive anti-TNF therapies as expensive and worry about failing to 'qualify' for this treatment (Sanderson *et al,* 2009). This may explain why they worry more about wasting the rheumatology team's time and feel they should manage alone. This study does not establish the cause and effect of the relationship between help-seeking and drug treatment, and so it is also possible that some patients have been prescribed anti-TNF therapies due to their help-seeking behaviours, therefore enabling the rheumatology team to treat their symptoms effectively.

A further reason for the difference between the two types of help-seeking behaviour could be due to the definition of flare that patients were using. The researcher did explain that flare was thought of as the type of flare that causes patients to seek medical help, but patients seemed to be using more than one definition of flare, such as one painful, swollen joint:

> *"Sometimes just my thumb or just my knee hurts"* (P1)

The use of more than one definition of flare by patients supports previous qualitative research in RA, which found that patients use five different definitions of the word flare (Hewlett *et al,* 2012). These different types of flare may create different help-seeking behaviours due to differences in severity and perceived cause and therefore differences in the impact the flare has on patients' lives.

8.7.1 Strengths and limitations

This study may be criticised for lack of generalisability, due to the relatively small number of participants. However, Q-methodology does not aim to be generalisable, it aims to sample the range of opinions and beliefs held about the subject. As patients were sampled from three different NHS Trusts, all of which have different ways for patients to access care, it is likely that a wide range of opinions were represented.

This study used patient-defined flare (patients were asked whether they felt they were in a flare or not at the time of participating), rather than an objective measure, it is therefore not possible to tell whether patients were in a clinical flare or not at the time of participating in the study. Further, patients were not asked to provide their definition of flare, which would have aided interpretation in terms of why patients may delay help-seeking. However, this was a pragmatic study, and the lack of consensus of a flare definition may pose a clinical problem, which was reflected in this study.

Q-methodology can be criticised for imposing beliefs onto participants by giving them opinions to sort. However, the statements patients sorted came from interviews with 15 RA patients as well as the literature and should therefore represent a wide range of relevant opinions. Further, the comments booklets allowed patients to expand on their sorting, thus reducing the influence of the researcher's beliefs on the factor explanations.

A strength of these Q-studies is that they were carried out on a one-to-one basis, thus removing conformity bias (Asch, 1958) in which people conform to the majority, which may occur with other consensus techniques (Chapter 5.5.4). As patients were sorting cards across a grid they could not perceive the full story they were telling and were therefore able to be more open with their responses. This was particularly important for the male participants, as men will tend to provide a discourse that protects their masculinity (Knight *et al*, 2012). It has been proposed that men discuss their health in ways that draw on and reproduce idealised masculine expectations (what it means to be a 'real' man) (Knight *et al*, 2012) and it has been suggested that men need to be given explicit permission to break with the ideals of what men talk about (Oliffe and Mroz, 2005). It is therefore possible that the finding that men appear to be struggling with their RA may not have been discovered through qualitative interviews, when they had to present a cohesive story to another person (female) and thus might have been tempted to preserve their masculinity by hiding certain feelings or thoughts, or editing their narrative.

8.10 Summary

Daily life with RA has less impact on some patients than others, which can be due to less disease severity, expert self-management or attaching less importance to their RA. However, RA has a larger impact on other patients, the majority of whom seem to be male, due to concentrating on physical symptoms and rejecting self-management techniques.

In an RA flare some patients will seek help quickly, whilst others will wait due to beliefs that they should manage alone. Patients will seek help when their pain is too intense, their flare has gone on longer than expected and they are no longer able to control their flare. Patients may therefore see medical help-seeking as a last resort, when they are no longer able to cope alone.

Studies 1 and 2 explored daily life with RA and help-seeking behaviour in a flare, first through qualitative methods and then explored these further for clustering and by consensus, their importance. In study 3 therefore, the daily symptoms and behaviours patients identified as most important will be examined in quantitative terms to understand the daily variation of symptoms and the levels that prompt help-seeking.

Chapter 9: Study 3: Understanding daily life and flare help-seeking (Exploratory and feasibility survey)

The current chapter presents the results of Study 3, which used items that were identified as important by patients in Study 2 to further understand daily variation and flare help-seeking.

9.1 Aims and objectives for Study 3

The aims of Study 3 were:

1. To explore the range, variation and level of patients' symptoms over time
2. To explore patients' tipping points for seeking help
3. To explore the feasibility of collecting daily data
4. To explore the feasibility of collecting data from patients in a flare

Thus the objectives of Study 3 were:

1. To assess the recruitment and attrition rates
2. To assess the acceptability of the questions and the rate of completion
3. To assess the effect of missing data and how to handle this
4. To provide initial data on the range and variation of experiences over time

9.2 Summary of Study 3 methods

This study was divided into two parts, in both of which patients completed a baseline questionnaire (Appendix C) comprising demographic questions and the HAQ (Fries *et al,* 1980). Patients in Study 3a (Daily Variation) then completed a Daily Symptoms Questionnaire for three months (Appendix L1) with an accompanying Weekly Impact and Management Questionnaire (Appendix L2). They had the option of completing the questionnaires online, or through traditional pen and paper responses, patients who chose the latter posted their responses back at the end of each week.

Patients in Study 3b (Flare Help-Seeking) needed to be experiencing a flare, therefore Study 3b involved patients who phoned the rheumatology helpline (where patients leave a message for a rheumatology specialist nurse to call them back for help or to make an emergency appointment) in a self-defined RA flare. Those who arranged an appointment to have their symptoms reviewed were invited to find out more about the study by the rheumatology specialist nurse who responded to their call. Patients were then approached by the researcher to explain the study. Those who agreed to take part completed a questionnaire pack in clinic that comprised the same Daily Symptoms Questionnaire (Appendix N1), a Flare Help-Seeking

Questionnaire (Appendix N2) to explore motivations for seeking help, and a Flare Early Warnings Questionnaire (Appendix N3); and were sent the Daily Symptoms Questionnaire to complete again four weeks after their appointment (when they should no longer be in a flare) in order to examine change in experienced symptoms. For the full study methods see Chapter 5.6.

9.3 Questionnaire development

The Daily Symptoms Questionnaire items were developed from Study 2 (Q-methodology) and comprised issues that either gained overall consensus in the Q-methodology study, or were rated as important by one subset of participants (Factor). Where possible a single validated item was used for each issue, but where this did not exist a single item was created based on the words used by patients in Studies 1 and 2, and with the advice of a patient partner and the study team. The Weekly Impact and Management Questionnaire was developed in the same manner. The justification and source for each item on each questionnaire are provided in Tables 9.1 and 9.2.

Flare early warnings were not included as an item in Study 2 as few patients in Study 1 mentioned these. However, a previous qualitative study across five countries found that RA patients could identify early warnings of their flares (Hewlett *et al*, 2012) and a questionnaire was developed to capture this (Bartlett *et al*, 2012) and a Flare Early Warnings Questionnaire was included in Study 3b to explore the issue further. Items were informed by the previous publications (Hewlett *et al,* 2012, Bartlett *et al,* 2012) (Table 9.3).

Table 9.1: Justification and sources for Daily Symptoms Questionnaire items

Questionnaire item 0-10	**Justification for inclusion**	**Source**
1. How much pain do you have?	Study 2: Factor B- scored +4 on the daily life item "*Experiencing pain daily"*	Pain numerical rating scale (NRS) Farrar *et al* (2001)
2. What is your average level of fatigue?	Study 2: Factor B- scored +4 on the daily life item "*Experiencing unexplainable fatigue/exhaustion daily"*	Bristol Rheumatoid Arthritis Fatigue (BRAF) scale Nicklin *et al* (2010a)
3. How much joint swelling do you have?	Study 2: Factor B- scored +1 on the daily life item "*Experiencing swelling daily"*	Item created*
4. How much joint stiffness do you have?	Study 2: Factor B- scored +2 on the daily life item "*Experiencing stiffness daily"*	Item created*
5. How much time today did you spend being frustrated by your RA?	Study 2: Factor B- scored +3 and Factor C score +2 on the daily life item "*Getting frustrated due to my RA"*	Item created*
6. How much time today did you spend being angry about your RA?	Study 2: Factor B- scored +5 on the daily life item "*Being angry because of my RA"*	Item created*
7. How much time today was your RA a worry in your life?	Study 2: Factor B- scored +3 on the daily life item "*Worrying because of my RA"*	Item created*
8. Is your rheumatoid arthritis in a flare condition today?	To clarify whether current symptoms represent daily life or flare	Item created*

**Item created by the researcher as an existing item could not be found*

Table 9.2: Justification and sources for Weekly Impact and Management Questionnaire items

Questionnaire item	Justification for inclusion	Source
1. How many times (if at all) have you had to cancel/change your plans due to your RA?	Study 2: Consensus reached on the daily life item *"I sometimes have to cancel plans due to my RA"*	Item created*
2. Over the past week, what things have you <u>tried</u> to help you deal with your arthritis? (Tick)		
2a. Avoided or altered doing the things that might cause pain	Study 1: Identified as a self-management technique	Rheumatoid Arthritis Self-Efficacy (RASE) scale Hewlett *et al* (2001) Modified to indicate what patients *have* done rather than believe they could do
2b. Gave myself permission to leave a task half-finished	Study 2: Consensus reached on the daily life item *"Giving myself permission to leave a task half finished"*	Item created*
2c. Distracted myself from my symptoms	Study 2: Factor A scored +2 on the daily life item *"Distracting myself from my symptoms"*	Item created*
2d. Asked for help with the difficulties of everyday tasks	Study 2: Factor A scored +2 on the daily life item *"Finding a balance between asking for help and remaining independent"*	Rheumatoid Arthritis Self-Efficacy (RASE) scale Hewlett *et al* (2001) Altered to indicate what patients *have* done rather than believe they could do
2e. Made small adjustments to my day to deal with the difficulties of everyday tasks	Study 2: Factor A scored +5 on the daily life item *"Making small adjustments to my day or activities constantly because of my RA"*	Item created*

Table 9.2 continued overleaf

2f. Made time for socialising	Phase 1: Socialising identified as a self-management technique	Rheumatoid Arthritis Self-Efficacy (RASE) scale Hewlett *et al* (2001) Altered to indicate what patients *have* done rather than believe they could do
2g. Allocated time for relaxation	Study 2: Factor A scored +2 and Factor B+ scored +1 on the daily life item *“Planning rest time into my week”*	Rheumatoid Arthritis Self-Efficacy (RASE) scale Hewlett *et al* (2001) Altered to indicate what patients *have* done rather than believe they could do
2h. Managed my medication (knowing when and how to take it)	Study 2: Factor A scored +3, Factor B+ scored +1 and Factor C scored +2 on the daily life item *“Taking my medication exactly as prescribed”*	Rheumatoid Arthritis Self-Efficacy (RASE) scale Hewlett *et al* (2001) Altered to indicate what patients *have* done rather than believe they could do
2i. Contacted my doctor or other health professional	To understand patients help-seeking behaviours in relation to their daily symptoms	Item created*
3. Considering your arthritis overall, how would you rate your level of physical well-being during the past week? Circle the number that best describes your level of physical well-being.	To provide an overview of how patients view their physical well-being each week	Rheumatoid Arthritis Impact of Disease (RAID) scale Gossec *et al* (2008)
4. Considering your arthritis overall, how would you rate your level of emotional well-being during the past week? Circle the number that best describes your level of emotional well-being.	To provide an overview of how patients view their emotional; well-being each week	Rheumatoid Arthritis Impact of Disease (RAID) scale Gossec *et al* (2008)

**Item created by the researcher as an existing item could not be found*

Table 9.3: Justification and sources for Flare Help-Seeking Questionnaire items

Questionnaire item	Justification for inclusion	Source
1. Please circle the number that describes the severity of your RA flare	Study 2: Consensus of +3 reached on the flare help-seeking item *"I seek help from the medical team when the pain becomes too intense"*. Thus overall severity was measured in this study	Rheumatoid arthritis flare evaluation 1.0 OM RA Flare working group. Dec 2010
2. Considering your normal ability to run or manage your life (at work or home), please circle the number that describes how you are currently managing	Study 2: Factor B scored +4 on the flare help-seeking item *"I seek help from the medical team once flare starts to affect my quality of life too much".* Divided into two separate questions for this study	Rheumatoid arthritis flare evaluation 1.0 OM RA Flare working group. Dec 2010 *(Question wording slightly modified. One question divided between questions 2 and 3 to provide clarity)*
3. Considering your ability to take part in social and/or pleasurable activities that are normal for you, please circle the number that describes your current level of involvement	Study 2: Factor B scored +4 on the flare help-seeking item *"I seek help from the medical team once flare starts to affect my quality of life too much".* Divided into two separate questions for this study	Rheumatoid arthritis flare evaluation 1.0 OM RA Flare working group. Dec 2010 *(Question wording slightly modified. One question divided between questions 2 and 3 to provide clarity)*
4. Considering your arthritis overall, please circle how well you coped with your disease during the last week?	Study 2: Consensus of +3 reached on the flare help-seeking item *"I seek help from the medical team when my symptoms become uncontrollable"*	Rheumatoid arthritis flare evaluation 1.0 OM RA Flare working group. Dec 2010
5. As a result of this flare, what did you do? *(Tick as many boxes as apply):*	Study 1: Identified that patients will go through a period of crisis management prior to seeking help for an RA flare.	Overall question: Rheumatoid arthritis flare evaluation 1.0 OM RA Flare working group. Dec 2010 Some individual items have been altered - see below

Table 9.3 continued overleaf

5a. I didn't do anything different	N/A	Unaltered
5b. I reduced the amount of activities I did	Study 1: Identified patients cancel plans due to RA flares	Unaltered
5c. I increased my rest time	Study 1: Identified as a self-management technique Study 2: Factor A scored +2 on the daily life item "*Planning rest time into my week"*	Item added by researcher, due to the lack of practical management items in the rheumatoid arthritis flare evaluation questionnaire
5d. I avoided doing activities I had planned to do	Study 1: Identified patients cancel plans due to RA flares	Unaltered
5e. I asked for help with everyday Tasks	Study 1: Identified as a self-management technique Study 2: Factor A scored +2 on the daily life item "*Finding a balance between asking for help and remaining independent"*	Item added by researcher, due to the lack of practical management items in the rheumatoid arthritis flare evaluation questionnaire
5d. I tried to distract myself from my symptoms	Study 1: Identified as a self-management technique Study 2: Factor A scored +2 on the daily life item *"Distracting myself from my symptoms"*	Item added by researcher, due to the lack of practical management items in the rheumatoid arthritis flare evaluation questionnaire
5e. I took more painkillers or extra anti-inflammatory medications (NSAIDS)	Study 1: Identified patients increase medication before seeking medical help for an RA flare	Examples of medication removed from this item as the researcher felt this made the item confusing
5f. I took more steroid tablets	Study 1: Identified patients increase medication before seeking medical help for an RA flare	Examples of medication removed from this item as the researcher felt this made the item confusing
6. What finally caused you to decide to contact the medical team?	An open question to capture patients' final tipping points and to highlight any issues not captured in Studies 1 and 2.	Item created*

Table 9.3 continued overleaf

7. Do any of the following apply to you?		
7a. I avoided seeking medical help as I didn’t want to be given any more medication	Study 1: Identified as a reason for delaying help-seeking	Item created*
7b. I waited until the Flare had lasted longer than I expected before seeking help	Consensus of +2 reached on the flare help-seeking item “*I seek help from the medical team when the flare has gone on longer than I expected”*	Item created*
7c. I waited until I had more than one Flare symptom before seeking medical help	Consensus of 0 reached on the flare help-seeking item *“I wait until I have more than one flare symptom before seeking help”.* Although only scored at 0, the comments suggest that this placing is because this depends on the type of flare patients are experiencing, thus this item has been included	Item created*
7d. I was prompted by a family member/friend to seek medical help	Study 2: Factor B scored +2 on the flare help-seeking item “*A loved one tells me I ought to seek medical help”*	Item created*

**Item created by the researcher as an existing item could not be found*

9.4 Results: Study 3a: Daily and weekly symptoms, impact and self-management

9.4.1 Study 3a participants

45 people with RA were invited to participate from UHBT, NBT and ASPH and 28 (62%) agreed to take part. One participant did not begin completing the daily measures, despite two reminders, thus 27 patients took part in Study 3a (Fig 9.1). 7 participants (26%) chose to complete the measures online, 20 chose the pen and paper option and no patients chose the telephone option. The majority of the participants were female (82%) and ages ranged from 24 to 83 years (mean: 59.7yrs; SD: 14.4) (Table 9.4). Patients were on a range of treatment regimes and had a disease duration of 1 to 57 years (mean: 16.2yrs; SD: 14.4), and a wide range of self-reported disease activity (DAS global) and disability (HAQ). The majority of patients were retired and all were White British in ethnic origin (Table 9.4).

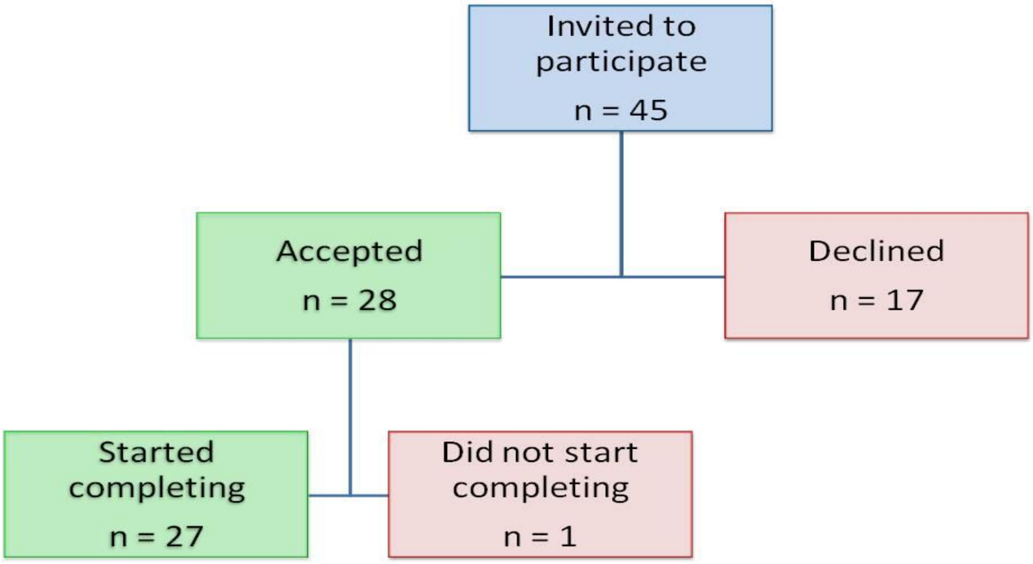

Figure 9.1: Flow diagram of recruitment for Study 3a: Daily and weekly measure

Table 9.4: Demographic information for participants in Study 3a: Daily and weekly symptoms, impact and self-management

ID	Gender	Age (yrs)	Dis Dur (yrs)	HAQ	DAS VAS	Med	NHS Trust*	Work status	Help at home	Dependents
P1	F	64	32	2.50	Unknown*	DMARDs	1	Retired	Husband	None
P2	F	78	21	1.13	2.0	Steroids	1	Retired	Husband**	Husband**
P3	F	59	4	0.88	2.5	DMARDs Steroids	1	Retired	None	None
P4	M	55	12	2.25	5.1	DMARDs Steroids	2	Employed	Wife	None
P5	F	61	13	2.63	8.7	DMARDs Steroids	2	Retired	Grown-up children	None
P6	M	48	18	0.88	4.9	Anti-TNF DMARDs	2	Employed	Grown up children	None
P7	F	73	48	2.25	4.5	DMARDs Steroids	2	Retired	Grown-up children	None
P8	M	57	10	1.00	5.4	DMARDs	1	Employed	Wife	None
P9	F	36	2	0.75	2.3	DMARDs	1	Employed	Partner, Grown-up child	None
P10	F	42	8	1.38	2.6	DMARDs Steroids	1	Employed	Husband	2 children
P11	F	24	10	1.50	4.9	Anti-TNF DMARDs	3	Employed	Partner	1 child
P12	M	62	1	0.00	1.3	DMARDs	3	Employed	Wife	None
P13	F	49	10	1.38	7.8	DMARDs	3	On sick leave,	Child (17yrs)	1 child
P14	F	83	15	2.00	5.0	DMARDs	3	Retired	Husband	None
P15	M	68	57	2.63	7.6	DMARDs Steroids	3	Retired	Wife	Wife
P16	F	80	4	2.63	3.3	Anti-TNF	3	Retired	Husband	None
P17	F	78	28	3.00	7.2	DMARDs Steroids	1	Retired	Husband	None
P18	F	60	10	1.13	4.1	DMARDs	1	Retired	Husband**	Husband**
P19	F	61	11	2.38	4.7	Steroids	2	Retired	Husband	None
P20	F	52	22	2.38	3.1	Anti-TNF DMARDs	2	Incapacity	Husband & home help	None

Table 9.4 continued overleaf

P21	F	52	33	0.25	0.2	NSAIDs	2	Employed	Partner	None
P22	F	64	15	1.75	1.3	Anti-TNF DMARDs	2	Retired	Husband	None
P23	F	74	8	2.75	6.1	DMARDs Steroids	3	Retired	Husband	None
P24	F	73	7	1.25	0.8	DMARDs Steroids	1	Retired	Husband	None
P25	F	60	4	2.75	8.4	Steroids	3	Retired	Husband	None
P26	F	37	18	1.88	3.4	Anti-TNF DMARDs	2	Self-employed	Husband and young carer	2 children
P27	F	61	Unknown***	Unknown***	Unknown***	Unknown*	3	Retired	Husband	None
Mean		59.7	16.2	1.7	4.3					
Stan dev		14.4	13.7	0.8	2.4					

*Nb NHS Trusts have been distinguished by numbers due to concerns about retaining patients' anonymity
*****Nb patient and husband both care for and depend on each other
**Not completed by patient

Key:
Dis Dur = Disease Duration
HAQ = Health Assessment Questionnaire score
DAS VAS = Disease activity score visual analogue scale (DAS global)
Medication: Anti-TNF = Anti-Tumour Necrosis Factor; DMARDs = Disease Modifying Anti-Rheumatic Drugs; NSAIDs = Non-steroidal anti-inflammatory; Steroids = Glucocorticosteroids

9.4.2 Missing data

7 participants (26%) completed all 91 days of data collection, while 16 participants (59%) had between 1 and 45 days of missing data due to forgetting to complete or illness. Four participants (15%) withdrew from the study early, one due to illness; the others did not provide a reason (Table 9.5). Seventeen patients (63%) returned at least 81/91 days data and were taken forward for further analysis. Patients with fewer completed days than this had too many gaps to analyse the data with any certainty.

Table 9.5: Summary of missing data for participants in Study 3a: Daily and weekly measures

Participant	Missing days	Reason
P1	*11*	*Consecutive days - Ill with flu couldn't distinguish between symptoms so did not complete*
P2	1	1st day – forgot to start
P3	*13*	*Individual days - forgot to complete*
P4	*31*	*1 individual day – forgot to complete* *30 consecutive days – finished study early, no reason given*
P5	1	Forgot to complete
P6	*42*	*Completed sporadically with no explanation, despite reminders*
P7	2	Individual days – forgot to complete
P8	1	Forgot to complete
P9	*56*	*All consecutive – finished study early, no reason given*
P10	1	Forgot to complete
P11	4	Individual days - forgot to complete
P12	*55*	*13 Individual days - forgot to complete* *Finished 42 days early, no reason given*
P13	*45*	*Completed sporadically with no explanation, despite reminders*
P14	0	
P15	3	Individual days - forgot to complete
P16	*42*	*3 individual days – forgot to complete* *Finished 39 days early due to severe flu*
P17	0	
P18	4	Individual days – forgot to complete
P19	1	Forgot to complete
P20	*17*	*Individual days - forgot to complete*
P21	0	
P22	0	
P23	0	
P24	0	
P25	0	
P26	*28*	*Individual days - forgot to complete*
P27	9	2 individual days - forgot to complete Finished 7 days early, no reason given
Mean	**13.5**	
Stan Dev	**18.8**	

Nb: Patients highlighted in *italic* have more than 10 days of missing data

9.4.3 Symptom scores

Every day for 3 months, patients recorded all symptoms from 0 to 10 on a numerical rating scale, with 10 being worst symptoms imaginable. These data were not significantly skewed (Table 9.6), where significance was calculated as at least twice the standard error (SE):

$SE = \sqrt{(6/n)} = \sqrt{(6/17)} = 0.6$

$2 \times SE = 0.6 \times 2 = 1.2$

Thus the means rather than the medians have been reported. The 17 patients included in this analysis reported a mean pain score of 4.3 (SD 2.7), mean fatigue score of 4.7 (SD 2.7), mean joint stiffness score of 3.6 (SD 2.6), mean swollen joints score of 3.9 (SD 2.6), mean frustration score of 3.7 (SD 2.9), mean anger score of 3.1 (SD 3.3) and mean worry score of 3.7 (SD 3.1). Thus pain and fatigue have the highest average severity and anger is the lowest. Patient’s scores ranged from 0 to 10, and thus these overall means mask the range of symptoms experienced.

Patients were asked daily whether they felt their symptoms constituted an RA flare (“Is your rheumatoid arthritis in a flare condition today?”), and examination of these data suggested that there were three groups of patients with broadly common patterns: 1) those who did not report being in an RA flare for the entire three month data collection period, suggesting that these symptoms are how normal daily life can be experienced by people with RA (Daily Life patients, n=8); 2) those who reported one or more flares intermittently throughout the three months (Intermittent Flare patients, n=6); and 3) those who reported being in an RA flare for the entire three months (Constant Flare patients, n=3). For the purpose of analysis, patients have been separated into these three groups (Table 9.6).

Table 9.6: Summary of mean, standard deviation and range of symptoms

Patients		Pain	Fatigue	Stiff Joints	Swollen Joints	Frustration	Anger	Worry
Daily Life	Mean	3.1	3.6	2.4	2.7	2.8	2.2	2,7
	SD	2.3	2.6	1.5	1.9	2.9	3.3	3.1
	Range	10.0	10.0	10.0	10.0	10.0	10.0	10.0
	Min score	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Max score	10.0	10.0	10.0	10.0	10.0	10.0	10.0
Intermittent flare	Mean	4.8	4.9	4.0	4.4	4.1	3.1	4.3
	SD	2.3	2.0	2.1	2.1	2.2	2.6	2.4
	Range	9.0	8.0	9.0	8.0	9.0	8.0	9.0
	Min score	0.0	1.0	0.0	1.0	0.0	0.0	0.0
	Max score	9.0	9.0	9.0	9.0	9.0	8.0	9.0
Constant flare	Mean	6.4	7.0	6.4	6.3	5.5	5.2	5.3
	SD	3.1	2.5	3.3	3.2	3.5	3.6	3.6
	Range	9.0	9.0	9.0	9.0	10.0	10.0	10.0
	Min Score	1.0	1.0	1.0	1.0	0.0	0.0	0.0
	Max Score	10.0	10.0	10.0	10.0	10.0	10.0	10.0
Study Total	**Mean**	**4.3**	**4.7**	**3.6**	**3.9**	**3.7**	**3.1**	**3.7**
	SD	**2.7**	**2.7**	**2.6**	**2.6**	**2.9**	**3.3**	**3.1**
	Range	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**
	Skew	**0.4**	**0.3**	**0.8**	**0.6**	**0.4**	**0.6**	**0.5**

9.4.3.1 Symptoms of Daily Life

Daily Life patients reported a mean pain score of 3.1 (SD 2.3), mean fatigue score of 3.6 (SD 2.6), mean joint stiffness score of 2.4 (SD 1.5), mean swollen joints score of 2.7 (SD 1.9), mean frustration score of 2.8 (SD 2.9), mean anger score of 2.2 (SD 3.3) and mean worry score of 2.7 (SD 3.1) (Table 9.7a). Thus in daily life pain and fatigue are still the highest average scored symptoms and anger is still the lowest scored. These scores are all lower than the respective overall study means, indicating that patients who do not report being in flare are experiencing lower than average symptoms. However, it is of note that even in normal daily life, on average patients are not symptom free. Patients' individual daily scores ranged from 0 to 10 for all symptoms and therefore despite being divided into a smaller group, reporting only the mean scores may still be masking individual differences. For example, daily life patients' mean pain scores ranged from 0.2 (SD 0.5) in patient P24 to 5.8 (SD 2.2) in patient P19, and fatigue scores ranged from 0.4 (SD 0.9) to 7.6 (SD 2.0) (P24 and P23). This demonstrates the wide variation in symptoms experienced between patients who do not consider themselves to be in a flare. However, a mean symptom score, even per patient, does not address the daily fluctuation of RA symptoms over the 3 months, which will be addressed in section 9.4.4.

9.4.3.2 Symptoms of Intermittent Flare

Intermittent Flare patients reported a mean pain score of 4.8 (SD 2.3), mean fatigue score of 4.9 (SD 2.0), mean joint stiffness score of 4.0 (SD 2.1), mean swollen joints score of 4.4 (SD 2.1), mean frustration score of 4.1 (SD 2.2), mean anger score of 3.1 (SD 2.6) and mean worry score of 4.3 (SD 2.4) (Table 9.7b). Thus for patients experiencing intermittent flares, pain and swollen joints are the highest average scored symptoms and anger is still the lowest scored. These scores are all higher than the respective overall study means, indicating that patients experience higher average symptoms when they are in and out of flare than in normal daily life. Patients' individual daily scores ranged from 0 to 9 and therefore, despite being divided into a smaller group, these mean scores may be masking individual differences. Over the 91 days, intermittent flare patients' mean pain scores ranged from 2.5 (SD 1.2) to 7.0 (SD 0.6) (P14 and P17), and swollen joint scores ranged from 2.3 (SD 0.8) to 6.5 (SD 1.6) (P21 and P17), again demonstrating the difference in symptoms experienced between patients. It is of note that all the lowest mean symptom scores for these patients are lower than the highest mean symptom scores for daily life patients. This indicates that some patients experience higher level of symptoms in daily life than others do when experiencing intermittent flares. Individual fluctuations of symptoms will be addressed in Section 9.4.5.

9.4.3.3 Symptoms of Constant Flare

Constant Flare patients reported a mean pain score of 6.4 (SD 3.1), mean fatigue score of 7.0 (SD 2.5), mean joint stiffness score of 6.4 (SD 3.3), mean swollen joints score of 6.3 (SD 3.2), mean frustration score of 5.5 (SD 3.5), mean anger score of 5.2 (SD 3.6) and mean worry score of 5.3 (SD 3.6) (Table 9.7c). Thus for patients in a constant flare, pain and stiff joints are the highest average scored symptoms and anger is still the lowest scored. These scores are all higher than the respective overall study means, indicating that patients experience higher average symptoms when they are in a flare than in normal daily life or experiencing intermittent flares. Patients' individual daily scores ranged from 0 to 10 and therefore despite being divided into a smaller group, these mean scores may be masking individual differences. Constant flare patients' mean pain scores ranged from 2.4 (SD 1.3) to 9.3 (SD 0.8) (P11 and P5) and stiff joint scores ranged from 2.3 (SD 01.5) to 9.5 (SD 0.8) (P11 and P5), demonstrating the range of variation in symptoms experienced between patients. It is again of note that all the lowest mean symptom scores for these patients are lower than the highest mean symptom scores for daily life patients. This indicates that some patients experience higher level of symptoms in daily life than others do when they consider themselves in a flare. Individual fluctuations of symptoms will be addressed in section 9.4.6.

Table 9.7a: Mean, standard deviation and range of symptoms reported by Daily Life patients

Patients		Pain	Fatigue	Stiff Joints	Swollen Joints	Frustration	Anger	Worry
P2	Mean	1.7	1.9	1.5	1.4	1.1	0.0	0.9
	SD	0.8	0.6	0.7	0.5	0.7	0.2	0.5
	Range	2.0	3.0	3.0	2.0	3.0	1.0	2.0
	Min Score	1.0	0.0	0.0	1.0	0.0	0.0	0.0
	Max Score	3.0	3.0	3.0	3.0	3.0	1.0	2.0
P8	Mean	3.6	4.3	3.5	3.5	3.8	3.6	3.7
	SD	1.0	0.9	0.8	0.8	0.6	0.8	0.6
	Range	4.0	3.0	2.0	2.0	3.0	3.0	2.0
	Min Score	1.0	2.0	2.0	2.0	2.0	2.0	2.0
	Max Score	5.0	5.0	4.0	4.0	5.0	5.0	4.0
P10	Mean	2.3	3.0	2.3	2.4	2.2	0.0	2.7
	SD	0.5	0.4	0.5	0.5	0.5	0.2	0.6
	Range	3.0	2.0	3.0	3.0	2.0	1.0	2.0
	Min Score	1.0	2.0	1.0	1.0	1.0	0.0	1.0
	Max Score	4.0	4.0	4.0	4.0	3.0	1.0	3.0
P19	Mean	5.8	6.3	4.8	6.5	4.5	4.5	3.9
	SD	2.2	2.5	1.6	1.6	1.9	2.1	1.7
	Range	8.0	9.0	8.0	7.0	8.0	8.0	7.0
	Min Score	1.0	1.0	0.0	2.0	0.0	0.0	0.0
	Max Score	9.0	10.0	8.0	9.0	8.0	8.0	7.0
P22	Mean	2.0	2.8	1.9	2.2	0.0	0.0	0.0
	SD	0.6	0.7	0.7	0.5	0.0	0.0	0.1
	Range	2.0	1.0	2.0	2.0	0.0	0.0	1.0
	Min Score	1.0	2.0	1.0	1.0	0.0	0.0	0.0
	Max Score	3.0	3.0	3.0	3.0	0.0	0.0	1.0
P23	Mean	5.6	7.6	2.3	2.8	8.7	9.2	9.4
	SD	2.2	2.0	0.8	1.2	0.7	0.7	0.6
	Range	8.0	8.0	5.0	7.0	3.0	2.0	2.0
	Min Score	2.0	2.0	0.0	1.0	7.0	8.0	8.0
	Max Score	10.0	10.0	5.0	8.0	10.0	10.0	10.0
P24	Mean	0.2	0.4	0.3	0.5	0.0	0.0	0.0
	SD	0.5	0.9	0.7	0.9	0.0	0.0	0.0
	Range	3.0	3.0	2.0	3.0	0.0	0.0	0.0
	Min Score	0.0	0.0	0.0	0.0	0.0	0.0	0.0
	Max Score	3.0	3.0	2.0	3.0	0.0	0.0	0.0
P27	Mean	3.5	2.6	2.3	2.3	1.8	0.1	0.7
	SD	1.2	1.3	0.9	1.1	0.9	0.3	0.6
	Range	5.0	5.0	3.0	4.0	4.0	1.0	2.0
	Min Score	1.0	0.0	1.0	1.0	0.0	0.0	0.0
	Max Score	6.0	5.0	4.0	5.0	4.0	1.0	2.0
Total	**Mean**	**3.1**	**3.6**	**2.4**	**2.7**	**2.8**	**2.2**	**2,7**
	SD	**2.3**	**2.6**	**1.5**	**1.9**	**2.9**	**3.3**	**3.1**
	Range	**10.0**	**10.0**	**10.00**	**10.0**	**10.0**	**10.0**	**10.0**
	Min score	**0.0**	**0.0**	**0.00**	**0.0**	**0.0**	**0.0**	**0.0**
	Max score	**10.0**	**10.0**	**10.00**	**10.0**	**10.0**	**10.0**	**10.0**

Nb. Highest mean scores for each patient group highlighted in blue, lowest mean scores for each patient group highlighted in yellow

Table 9.7b: Mean, standard deviation and range of symptoms reported by Intermittent Flare patients

Patients		Pain	Fatigue	Stiff Joints	Swollen Joints	Frustration	Anger	Worry
P7	Mean	6.6	7.4	4.9	5.4	6.3	5.7	7.8
	SD	1.0	1.0	1.0	1.0	1.2	1.3	1.2
	Range	5.0	4.0	4.0	3.0	7.0	6.0	6.0
	Min Score	4.0	5.0	3.0	4.0	2.0	2.0	3.0
	Max Score	9.0	9.0	7.0	7.0	9.0	8.0	9.0
P14	Mean	2.5	3.9	1.7	3.0	2.1	0.0	1.9
	SD	1.2	0.8	0.7	0.8	0.7	0.3	0.8
	Range	6.0	5.0	3.0	4.0	4.0	3.0	4.0
	Min Score	0.0	2.0	0.0	1.0	0.0	0.0	0.0
	Max Score	6.0	7.0	3.0	5.0	4.0	3.0	4.0
P15	Mean	6.9	5.8	6.2	6.5	5.9	5.1	5.8
	SD	0.8	0.7	1.1	1.0	0.9	0.8	0.8
	Range	4.0	4.0	5.0	4.0	5.0	4.0	4.0
	Min Score	5.0	4.0	3.0	4.0	3.0	3.0	3.0
	Max Score	9.0	8.0	8.0	8.0	8.0	7.0	7.0
P17	Mean	7.0	6.4	6.1	6.5	6.0	5.6	5.6
	SD	0.6	0.9	0.9	0.9	1.0	1.2	1.0
	Range	3.0	4.0	4.0	5.0	6.0	6.0	4.0
	Min Score	5.0	4.0	4.0	4.0	2.0	2.0	4.0
	Max Score	8.0	8.0	8.0	9.0	8.0	8.0	8.0
P18	Mean	2.8	2.7	2.6	2.8	2.6	2.3	2.3
	SD	1.4	1.2	1.5	1.5	1.4	1.2	1.1
	Range	8.0	8.0	8.0	8.0	7.0	6.0	6.0
	Min Score	1.0	1.0	1.0	1.0	1.0	1.0	1.0
	Max Score	9.0	9.0	9.0	9.0	8.0	7.0	7.0
P21	Mean	3.2	3.0	2.3	2.3	2.1	0.0	2.4
	SD	0.7	0.9	0.9	0.8	0.8	0.1	0.7
	Range	3.0	3.0	3.0	3.0	4.0	1.0	3.0
	Min Score	2.0	1.0	1.0	1.0	0.0	0.0	1.0
	Max Score	5.0	5.0	4.0	4.0	4.0	1.0	4.0
Total	**Mean**	**4.8**	**4.9**	**4.0**	**4.4**	**4.1**	**3.1**	**4.3**
	SD	**2.3**	**2.0**	**2.1**	**2.1**	**2.2**	**2.6**	**2.4**
	Range	**9.0**	**8.0**	**9.0**	**8.0**	**9.0**	**8.0**	**9.0**
	Min score	**0.0**	**1.0**	**0.0**	**1.0**	**0.0**	**0.0**	**0.0**
	Max score	**9.0**	**9.0**	**9.0**	**9.0**	**9.0**	**8.0**	**9.0**

Nb. Highest mean scores for each patient group highlighted in blue, lowest mean scores for each patient group highlighted in yellow

Table 9.7c: Mean, standard deviation and range of symptoms reported by Constant Flare patients

Patients		Pain	Fatigue	Stiff Joints	Swollen Joints	Frustration	Anger	Worry
P5	Mean	9.3	9.3	9.5	9.5	9.0	8.9	8.9
	SD	0.8	0.7	0.8	0.7	0.7	0.7	0.7
	Range	4.0	3.0	4.0	4.0	4.0	4.0	5.0
	Min Score	6.0	7.0	6.0	6.0	6.0	6.0	5.0
	Max Score	10.0	10.0	10.0	10.0	10.0	10.0	10.0
P11	Mean	2.4	4.4	2.3	2.2	1.1	0.7	0.6
	SD	1.3	2.1	1.5	1.4	1.3	0.9	0.9
	Range	6.0	8.0	6.0	5.0	7.0	5.0	5.0
	Min Score	1.0	1.0	1.0	1.0	0.0	0.0	0.0
	Max Score	7.0	9.0	7.0	6.0	7.0	5.0	5.0
P25	Mean	7.3	7.3	7.3	7.2	6.2	5.9	6.2
	SD	1.4	1.4	1.1	1.3	1.4	1.5	1.2
	Range	6.0	6.0	6.0	6.0	8.0	9.0	9.0
	Min Score	4.0	4.0	4.0	4.0	2.0	1.0	1.0
	Max Score	10.0	10.0	10.0	10.0	10.0	10.0	10.0
Total	**Mean**	**6.4**	**7.0**	**6.4**	**6.3**	**5.5**	**5.2**	**5.3**
	SD	**3.1**	**2.5**	**3.3**	**3.2**	**3.5**	**3.6**	**3.6**
	Range	**9.0**	**9.0**	**9.0**	**9.0**	**10.0**	**10.0**	**10.0**
	Min Score	**1.0**	**1.0**	**1.0**	**1.0**	**0.0**	**0.0**	**0.0**
	Max Score	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**
Study total	**Mean**	**4.3**	**4.7**	**3.6**	**3.9**	**3.7**	**3.1**	**3.7**
	SD	**2.7**	**2.7**	**2.6**	**2.6**	**2.9**	**3.3**	**3.1**
	Range	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**
	Min Score	**1.0**	**1.0**	**1.0**	**1.0**	**0.0**	**0.0**	**0.0**
	Max Score	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**	**10.0**

Nb. Highest mean scores for each patient group highlighted in blue, lowest mean scores for each patient group highlighted in yellow

9.4.4 Symptom patterns

Patients recorded the severity of four physical symptoms and three emotional symptoms, and these have been combined to produce overall physical and emotional scores for each patient in the form of the percentage of the total possible score. For example on day 1 patient P18 scored 2 (out of a possible 10) for pain, 3 for fatigue, 2 for swollen joints and 2 for stiffness and thus scored 9 out of a possible 40 for physical symptoms, or 22.5% of the total possible physical symptoms score. In order to visualise the fluctuation of symptoms across time and to identify patterns, these overall symptom scores have been displayed in a graph, per patient. Whilst these graphs provide the overall patterns of physical and emotional symptoms per patient, they do not address the fluctuations of individual symptoms. Thus graphs displaying individual symptoms for each patient were created and examples of these are used to exemplify patterns of symptoms.

It was anticipated that patients would display a low level of fluctuating symptoms in daily life and simultaneous peak if they reported experiencing a flare. This belief was due to the researcher's experience of observing how clinicians explain life with RA to newly diagnosed patients. However, only one patient displayed this ‘typical’ pattern of RA (Fig 9.2). When this patient reported a flare, all physical and emotional symptoms peaked together (Figs 9.3 to 9.4). Further, this patient increased the number of self-management strategies used when a flare was reported (Fig 9.5).

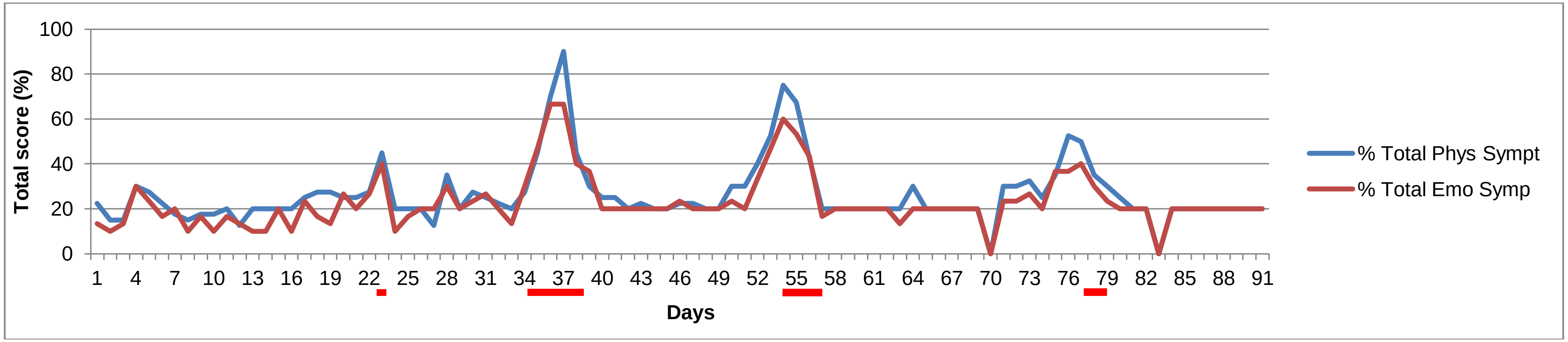

Figure 9.2: Graph showing total (%) physical and emotional symptoms for patient P18 (Intermittent flares underlined in red)

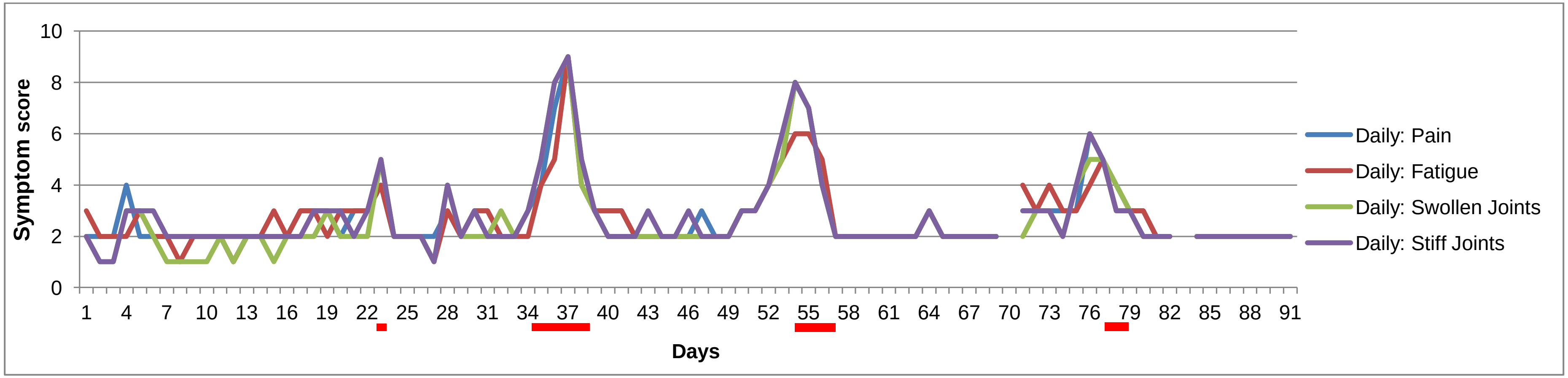

Figure 9.3: Graph showing individual physical symptoms for patient P18 (Intermittent flares underlined in red)

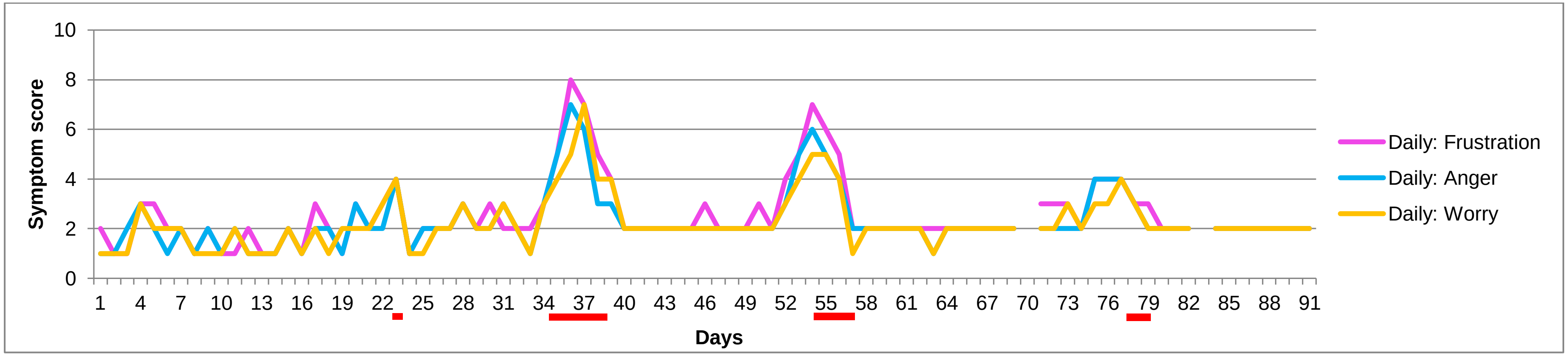

Figure 9.4: Graph showing individual emotional symptoms for patient P18 (Intermittent flares underlined in red)

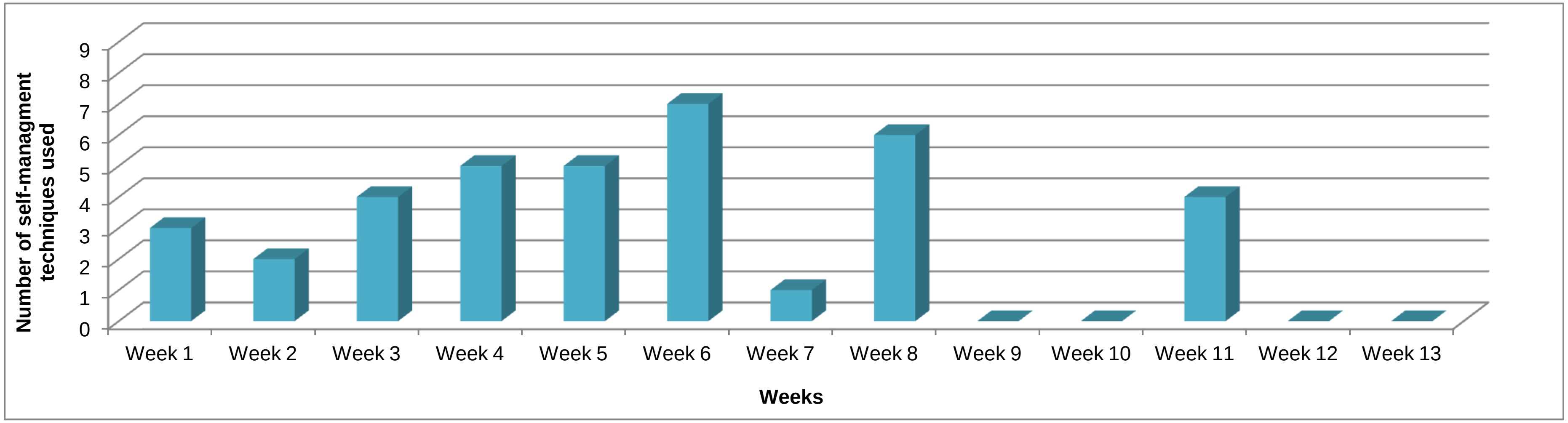

Figure 9.5: Graph showing the number of self-management techniques used per week by patient P18 (Intermittent flare patients)

9.4.5 Symptom patterns in Daily Life

Eight patients reported no flares at all in 3 months, suggesting that for them this is what everyday life is like with RA. However, even in daily life individual patients appear to have a range of very different experiences of the fluctuations of RA symptoms. Three different potential daily patterns have been identified in these daily life patients 1) Low symptoms, little fluctuation; 2) Low symptoms, daily fluctuation; 3) High symptoms, daily fluctuation.

9.4.5.1 Daily Life: Low symptoms, little fluctuation

Two patients in this group (n=3) were female and one male, they had a mean age of 69.3 (SD 11.0), disease duration 12.7 years (SD 7.4), disability (HAQ) 1.13 (SD 0.13), and disease severity (DAS global) 2.4 (SD 2.7). Two patients were using DMARDs and one was using steroids, two patients were retired and one was working. These patients experienced low symptoms (less than 50% of possible total symptoms) daily and experienced up to 30 consecutive days without any fluctuation in symptoms (Figs 9.6 to 9.8, P8, P22, P24). Two patients reported none or very few emotional symptoms, whilst patient P8 reported her emotional and physical symptoms as tightly linked with each other (Fig 9.6).

Graphs displaying patients' individual physical and emotional symptoms show that pain and fatigue were generally, but not consistently, higher than the other reported symptoms. These patients reported no more than up to 2 points variation within individual symptoms each day. Further, these patients used nearly all the 9 measured self-management strategies weekly, which may indicate why they are able to maintain this level of RA symptoms. These findings are exemplified by patient P8 (Figs 9.9 to 9.11).

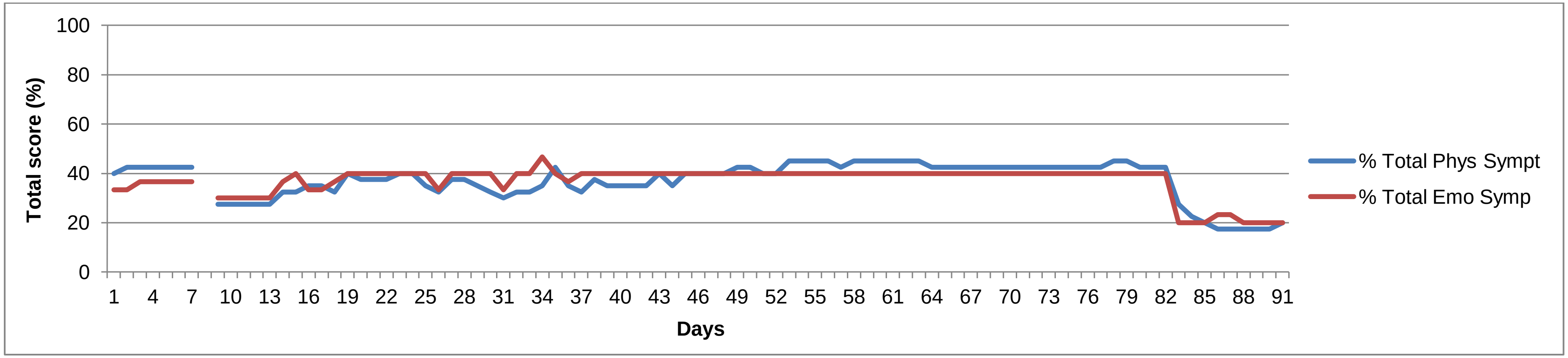

Figure 9.6: Graph showing total (%) physical and emotional symptoms for patient P8 (daily life patient)

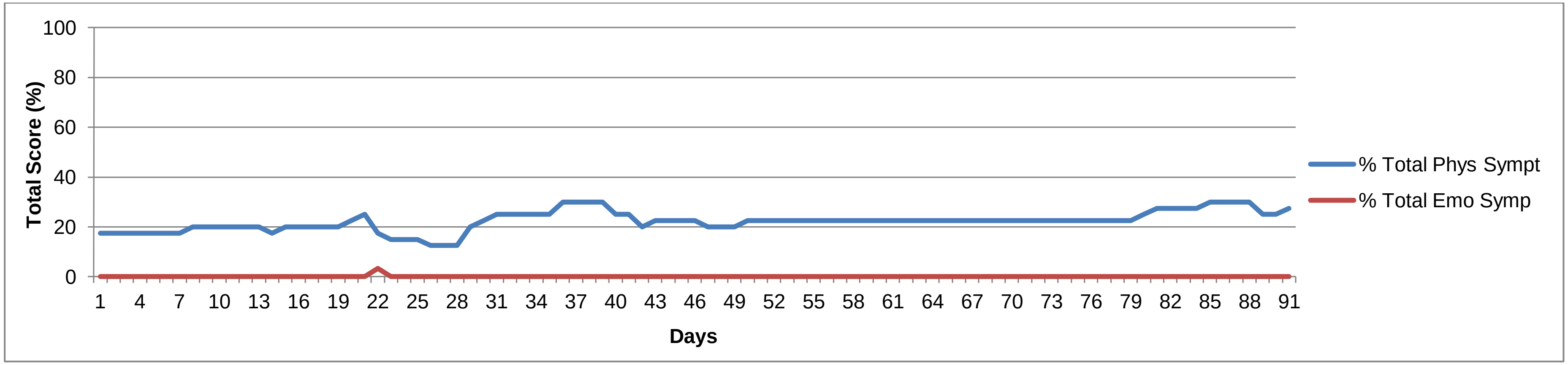

Figure 9.7: Graph showing total (%) physical and emotional symptoms for patient P22 (daily life patient)

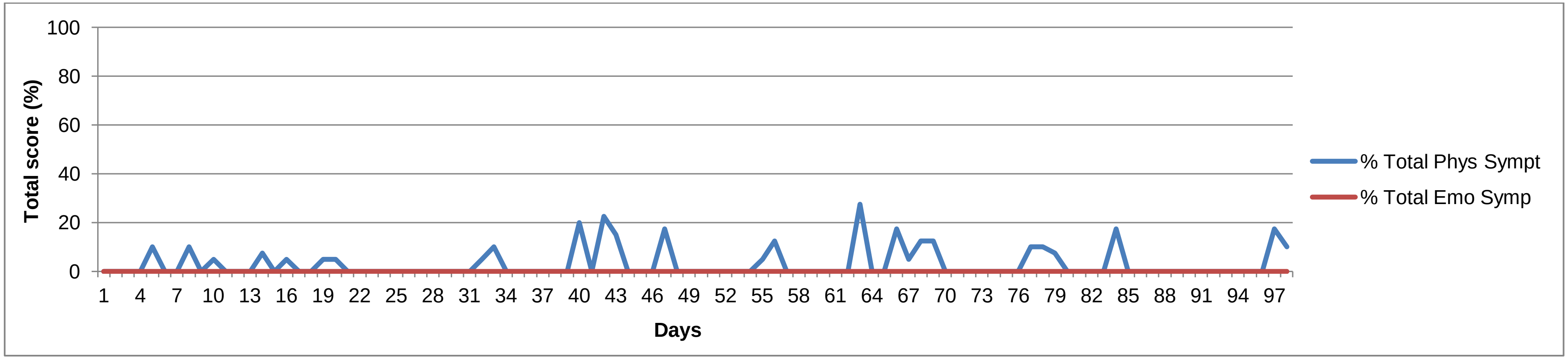

Figure 9.8: Graph showing total (%) physical and emotional symptoms for patient P24 (daily life patient)

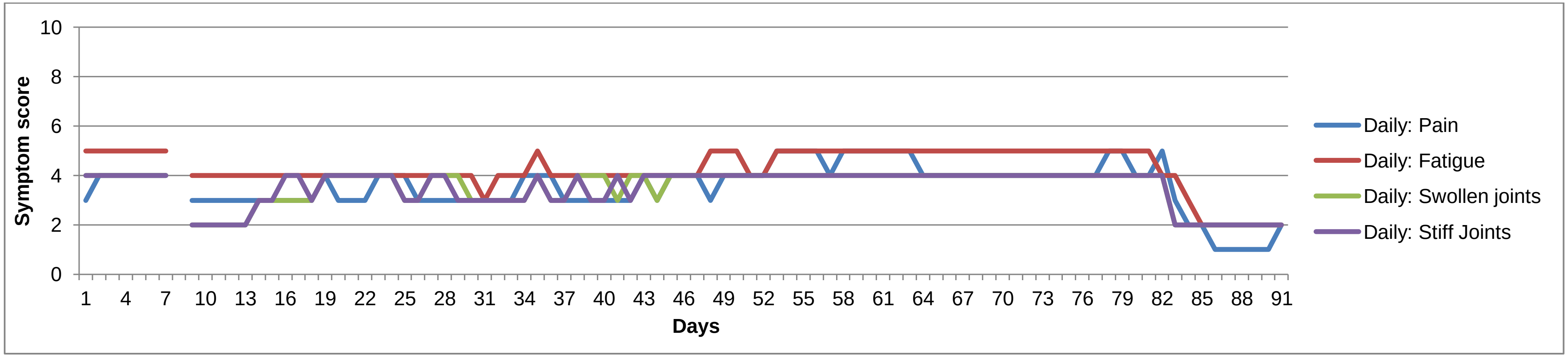

Figure 9.9: Graph showing individual physical symptoms for patient P8 (daily life patient)

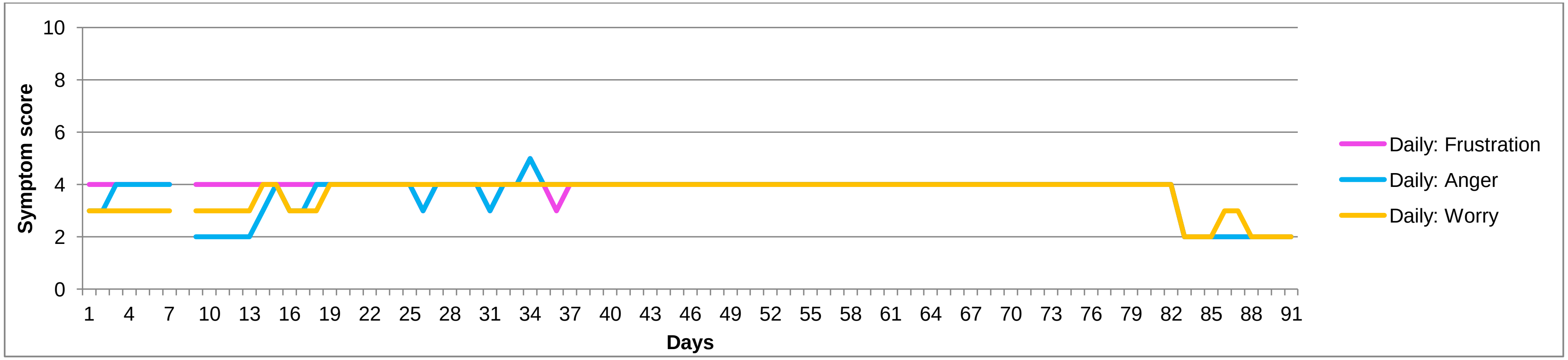

Figure 9.10: Graph showing individual emotional symptoms for patient P8 (daily life patient)

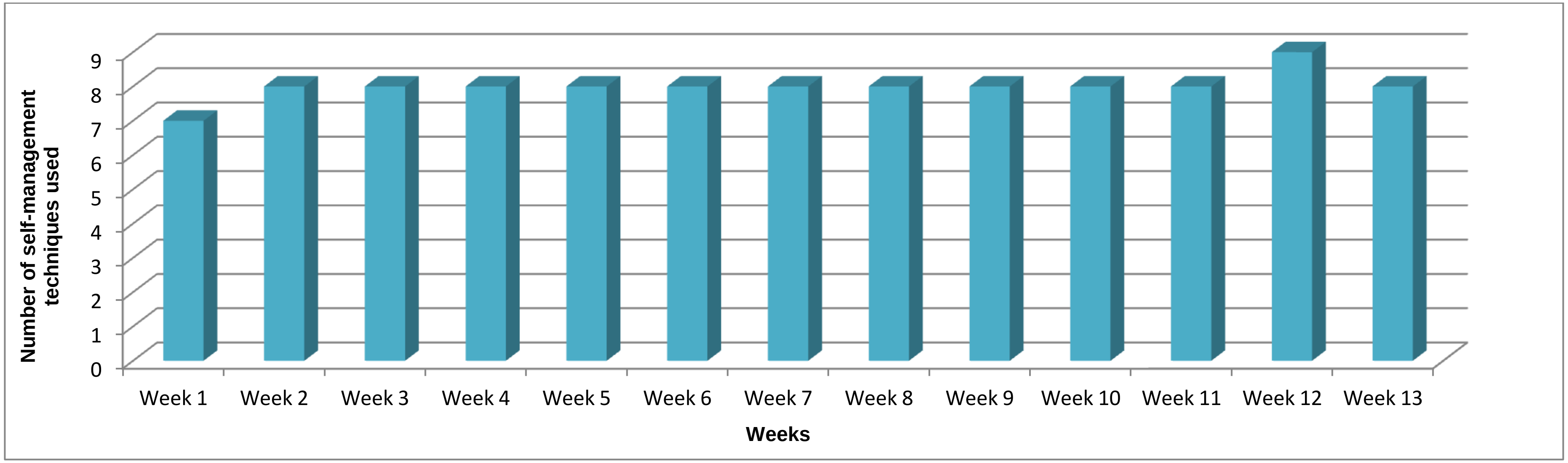

Figure 9.11: Graph showing the number of self-management techniques used per week for patient P8 (daily life patient)

9.4.5.2 Daily Life: Low symptoms, daily fluctuation

Patients in this group (n=3) were all female, had a mean age of 60 (SD 25.5), disease duration 9.2 years (SD 14.5), disability (HAQ) 0.2 (SD 1.3), and disease severity (DAS global) 0.4 (SD 2.3). One patient was using DMARDs, one was using steroids, one patient was retired and one was working. One patient did not complete the baseline questionnaire and therefore this information is unknown. These patients experienced low symptoms (less than 50% of possible total symptoms) daily, with almost daily fluctuation of symptoms. In 3 months, these patients did not have more than 3 consecutive days without fluctuations in physical symptoms, or 7 consecutive days without variation in emotional symptoms (Figs 9.12 to 9.14, P2, 10, 27). They reported physical and emotional symptoms as similar in severity, with physical symptoms being consistently slightly higher than emotional. In general, as physical symptoms increase in severity, so do emotional symptoms.

Graphs displaying patients' individual physical and emotional symptoms show that these patients' symptoms fluctuated by up to 4 points out of a possible 10 difference between individual symptoms daily. No physical symptom was consistently higher than any other, and frustration was often reported as more severe than the other emotional symptoms. The fluctuations show that when pain increases, fatigue increases within a few days. Swollen and stiff joints appear to follow a similar pattern to each other and increases follow increases in pain, but to a lesser extent. These patients use the majority of the measured self-management strategies weekly, indicating that they may be able to manage the level of their symptoms, but not the amount of fluctuation. This is exemplified by patient P27 (Figs 9.15 to 9.17).

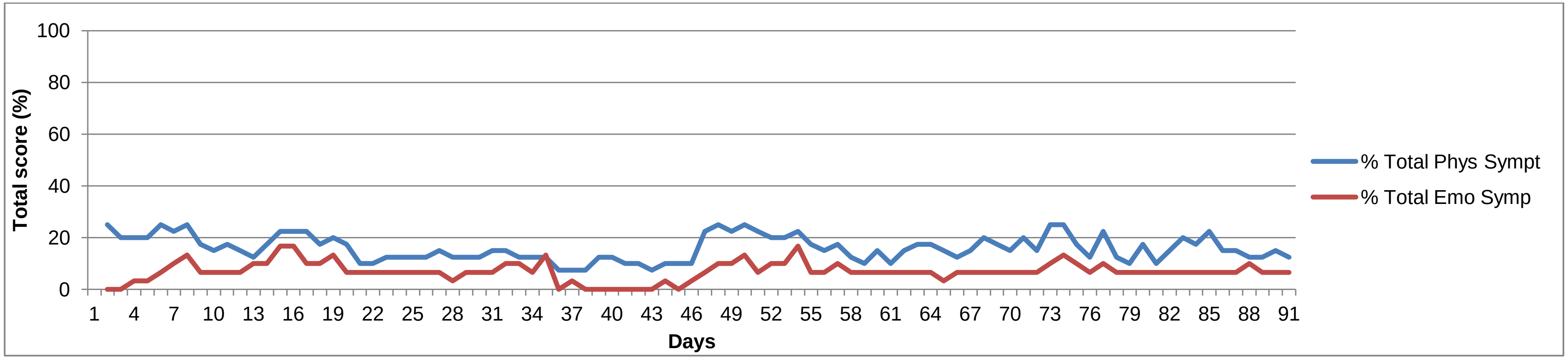

Figure 9.12: Graph showing total (%) physical and emotional symptoms for patient P2 (daily life patient)

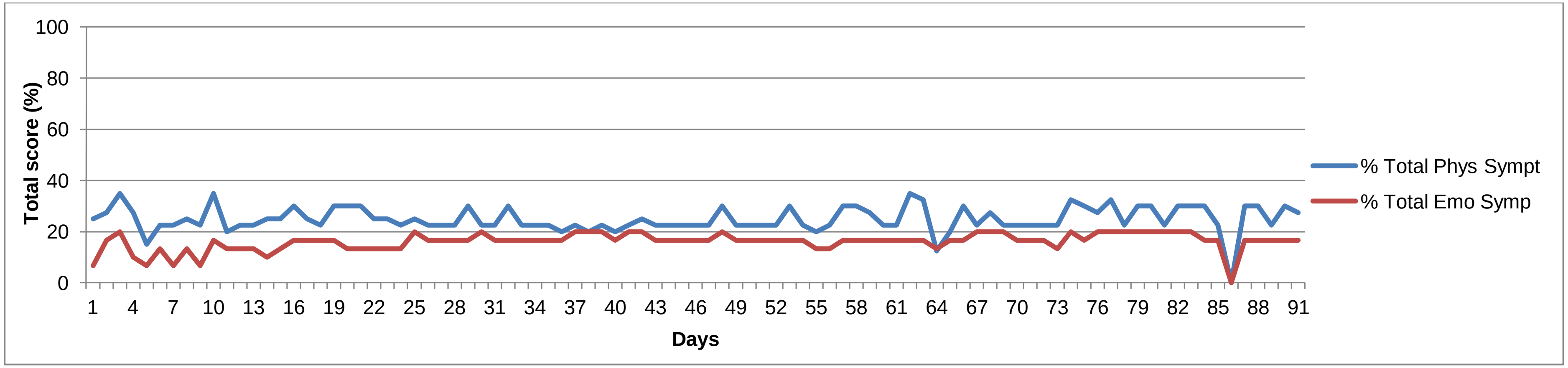

Figure 9.13: Graph showing total (%) physical and emotional symptoms for patient P10 (daily life patient)

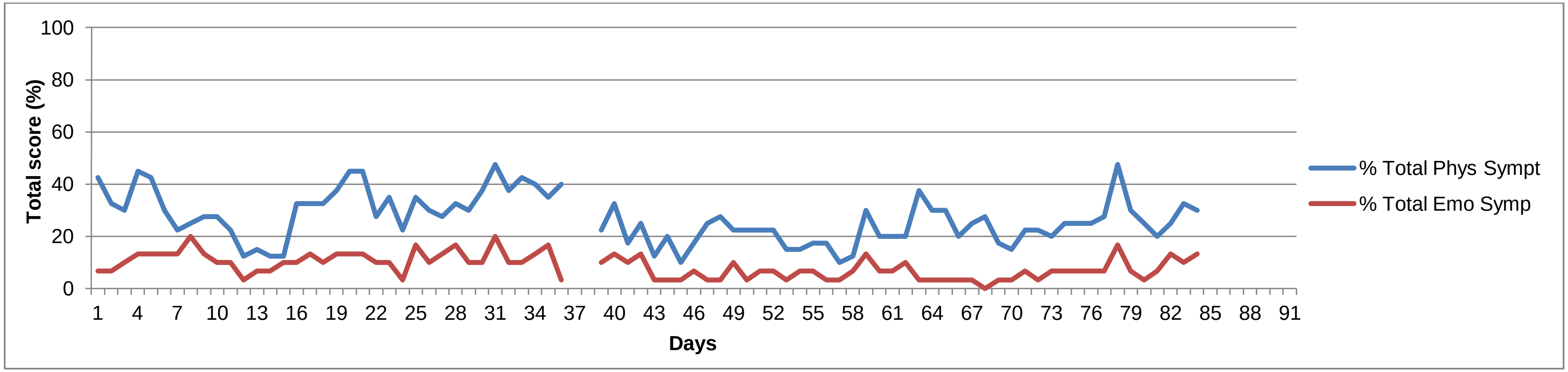

Figure 9.14: Graph showing total (%) physical and emotional symptoms for patient P27 (daily life patient)

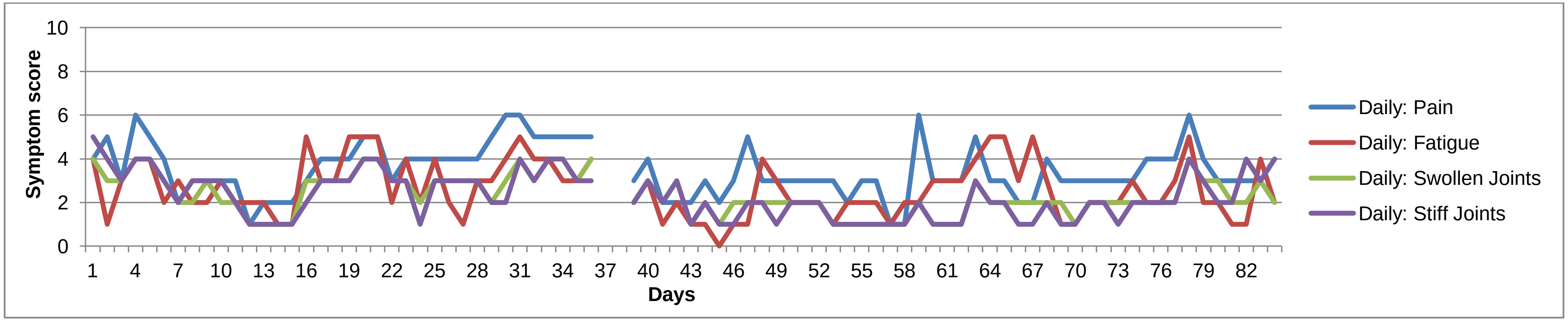

Figure 9.15: Graph showing individual physical symptoms for patient P27 (daily life patient)

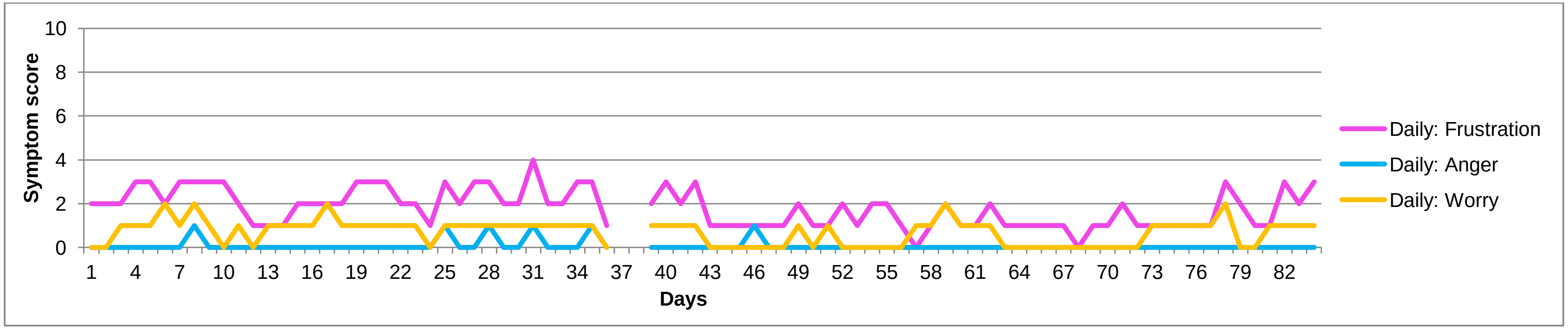

Figure 9.16: Graph showing individual emotional symptoms for patient P27 (daily life patient)

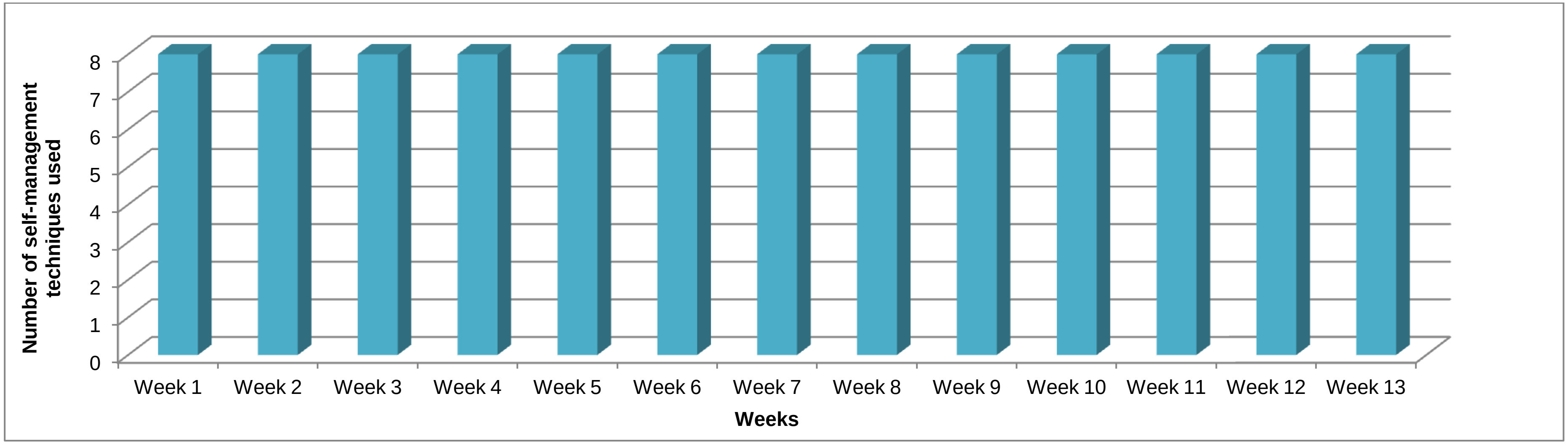

Figure 9.17: Graph showing the number of self-management techniques used per week for patient P27 (daily life patient)

9.4.5.3 Daily Life: High symptoms, daily fluctuation

Patients in this group (n=2) were both female, had a mean age of 67.5 (SD 9.2), disease duration 9.5 years (SD 2.1), disability (HAQ) 0.3 (SD 2.6), and disease severity (DAS global) 1.0 (SD 5.4). Both patients were using DMARDs and were retired. Despite not considering themselves in flare on any day for 3 months, both these patients reported symptoms that were higher than 70% of possible total symptoms. They reported daily fluctuations, with no more than 3 consecutive days without symptom variation (Figs 9.18 and 9.19, P19, P23). One patient (P19) reported physical and emotional symptoms as similar in severity, with physical symptoms being consistently slightly higher than emotional, whilst the other (P23) reported a larger difference between the severity of physical and emotional symptoms, with emotional symptoms being consistently higher than physical.

Graphs displaying patients' individual physical and emotional symptoms show that one patient (P19) scored up to 6 points out of a possible 10 points variation within physical symptoms daily and 4 points variation within emotional symptoms daily with no symptom being consistently higher than any other. It is of note that patient P19 uses less self-management strategies than patients with low average symptoms. However, between weeks 2 and 5 this patient increased the number of self-management strategies used, which corresponded with a decrease in reported symptom severity. Further, P19 reported some days with all physical symptoms scored 7 and above, yet did not consider herself to be in a flare. It is therefore possible that this patient considers a flare to be at least 8/10 in all symptoms, or that she is using different criteria, other than these symptoms, to define flare.

P23 scored greater fluctuation in daily physical symptoms (up to 8 points) and 3 points variation within emotional symptoms daily, with pain and fatigue being scored consistently higher than stiff and swollen joints. P23 used fewer self-management strategies than patients with low symptom scores, although still used at least 5 different strategies every day. This did not appear to correspond to changes in symptom scores. Despite scoring pain and fatigue as 10 (worst symptoms imaginable) on some days, P23 does not consider herself in a flare at any time, thus it is possible that either swollen or stiff joints need to be perceived as higher for this patient to define herself as in flare. As these patients display such differences in fluctuating symptoms, both patients' graphs are presented (Figs 9.20 to 9.25).

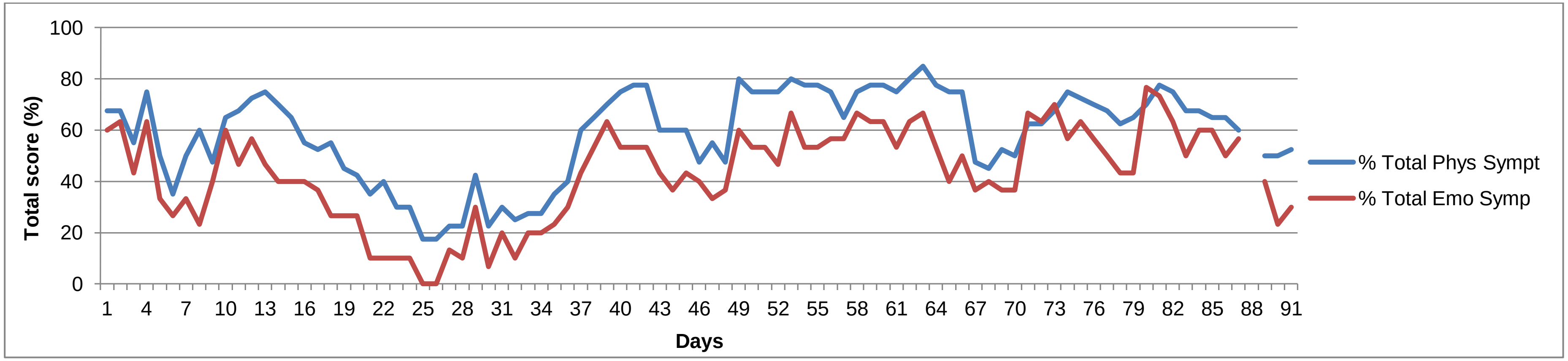

Figure 9.18: Graph showing total (%) physical and emotional symptoms for patient P19 (daily life patient)

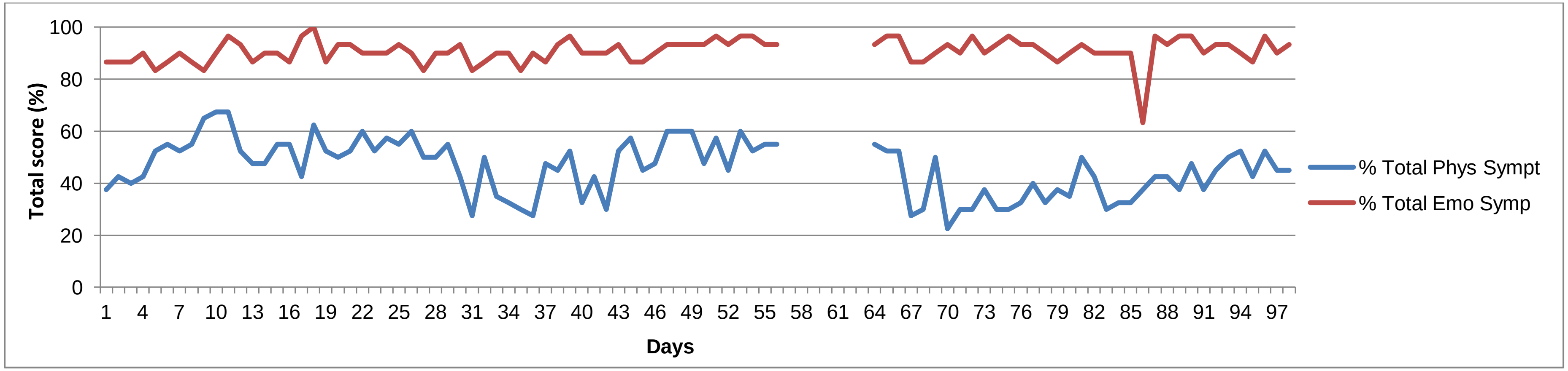

Figure 9.19: Graph showing total (%) physical and emotional symptoms for patient P23 (daily life patient)

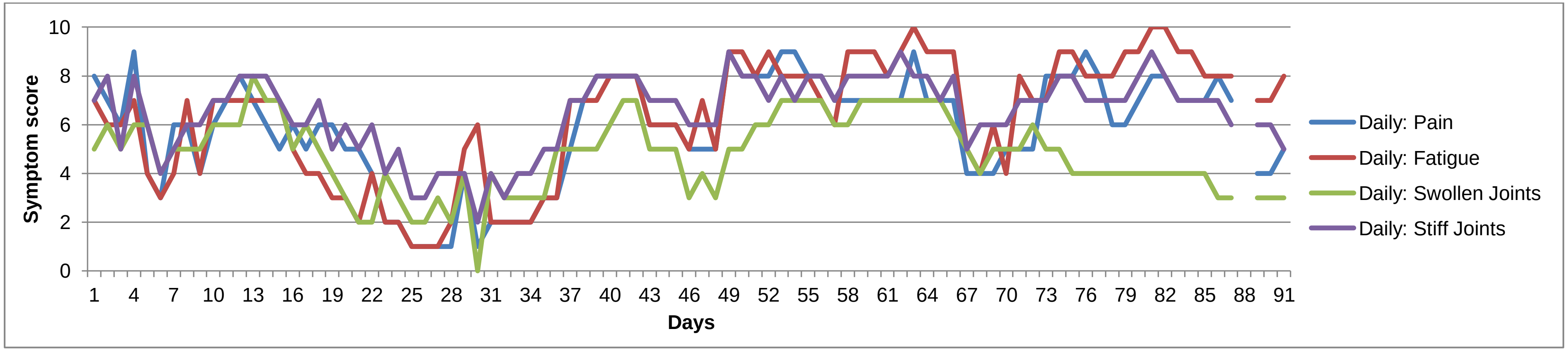

Figure 9.20: Graph showing individual physical symptoms for patient P19 (daily life patient)

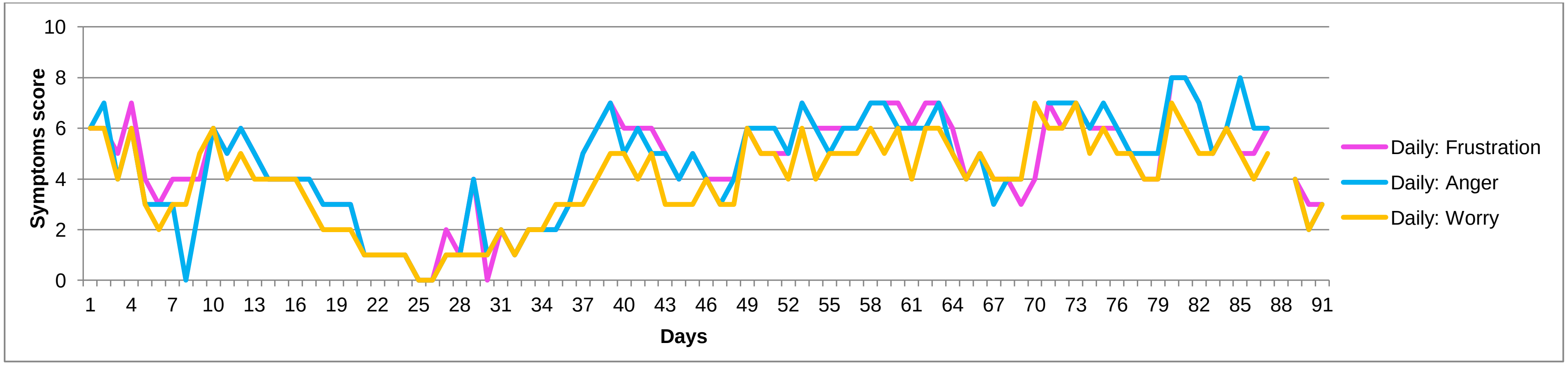

Figure 9.21: Graph showing individual emotional symptoms for patient P19 (daily life patient)

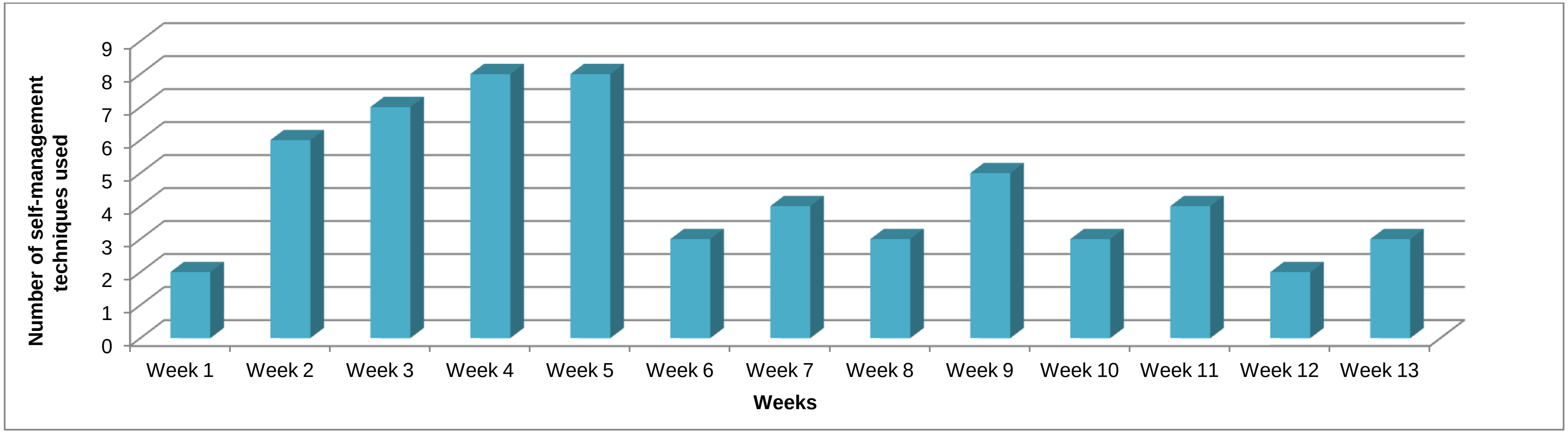

Figure 9.22: Graph showing the number of self-management techniques used per week for patient P19 (daily life patient)

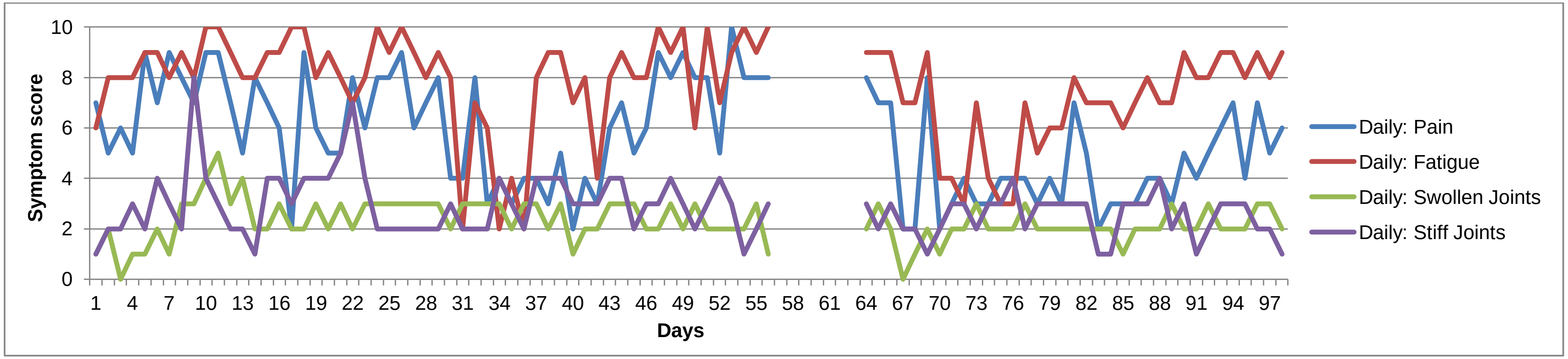

Figure 9.23: Graph showing individual physical symptoms for patient P23 (daily life patient)

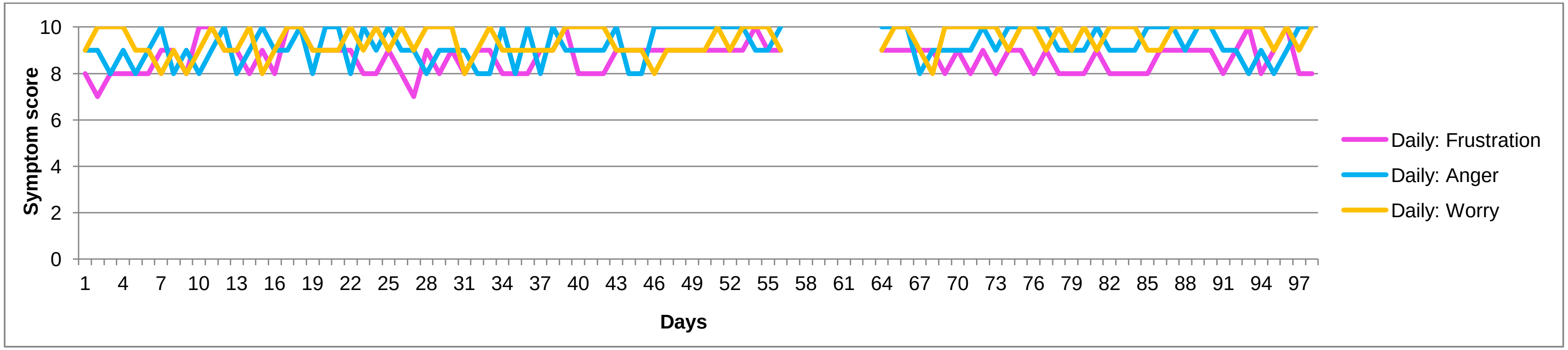

Figure 9.24: Graph showing individual emotional symptoms for patient P23 (daily life patient)

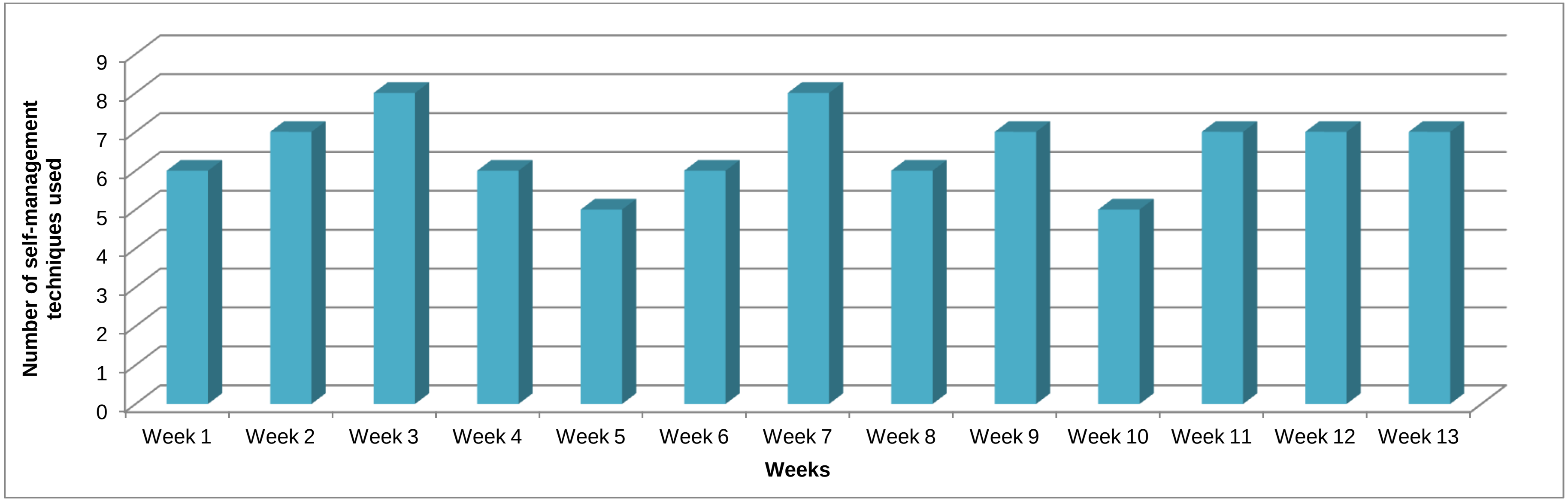

Figure 9.25: Graph showing the number of self-management techniques used per week for patient P23 (daily life patient)

9.4.6 Symptom patterns in Intermittent Flare

Patients in this group (n=6) were five women and one man, they had a mean age of 69 (SD 11.5), disease duration 31.8 years (SD 18.3), disability (HAQ) 1.9 (SD 1.0), and disease severity (DAS global) 4.8 (SD 2.7). Five patients were using DMARDs and one was using only NSAIDs. All the patients in this group reported at least one episode of flare during the 3 month data collection period. All these patients reported physical and emotional symptoms as similar in severity, with physical symptoms being consistently slightly higher than emotional. It is notable that all but one patient reported higher symptoms on some of the days on which they did not report being in flare, than on days that they reported being in a flare (Figs 9.26 to 9.30, P7 P14, P15, P17, P21). For example, patient P21 (Fig 9.30) reported higher symptoms on day 61 (non-flare) than all six instances when flare was reported. In contrast patient P18 reported a classic pattern of daily life and flare, in which she reported relatively low (yet not symptom free) symptoms in between flares and spikes of both physical and emotional symptoms during flares (Fig 9.2).

Graphs displaying patients' individual physical and emotional symptoms show that on days when patients considered themselves in a flare, their pain and fatigue symptoms were higher than most non-flare days (exemplified by P7 and P17, Figs 9.31-34). However, there were no symptoms that were reported as being consistently only higher when the patients were in flare. Thus patients may be using different criteria other than their symptoms to decide whether they are in a flare or not. It is of note that patients reported equal or higher swollen joint scores on some of the days on which they did not report being in flare, than on days that they reported being in a flare this is exemplified by patients P7 (Fig 9.31 days 16 - 19) and P17 (Fig 9.33 days 58 - 60). These patients used less self-management strategies weekly than the daily life patients. However, they all used at least five self-management strategies daily. With these patients, the number of strategies used did not appear to relate to symptom scores. Exemplified by P17 (Fig 9.35).

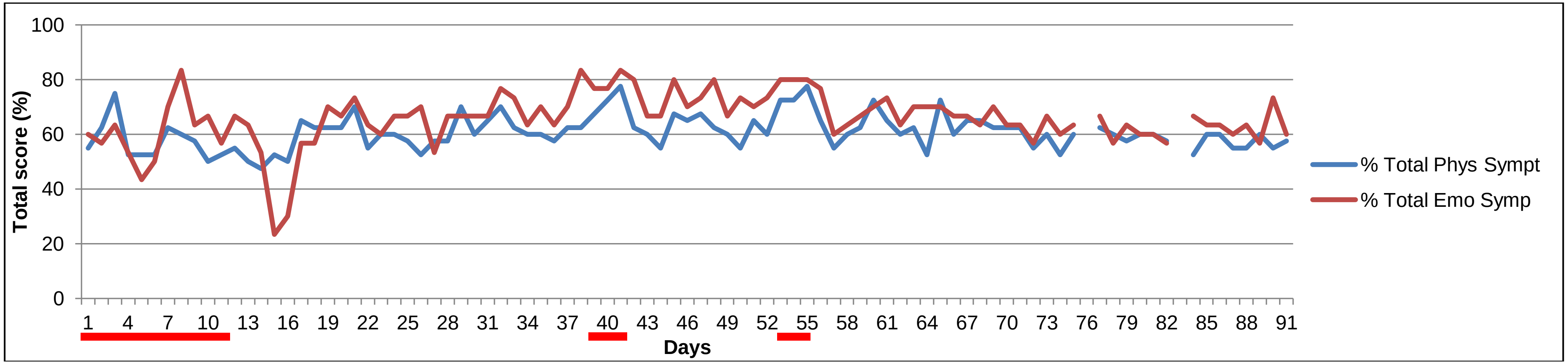

Figure 9.26: Graph showing total (%) physical and emotional symptoms for patient P7 (Intermittent flares underlined in red)

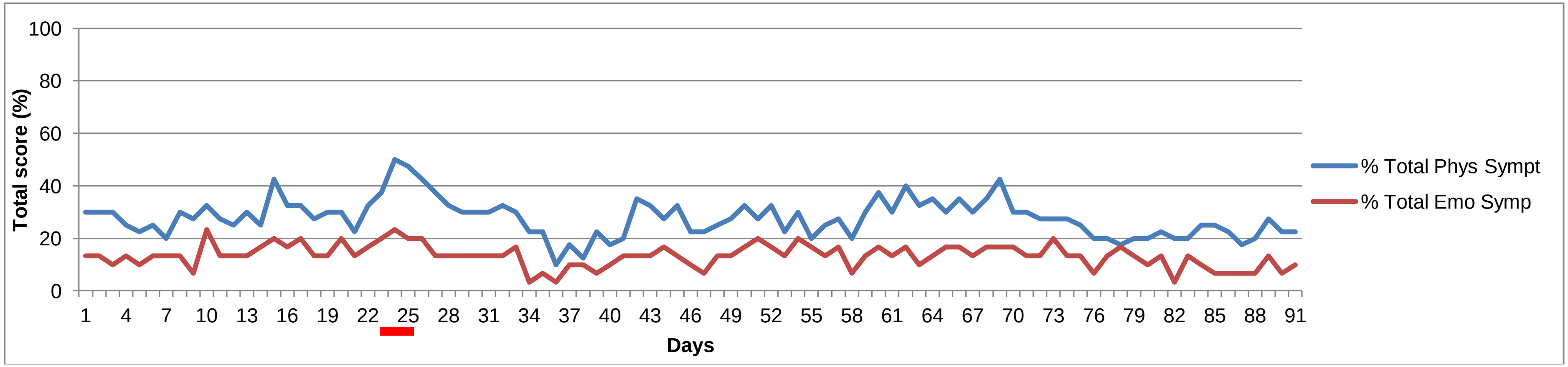

Figure 9.27: Graph showing total (%) physical and emotional symptoms for patient P14 (Intermittent flares underlined in red)

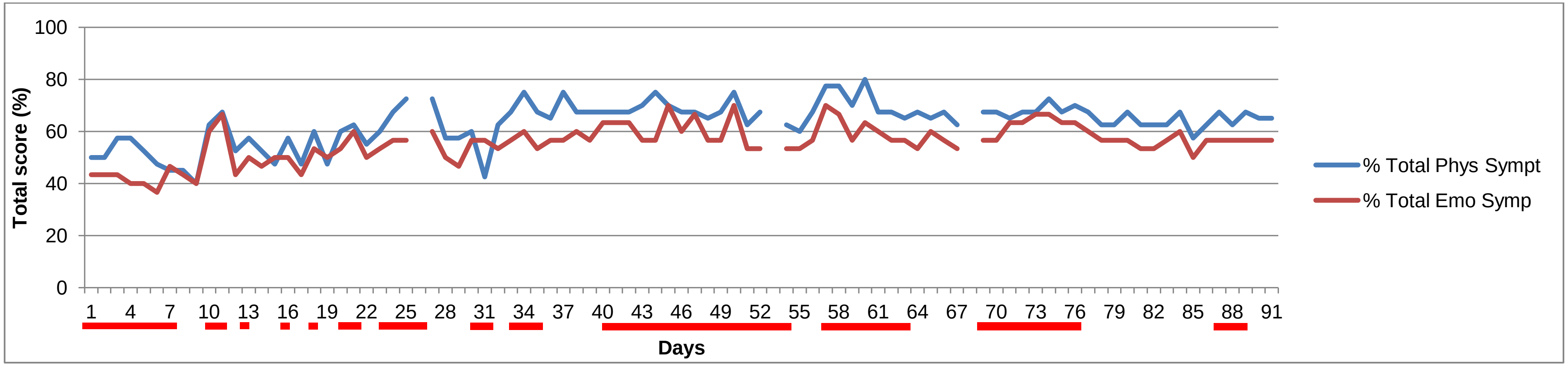

Figure 9.28: Graph showing total (%) physical and emotional symptoms for patient P15 (Intermittent flares underlined in red)

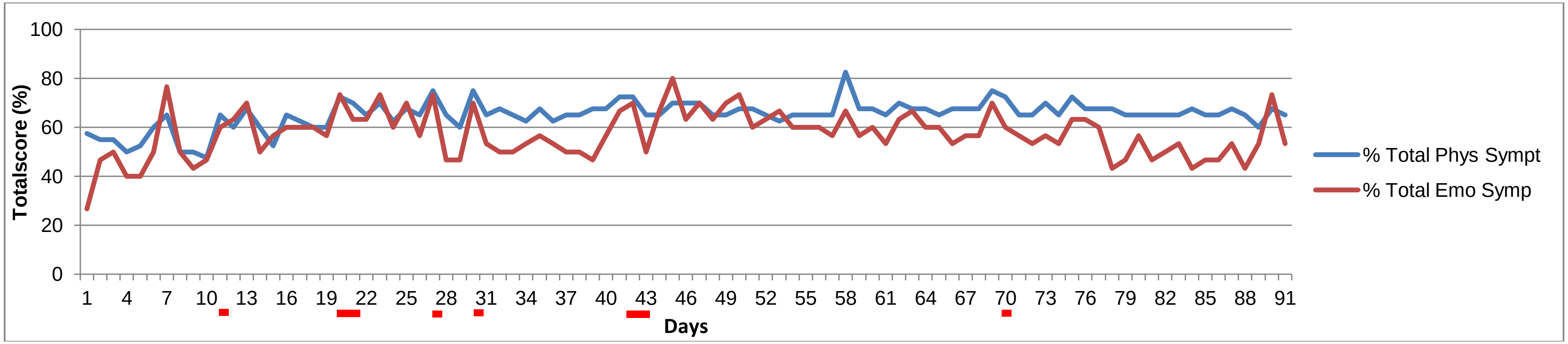

Figure 9.29: Graph showing total (%) physical and emotional symptoms for patient P17 (Intermittent flares underlined in red)

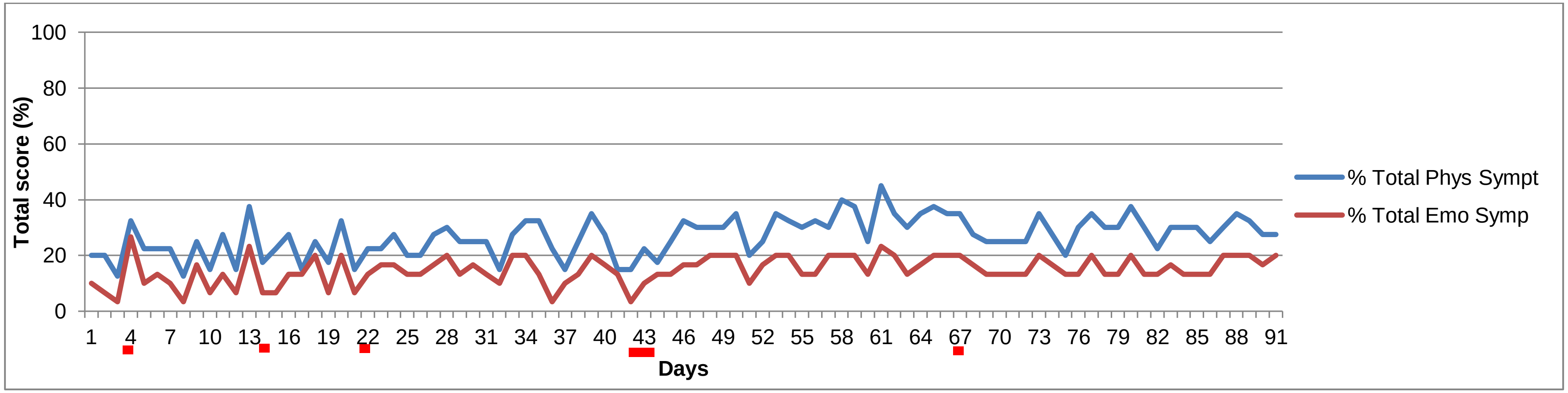

Figure 9.30: Graph showing total (%) physical and emotional symptoms for patient P21 (Intermittent flares underlined in red)

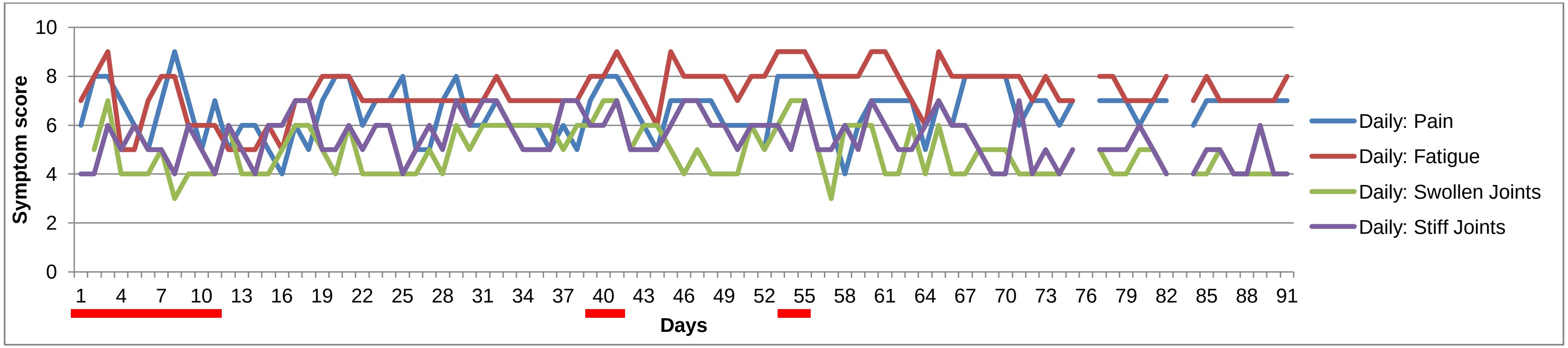

Figure 9.31: Graph showing individual physical symptoms for patient P7 (Intermittent flares underlined in red)

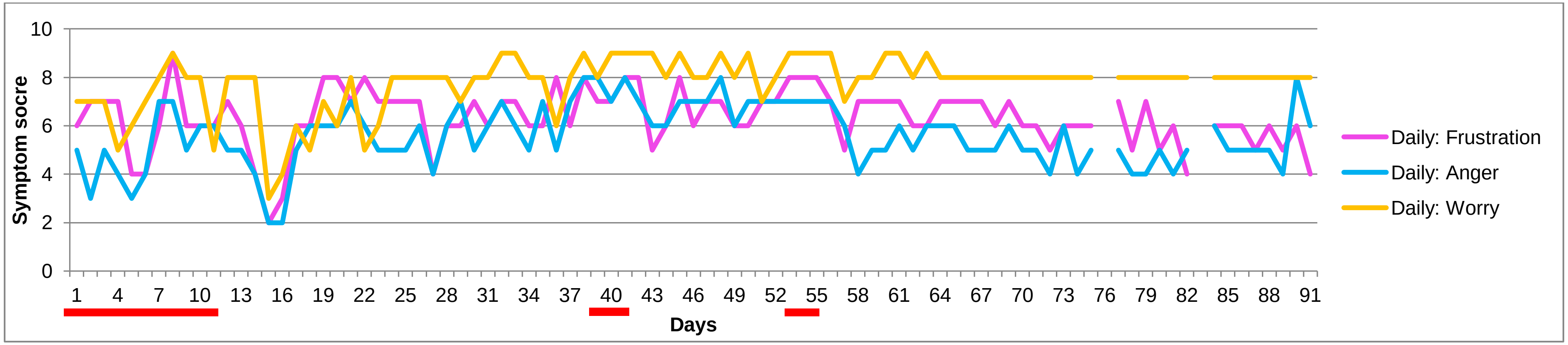

Figure 9.32: Graph showing individual emotional symptoms for patient P7 (Intermittent flares underlined in red)

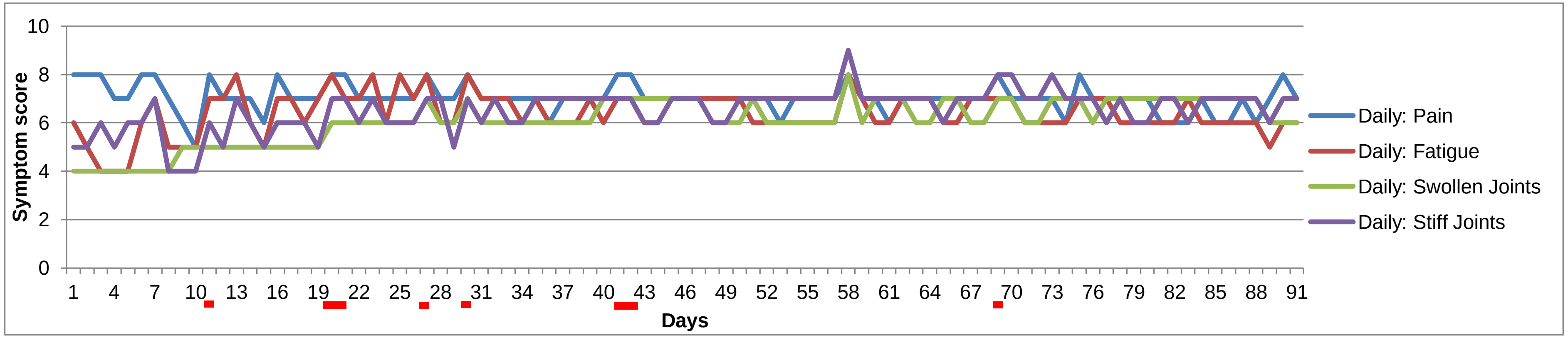

Figure 9.33: Graph showing individual physical symptoms for patient P17 (Intermittent flares underlined in red)

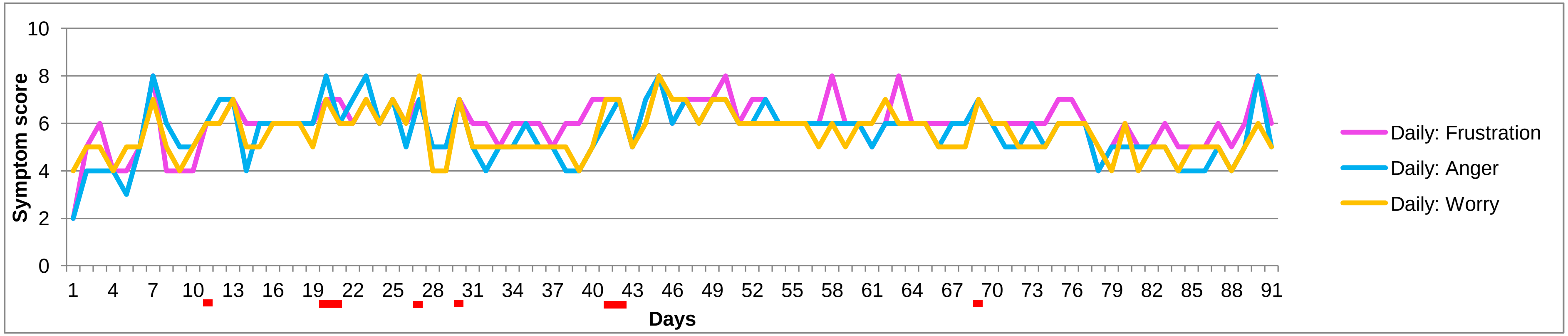

Figure 9.34: Graph showing individual emotional symptoms for patient P17 (Intermittent flares underlined in red)

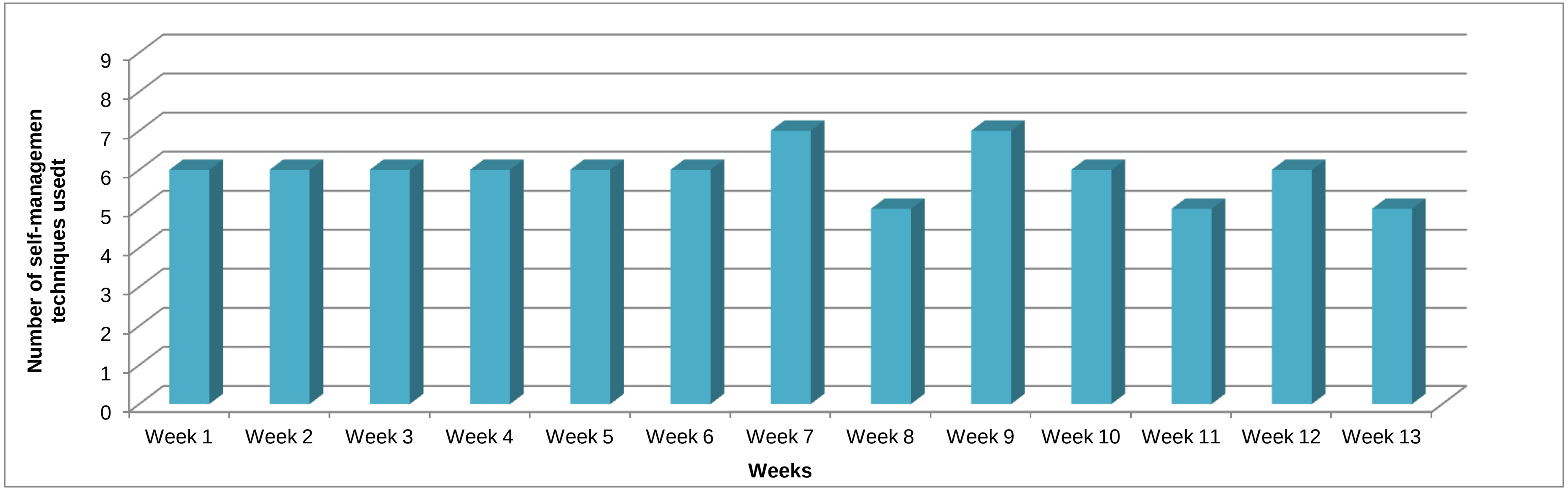

Figure 9.35: Graph showing the number of self-management techniques used per week for patient P17 (intermittent flare patient)

9.4.7 Symptom patterns in Constant Flare

Patients in this group (n=3) were all female with a mean age of 48.3 (SD 21.1), disease duration 12 years (SD 1.7), disability (HAQ) 2.3 (SD 0.6), and disease severity (DAS global) 7.4 (SD 2.2). One patient was using DMARDs, one was using steroids and one was using anti-TNF therapy. All the patients in this group reported being in a flare for the entire 3 month period. They all reported physical and emotional symptoms as similar in severity, with physical symptoms being consistently slightly higher than emotional. However, these three patients reported very different experiences of being in a prolonged flare. Whilst one patient (P5) reported consistently high symptoms, another (P25) reported symptoms that fluctuated between medium and high severity and the third patient (P11) reported low fluctuating symptoms that only spiked above 50% of total possible symptoms on 3 occasions. Thus patients reported a very wide range of experiences of symptoms that they considered to be an RA flare (Figs 9.36 to 9.38).

Two patients reported the severity of physical and emotional symptoms as similar to each other, with no one symptom being consistently higher than the others. This is exemplified by patient P25 (Figs 9.39 to 9.40). However, patient P11 reported high fatigue, whilst the other symptoms were reported as lower but still mirroring the fluctuations of fatigue. This patient may therefore be using her fatigue to define herself as in a flare (Figs 9.41 to 9.42). These patients also differed in the number of self-management strategies they used. Two patients reported using less self-management strategies weekly than other patients, exemplified by P11 (Fig 9.43). This indicates they may need to increase their self-management to control their symptoms, whilst P25 reported using all self-management strategies nearly every week, indicating she was doing all she could to manage her flare (Fig 9.44).

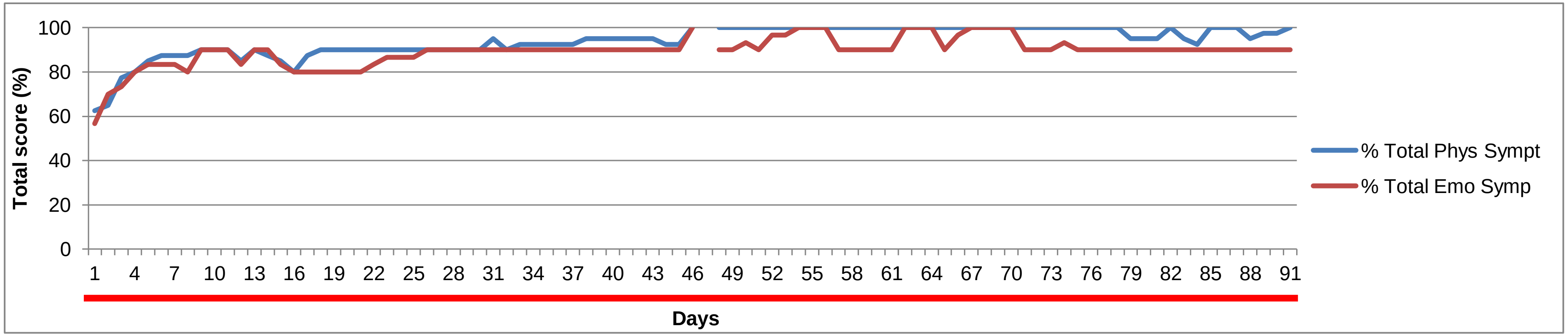

Figure 9.36: Graph showing total (%) physical and emotional symptoms for patient P5 (Constant flare patient)

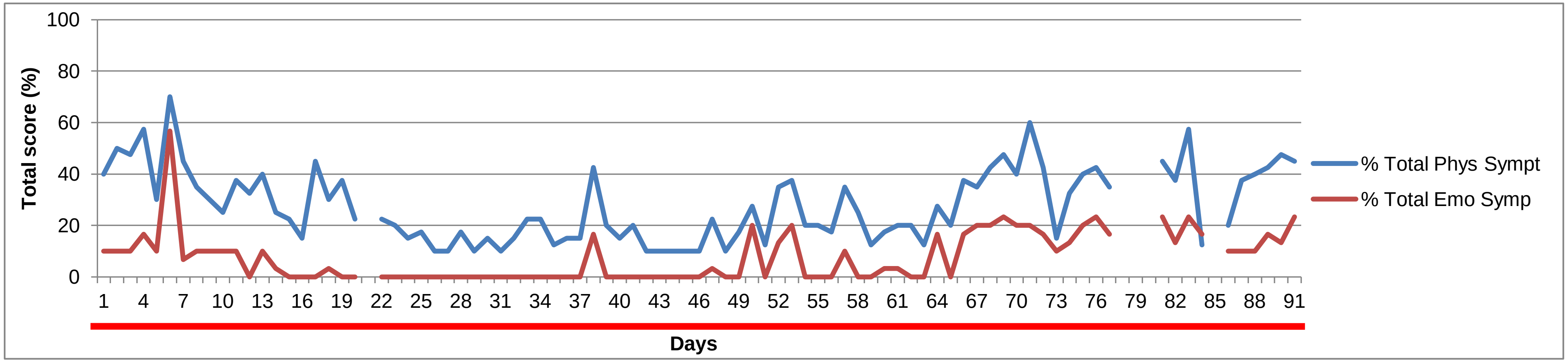

Figure 9.37: Graph showing total (%) physical and emotional symptoms for patient P11 (Constant flare patient)

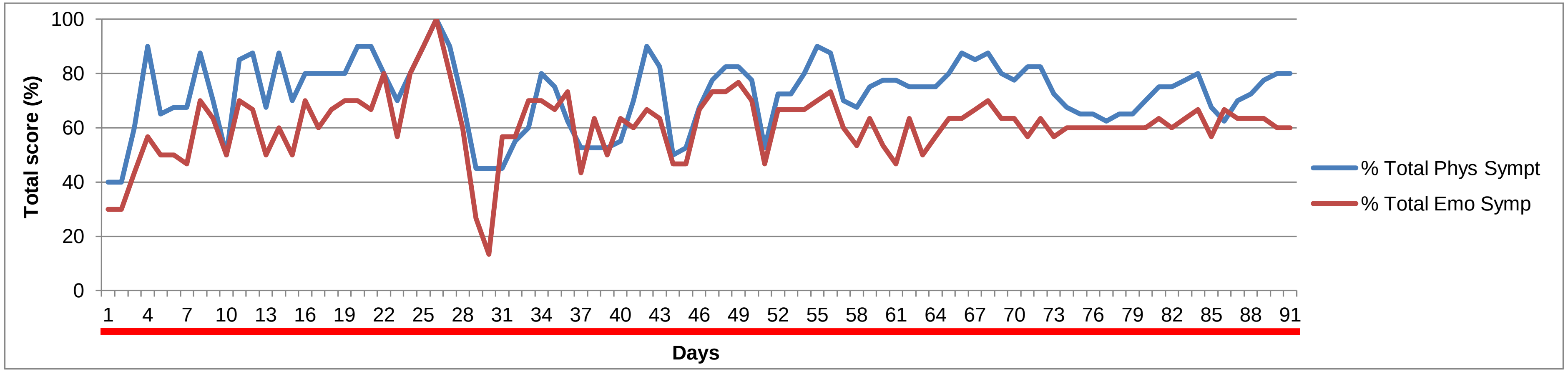

Figure 9.38: Graph showing total (%) physical and emotional symptoms for patient P25 (Constant flare patient)

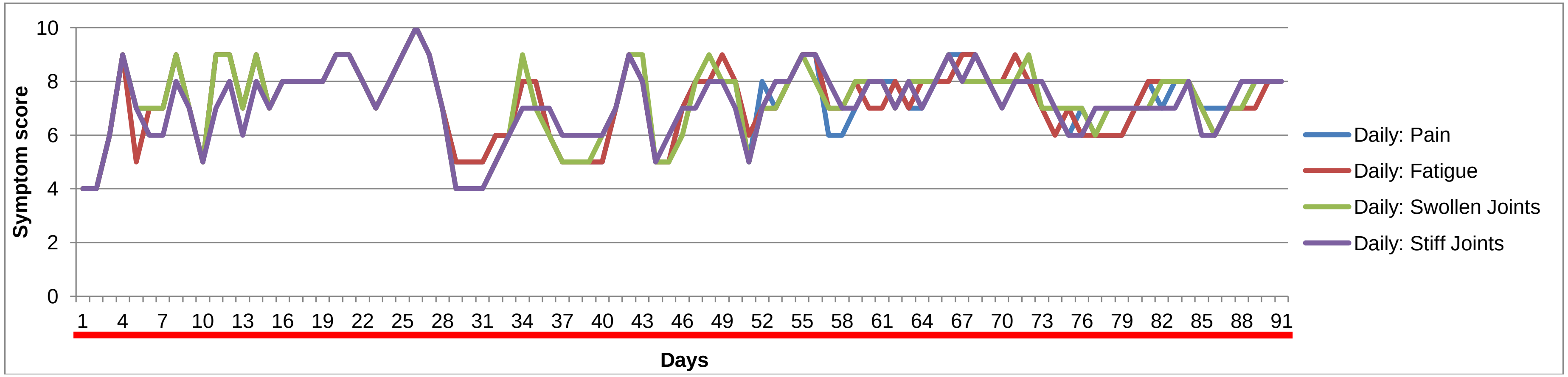

Figure 9.39: Graph showing individual physical symptoms for patient P25 (Constant flare patient)

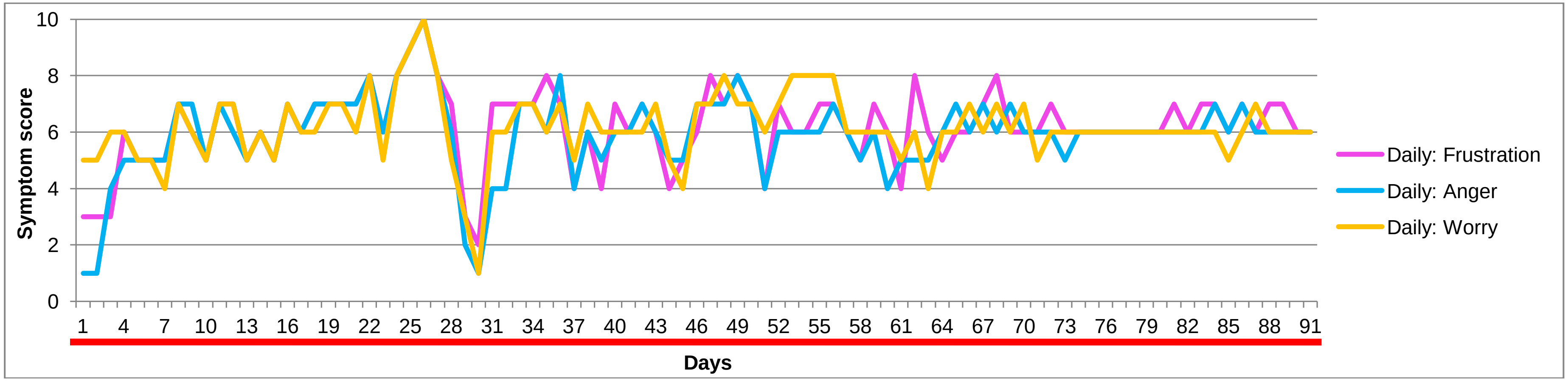

Figure 9.40: Graph showing individual emotional symptoms for patient P25 (Constant flare patient)

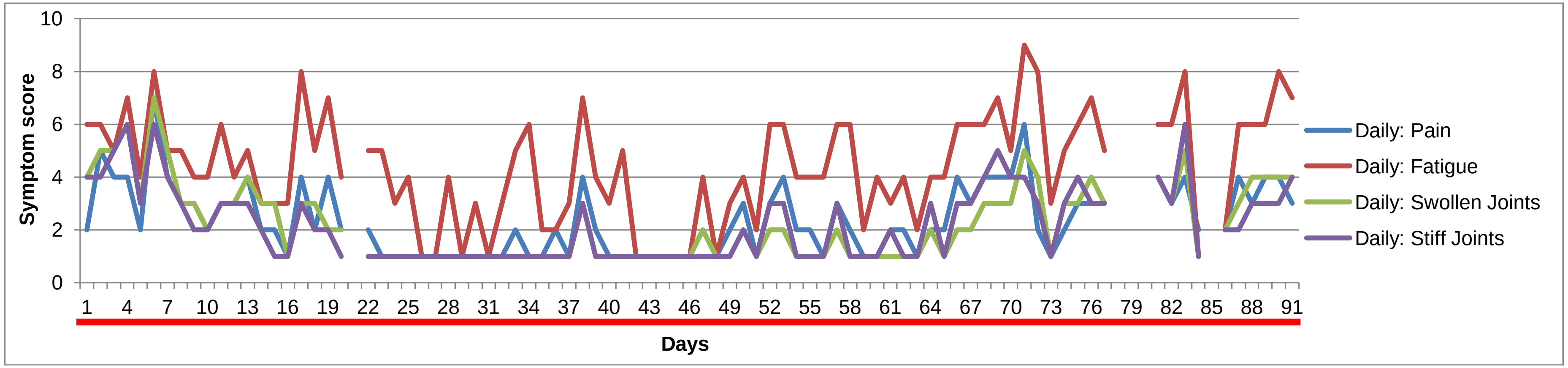

Figure 9.41: Graph showing individual physical symptoms for patient P11 (Constant flare patient)

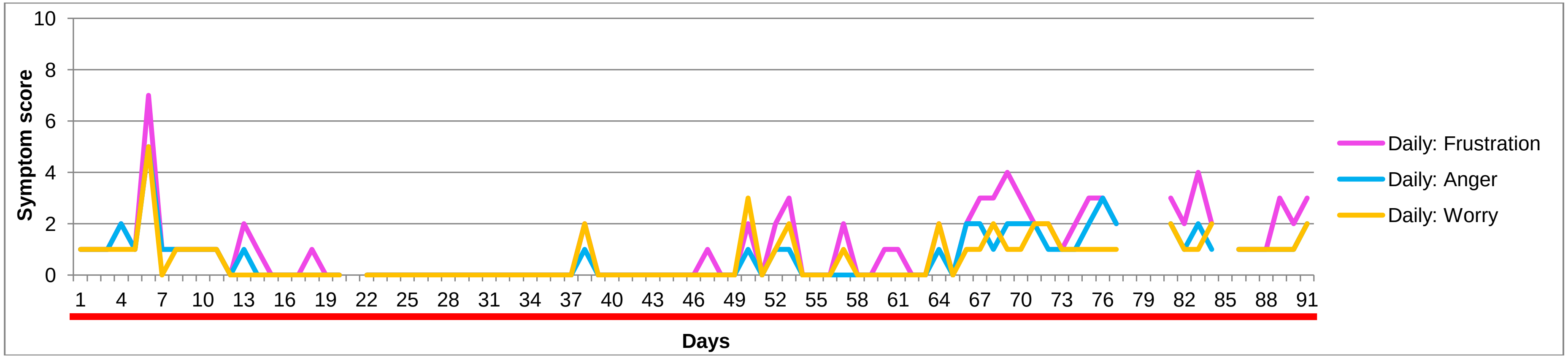

Figure 9.42: Graph showing individual emotional symptoms for patient P11 (Constant flare patient)

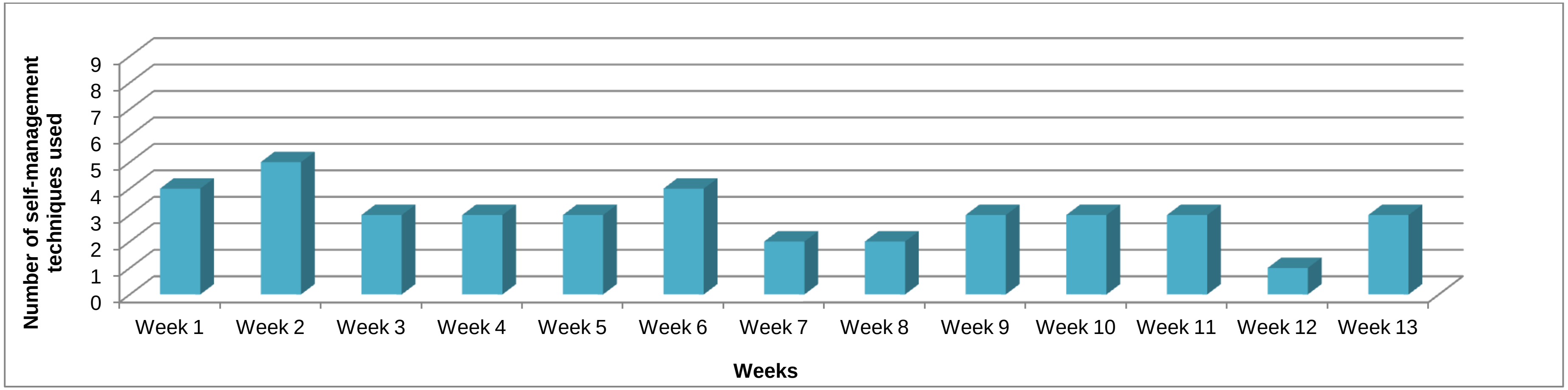

Figure 9.43: Graph showing the number of self-management techniques used per week for patient P11 (Constant flare patient)

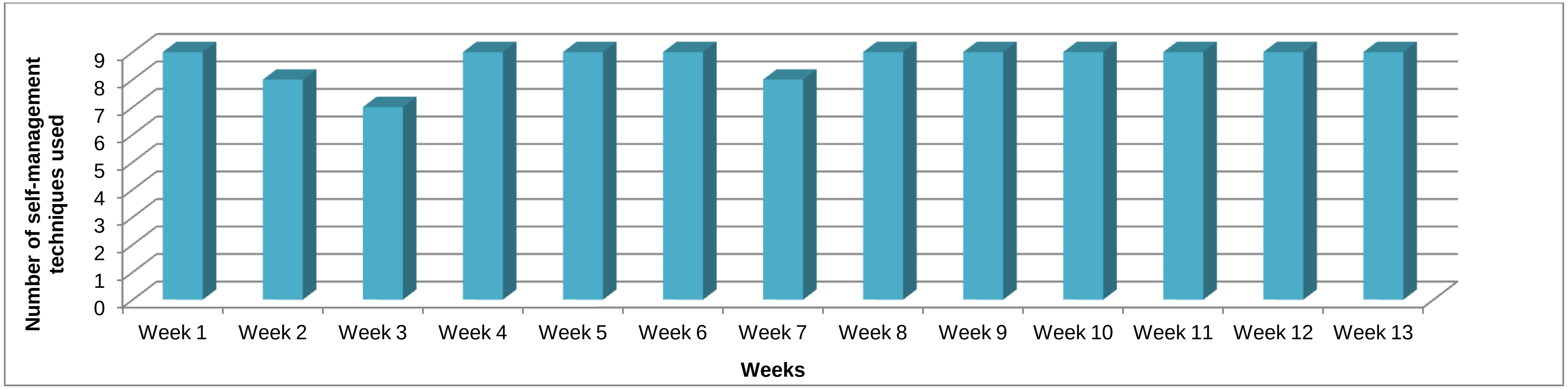

Figure 9.44: Graph showing the number of self-management techniques used per week for patient P25 (Constant flare patient)

9.4.8 Impact and self-management

Patients reported having to cancel plans due to their RA a total of 154 times across the three month data collection period, which is a mean of 1.4 cancellations per patient per week (Table 9.8). Daily life patients reported the lowest total mean of 0.5 times per patient per week. Even in daily life some of these patients reported cancelling their plans up to 4 times in one week. However, this group is skewed by one patient who reported 42 cancelled plans in three months. The remaining daily life patients reported cancelling a maximum of two plans in one week. Intermittent flare patients reported only a slightly higher mean than daily life patients (0.6 times per patient per week); they did not consistently cancel their plans more when in a perceived flare. Constant flare patients reported cancelling their plans a mean of 1.5 times per patient per week, indicating that patients do have more disrupted lives when in a flare.

Table 9.8: Number of times patients reported cancelling their plans due to their RA

Patient	**Week**													**Total**	**Mean (per week)**
	1	2	3	4	5	6	7	8	9	10	11	12	13		
Daily life patients															
P2	1	0	1	0	0	0	0	0	1	0	0	0	0	3	0.2
P8	2	4	2	2	4	4	4	4	4	4	4	2	2	42	3.2
P10	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0.0
P19	0	0	0	0	0	0	0	1	2	0	1	0	0	4	0.3
P22	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0.0
P23	0	0	0	0	1	0	0	0	0	0	0	0	0	1	0.1
P24	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0.0
P27	0	0	1	0	0	0	0	0	0	0	0	1	1	3	0.2
Total	3	4	4	2	5	4	4	5	7	4	5	3	3	53	0.5
Intermittent flare patients															
P7	4	1	2	3	1	2	1	2	0	2	1	0	0	19	1.5
P14	0	0	2	1	0	0	2	0	0	1	0	0	0	6	0.5
P15	3	0	0	0	0	0	0	0	0	0	0	0	0	3	0.2
P17	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0.1
P18	0	0	2	1	2	4	0	2	0	0	3	0	0	14	1.1
P21	0	0	0	0	0	0	0	0	1	0	0	0	0	1	0.1
Total	8	1	6	5	3	6	3	4	1	3	4	0	0	44	0.6
Constant flare patients															
P5	4	4	3	3	4	3	3	8	2	0	0	0	0	34	2.6
P11	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0.1
P25	1	1	1	3	2	2	2	1	2	2	2	2	1	22	1.7
Total	6	5	4	6	6	5	5	9	4	2	2	2	1	57	1.5
Overall Total	17	10	14	13	14	15	12	18	12	9	11	5	4	154	1.4

Nb: Scores highlighted in yellow indicate weeks in which patients reported a flare (they were not necessarily in a flare for the entire week)

Patients reported using a variety of self-management techniques. Those used by all the patients were *'avoided or altered doing the things that might cause pain'* and '*asking for help with the difficulties of daily tasks'* (Table 9.9). All the management techniques, except contacting their doctor, were used frequently by at least 14 of the patients a mean of between 8.3 and 10.5 weeks out of 13 weeks per patient (Table 9.9 and Fig 9.45). 8 patients contacted their doctor or other health professional. Whilst the 3 Daily Life patients each called for help once, this may not have been for a flare as the question asked if they had *"contacted [their] doctor or other health professional"* without specifying the reason and these patients reported no flares in 3 months. Of 6 the Intermittent Flare patients only 3 contacted the medical team, all of whom contacted within one week of first reporting being in flare. Of the 3 patients who considered themselves in a flare for the whole 3 months (Constant Flare patients), 2 contacted their medical team, one of whom waited at least 7 weeks from the start of data collection, but it is not known how long they had experienced flare prior to starting data collection (Table 9.10). Thus some patients who consider themselves in a flare may not contact the medical team at all or will wait a long time, whilst other patients will contact the team as soon as they consider themselves in a flare. It is of note that some patients contacted the team more than once during the data collection period.

Table 9.9: Frequency of self-management strategies used by patients in Study 3a

Self-Management Technique	No. of patients	No. of instances	Mean per patient
Avoided or altered doing the things that might cause pain	17	158	9.3
Gave myself permission to leave a task half-finished	16	143	8.9
Distracted myself from my symptoms	14	128	9.2
Asked for help with the difficulties of daily tasks	17	159	9.4
Made small adjustments to my day to deal with the difficulties of everyday tasks	16	148	9.3
Made time for socialising	16	133	8.3
Allocated time for relaxation	16	158	10.5
Managed my medication (knowing when and how to take it)	15	147	9.8
Contacted my doctor or other health professional	8	34	4.25

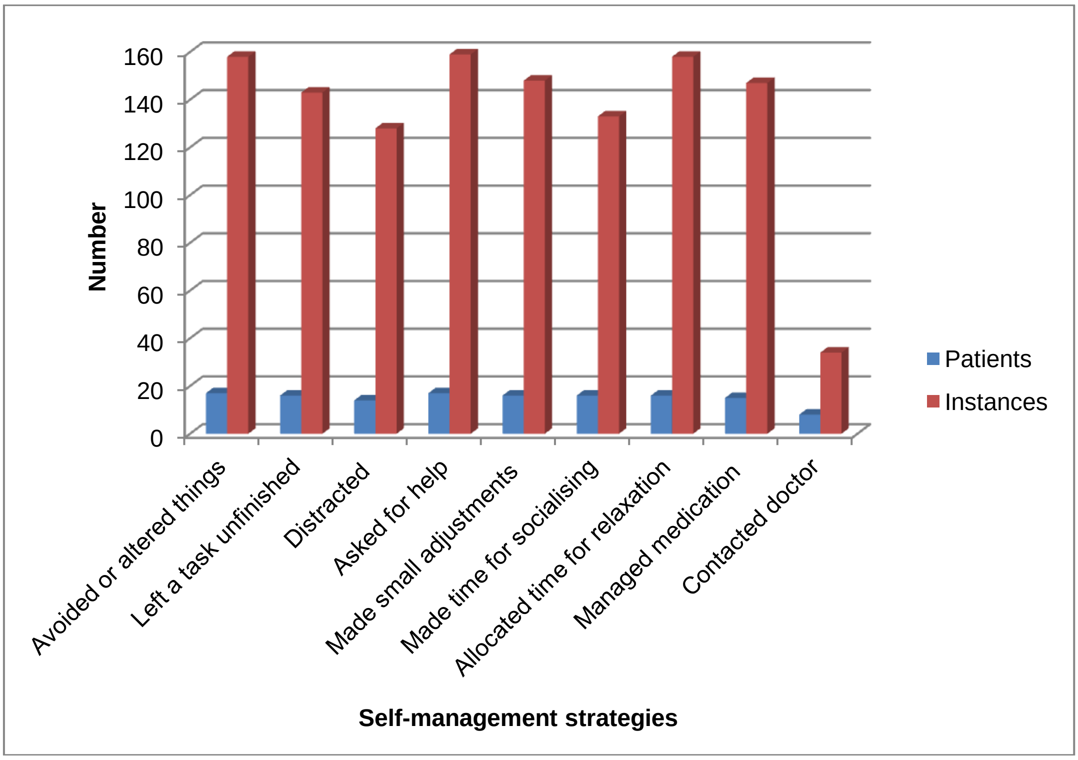

Figure 9.45: Graph showing self-management strategies used by patients in Study 3a

Table 9.10: Frequency of help-seeking for Study 3a patients

Patient	Medical help sought?	If yes, after how long?*
Intermittent flare patients		
P7	Yes	0
P14	No	N/A
P15	Yes	1
P17	Yes	0
P18	No	N/A
P21	No	N/A
Constant flare patients		
P5**	Yes	7
P11	No	N/A
P25	Yes	0

*How long in weeks after first reporting flare, before seeking help. Patients were asked daily about flares and weekly about help-seeking. Thus figures can only be accurate to within 1 week.
**The researcher was concerned about this patient during data entry as all symptoms were scored consistently highly. Thus the researcher contacted the patient (week 6) to remind her about the rheumatology helpline, which may have influenced this patient's decision

9.5 Results: Study 3b: Flare help-seeking

Study 3b used a different cohort of patients to Study 3a (Daily Variation). Following three months of recruitment at one NHS Trust for this study (Site 1), only 2 patients had agreed to take part. As patients were being recruited by the rheumatology specialist nurses through the rheumatology helpline, the researcher was unable to ascertain whether this low recruitment rate was due to a lack of patients calling the helpline in a flare, whether patients were declining to take part, or if they were not being asked. Thus for the fourth month of recruitment an additional site was added (Site 2) and a prospective audit of the rheumatology helpline at Site 1 was carried out, in order to audit the recruitment procedures. The NHS Trusts have been distinguished by numbers to preserve patients' anonymity.

9.5.1 Rheumatology helpline and recruitment audit

Over a one month period (6th Feb to 5th March 2012) the records kept to identify the reasons patients were calling and the outcome of the call were examined. During this one month period, 139 calls were made to the rheumatology helpline. Of these, 123 (89%) were patients with RA, 20 (16%) of whom were calling due to an RA flare, all of whom had appointments made for them. One of these patients was calling due to worsening symptoms, but made an appointment for an RA flare after a discussion with the rheumatology specialist nurse. The other three patients calling with worsening symptoms had recently changed medication and were advised on how long this should take to make a difference to their symptoms. Eight (40%) of the patients in an RA flare were not invited to participate, as when the nurse rang to give them their appointment date, they could only leave a message on the answer phone. Of the 12 patients invited only 4 (33%) agreed to discuss participating in Study 3b with the researcher and only 1 of these patients agreed to participate. RA patients phoned the rheumatology helpline for a range of reasons, which resulted in different outcomes of the call (Table 9.11).

Table 9.11: Summary of reasons and outcomes of patients contacting a rheumatology helpline

		Frequency	Percentage
Gender	Male	30	24.4
	Female	93	75.6
Reason for call	Request appointment for RA flare	19	15.4
	Request appointment for other reason	24	19.5
	Cancel appointment	6	4.9
	Discuss drug side effects	19	15.4
	Results query	9	7.3
	Worsening symptoms	4	3.3
	Other advice*	33	26.9
	Update the team**	7	5.7
	Request IM depomedrone***	2	1.6
Outcome of call	Verbal advice	64	52.0
	Appointment made or cancelled	20	16.3
	Appointment made for other reason	24	19.5
	Appointment cancelled	6	4.9
	IM depomedrone arranged	2	1.6
	No action needed	7	5.7
Applicable for study	Not applicable	103	83.7
	Accept study invitation****	4	3.3
	Decline study invitation	8	6.4
	Not asked	8	6.4

*Other advice included what patients could see their GP for, medication dose and physiotherapy advice
**Patients called to update the team with how their medication is working
***IM depomedrone requested due to an up-coming holiday, rather than RA flare
****Accepted study invitation from rheumatology specialist nurses (only 1 went on to participate)

9.5.2 Study 3b participants

The first three months recruitment rates are unknown, but 2 patients agreed to participate. In the final month of recruitment 40 patients were invited to participate and 29 (72.5%) agreed to take part. Thus 31 patients agreed to take part in this study, of whom 28 came from Site 2. Differences in recruitment rates are discussed in Section 9.6.

The majority of the participants were female (97%) and ages ranged from 27 to 84 years (mean: 59.5yrs; SD: 15.2) (Table 9.12). Patients were on a range of treatment regimes and had a disease duration of 2 months to 35 years (mean: 11.3yrs; SD: 9.9), and a wide range of self-reported disease activity (DAS global) and disability (HAQ). The majority of patients were retired and all were White British in ethnic origin.

Table 9.12: Summary of demographic information for participants in Study 3b: Flare help-seeking

ID	Gender	Age (yrs)	Dis Dur (yrs)	HAQ	DAS VAS	Med	NHS Trust*	Work status	Help at home	Dependents
P1	F	72	13	1.63	5.0	Unknown**	1	Retired	None	None
P2	F	73	7	Unknown**	5.2	DMARDs	1	Retired	None	None
P3	F	40	8	Unknown**	8.9	NSAIDs	1	Incapacity	Husband, adult child, young carer	2 children
P4	F	84	2	2.63	9.6	DMARDs	2	Retired	None	None
P5	F	55	2	0.25	1.1	DMARDs	2	Employed	None	None
P6	M	58	13	1.88	4.5	Steroids	2	Retired	Wife	Mother
P7	F	42	6	2.38	8.5	DMARDs	2	Employed	Husband	3 children
P8	F	68	35	2.38	9.1	Anti-TNF	2	Retired	Husband	None
P9	F	47	5	1.75	3.0	Steroids	2	Employed	Husband, young carer	3 children
P10	F	68	35	2.88	7.7	Regular Depo***	2	Retired	Husband	None
P11	F	60	9 Months	1.88	6.1	Regular Depo***	2	Employed	None	None
P12	F	79	5	2.38	1.5	Regular Depo***	2	Retired	Husband	None
P13	F	63	2 Months	2.75	10	Regular Depo***	2	Retired	Husband	None
P14	F	70	25	0.63	3.9	DMARDs Steroids	2	Employed	None	None
P15	F	51	5	2.00	4.6	Regular Depo***	2	Employed	None	None
P16	F	38	10	1.00	3.0	Steroids	2	Employed	Husband	1 child
P17	F	27	6	1.13	2.4	DMARDs	2	Employed	None	None
P18	F	54	18	2.75	7.5	Anti-TNF	2	Unemployed	Husband & adult child	None

Table 9.12 continued overleaf

P19	F	39	10	0.63	2.0	DMARDs Steroids	2	Employed	Husband & young carer	3 children
P20	F	44	4	1.63	4.9	DMARDs	2	Employed	Husband	1 child
P21	F	79	10	1.88	6.7	Regular Depo***	2	Retired	None	None
P22	F	50	9	2.38	8.1	DMARDs Steroids	2	Incapacity	Partner	Partner
P23	F	52	12	1.75	7.9	DMARDs Steroids	2	Retired	Husband****	Husband****
P24	F	42	8	1.50	8.7	DMARDs Steroids	2	Employed	Partner	Children
P25	F	55	18	2.25	6.6	DMARDs	2	Employed	Husband & grown-up child	Parents
P26	F	60	5	2.63	7.6	Regular Depo***	2	Employed	Husband	None
P27	F	82	30	1.50	7.4	Anti-TNF	2	Retired	None	None
P28	F	78	5	2.50	4.7	Regular Depo***	2	Retired	Grown-up child	None
P29	F	69	29	2.75	7.2	Anti-TNF DMARDs	2	Retired	Husband	None
P30	F	76	1	2.38	6.9	DMARDs	2	Retired	Husband & grown-up child	None
P31	F	69	13	2.25	6.6	Anti-TNF DMARDs	2	Retired	Husband	None
Mean		**59.5**	**11.3**	**1.9**	**6.0**					
Stan Dev		**15.2**	**9.9**	**0.7**	**2.5**					

*Nb NHS Trusts have been distinguished by numbers due to concerns about retaining patients' anonymity
**Not completed by patient
***These patients are controlled with regular depomedrone injections
**** Nb patient and husband both care for and depend on each other

Key:
Dis Dur = Disease Duration; HAQ = Health Assessment Questionnaire score; DAS VAS = Disease activity score visual analogue scale (DAS global); Med = Medication
Medication: Anti-TNF = Anti-Tumour Necrosis Factor; DMARDs = Disease Modifying Anti-Rheumatic Drugs; NSAIDs = Non-steroidal anti-inflammatory; Steroids = Glucocorticosteroids

9.5.3 Study completion

Of the 31 patients who agreed to take part in Study 3b, 20 patients completed the Daily Symptoms questionnaire (Appendix N1) at Time 1, when they attended clinic for their emergency flare appointment. Eleven patients from NHS Trust 2 were not given the symptom measures questionnaire due to a misunderstanding, and therefore were not sent the questionnaire at Time 2 (4 weeks after Time 1). Of the 20 patients that completed symptom measures at Time 1, 12 patients (60%) returned the questionnaire at Time 2. Only three patients completed the early warning signs questionnaire (Appendix N3), all explaining that they were only able to comment on these with the benefit of hindsight. Thus the results of this questionnaire have not been included. All 31 patients completed the flare help-seeking questionnaire (Appendix N2), which related to impact, self-management and tipping points for seeking help.

9.5.4 Flare symptoms

The 7 emotional and physical self-reported symptom scores were totalled (0-70). Patients reported a mean symptom score in flare of 41.7 (SD 14.0), with no one symptom being scored consistently higher than all other symptoms between patients (Table 9.13). Patients reported a wide range of symptom scores with the lowest range being 7.0 for stiff joints (scores ranged from 3 to 10) indicating that between-patients, different levels of symptoms cause them to define themselves as in flare. It is of note that patients' self-reported severity scores for their flare (0-10) do not correspond to their total symptom score. For example patient P8 scored their total symptoms as 36/70, but their single flare severity question as 8/10, whist P13 scored their total symptoms at 65/70, with a flare severity of 5/10. It was therefore decided to perform a correlational analysis between the individual reported symptom scores and the reported flare severity. A Spearman's rho correlation was chosen as the symptoms were self-reported scores and therefore may not have been normally distributed (Dancey and Reidy, 2008). A significant positive correlation was found for the relationship between patients' pain and their flare severity (Table 9.14: rho = 0.666, p = 0.01), but no significant correlation was found for the relationship between patients' flare severity and any of the other individually reported symptoms. Significant positive correlations were also found for the relationship between frustration and worry (rho = 0.855), anger and worry (rho = 0.728, p = 0.01), frustration and fatigue (rho = 0.632, p = 0.01) and stiff joints and fatigue (rho = 0.589, p = 0.01).

All patients were given an IM depomedrome as treatment, except one who received an intra-articular injection (P3). One patient (P4) also had their DMARDs changed. At Time 2, 11 out of 12 patients reported their total symptom score had decreased and one patient's score remained the same (P3), with a mean symptom score of 17.2 (SD 20.1). It is of note that four weeks after their appointment, two patients (P3 and P4) still considered themselves to be in a flare (Table 9.14).

Table 9.13: Flare help-seeking patients' symptom scores at Time 1

Patient	Pain	Fatigue	Swollen joints	Stiff joints	Frustration	Anger	Worry	Total	Flare severity
P1	4	4	6	6	1	1	1	23	6
P2	7	9	4	4	10	7	8	49	8
P3	8	8	8	10	10	8	9	61	8
P4	10	9	10	10	10	10	10	69	10
P5	9	5	1	5	4	0	1	25	9
P6	6	5	2	5	3	2	1	24	6
P7	8	7	6	7	10	4	10	52	8
P8	8	3	8	8	3	3	3	36	8
P9	7	7	6	7	9	9	9	54	7
P10	9	10	2	9	9	0	8	47	9
P11	7	8	3	7	7	1	3	36	9
P12	5	2	8	3	3	5	2	28	3
P13	8	9	8	10	10	10	10	65	5
P14	5	5	6	6	5	5	7	39	8
P15	7	9	9	10	6	0	0	41	8
P16	7	6	6	7	6	1	4	37	7
P17	9	8	7	7	2	2	3	38	8
P18	8	6	6	7	7	8	7	49	8
P19	2	7	2	7	1	1	1	21	2
P20	8	5	3	7	7	4	5	39	7
Mean	**7.1**	**6.6**	**5.55**	**7.1**	**6.2**	**4.1**	**5.1**	**41.7**	**7.2**
St Dev	**1.9**	**2.2**	**2.6**	**2.0**	**3.2**	**3.5**	**3.6**	**14.0**	**2.0**
Range	**8.0**	**8.0**	**9.0**	**7.0**	**9.0**	**10.0**	**10.0**	**48.0**	**8.0**

Table 9.14: Spearman’s rank correlation co-efficients for patients’ self-reported symptom scores and flare severity

			Pain	Fatigue	SwollenJoints	StiffJoints	Frustration	Anger	Worry	FlareSeverity
Spearman's rho	**Pain**	Correlation Coefficient	1.000							
		Sig. (2-tailed)	.							
		N	20							
	Fatigue	Correlation Coefficient	.406	1.000						
		Sig. (2-tailed)	.076	.						
		N	20	20						
	SwollenJoints	Correlation Coefficient	.155	.134	1.000					
		Sig. (2-tailed)	.515	.574	.					
		N	20	20	20					
	StiffJoints	Correlation Coefficient	.495*	.589**	.505*	1.000				
		Sig. (2-tailed)	.026	.006	.023	.				
		N	20	20	20	20				
	Frustration	Correlation Coefficient	.466*	.632**	.204	.440	1.000			
		Sig. (2-tailed)	.038	.003	.389	.052	.			
		N	20	20	20	20	20			
	Anger	Correlation Coefficient	.133	.091	.482*	.144	.549*	1.000		
		Sig. (2-tailed)	.576	.704	.031	.544	.012	.		
		N	20	20	20	20	20	20		
	Worry	Correlation Coefficient	.460*	.455*	.268	.394	.855**	.728**	1.000	
		Sig. (2-tailed)	.041	.044	.252	.085	.000	.000	.	
		N	20	20	20	20	20	20	20	
	FlareSeverity	Correlation Coefficient	.666**	.410	.006	.278	.392	-.120	.251	1.000
		Sig. (2-tailed)	.001	.073	.979	.236	.087	.615	.286	.
		N	20	20	20	20	20	20	20	20

*. Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.01 level (2-tailed)

Table 9.15: Flare help-seeking patients' symptom scores at Time 2

Patient	Pain	Fatigue	Swollen joints	Stiff joints	Frustration	Anger	Worry	Total	In Flare?
P3	9	10	9	8	10	8	7	61	Y
P4	8	7	8	7	8	9	9	56	Y
P6	2	2	0	2	1	0	0	7	N
P9	3	5	1	3	6	7	4	29	N
P11	1	2	1	2	1	0	0	7	N
P13	7	8	7	9	7	5	7	50	N
P14	3	4	4	4	1	1	3	20	N
P15	3	2	2	2	0	0	0	9	N
P16	2	2	2	3	2	0	2	13	N
P17	1	5	2	1	0	0	0	9	N
P18	2	4	6	3	4	4	3	26	N
P20	4	5	1	3	4	2	4	23	N
Mean	**3.8**	**4.7**	**3.6**	**4.0**	**3.7**	**3.0**	**3.3**	**17.2**	
St Dev	**2.7**	**2.6**	**3.1**	**2.6**	**3.4**	**3.4**	**3.1**	**20.1**	
Range	**8.0**	**8.0**	**8.0**	**8.0**	**10.0**	**9.0**	**9.0**	**54.0**	

9.5.5 Flare impact, self-management and help-seeking

9.5.5.1 Flare impact

Patients scored flare impact items from 0-10, with 10 relating to managing as normal, full involvement and coping very well (results displayed in a graph in Appendix S). Patients scored highest on being able to manage whilst in an RA flare (mean 4.7, SD 2.5) and lowest on their current level of involvement in social or pleasurable activities (mean 4.1, SD 2.4). It is of note that whilst some patients' managing, coping and involvement scores were similar, some patients (e.g. P11, circled in blue) reported they were able to manage well, whilst not coping or being involved, and others (e.g. P6, circled in red) reported they were able to cope, but not to manage (Fig 9.46)

9.5.5.2 Flare self-management

Increasing rest time was the most common self-management strategy (25 patients) and only 2 patients did not do anything differently when they realised they were in flare. It is of note that 26 out of 31 (84%) patients increased their medication themselves, all of whom increased their analgesics or anti-inflammatory medication, 3 of whom also increased their steroids (Table 9.16).

Table 9.16: Frequency of self-management strategies used by patient in Study 3b

Self-management strategy	Number of patients (n=31)
I didn't do anything different	2
I reduced the amount of activities I did	23
I increased my rest time	25
I avoided doing activities I had planned to do	17
I asked for help with everyday tasks	18
I tried to distract myself from my symptoms	20
I took more painkillers or extra anti-inflammatory medications	26
I took more steroid tablets	3

9.5.5.3 Delays and tipping points for flare help-seeking

Four patients (7%) reported delaying help-seeking due to not wanting to be prescribed any more medication, 13 patients (42%) reported waiting until they had more than one symptom before seeking help and 21 (66%) reported waiting until the flare had lasted longer than expected before seeking help. Further, 21 patients (66%) reported having been prompted to seek help by a family member or friend. Patients' free-form responses regarding their final tipping points for seeking help have been grouped into symptoms, impact, coping/self-management strategies and other. It is acknowledged that some overlap exists in the categories, for example *mobility being affected* could be placed within *quality of life being affected*. However, these data were separated in order to use participants' own words and to show the diversity in the specific final tipping points, rather than masking this diversity under one overall 'quality of life' heading. These results show that patients reported multiple tipping points with unbearable pain being the most common tipping point for patients, followed by being unable to sleep or rest (Table 9.17).

Table 9.17: Frequency table of final tipping points for flare help-seeking

Tipping Points		Number of patients
Symptoms	Unbearable pain	23
	Stiffness	2
	Swelling	2
	Fatigue	3
	Dark thoughts/low mood	2
Impact	Quality of life affected	2
	Unable to rest/sleep	7
	Mobility affected	3
	Unable to do daily tasks	2
	Paid work affected	3
	Social withdrawal/isolation	2
Coping/Self-management	Not coping	2
	Self-management not working	2
	Painkillers not working	3
Other	Feeling desperate	2
	Knew it would get worse without help	2
	Family member phoned helpline (choice removed)	1
	Prompted by rheumatology nurse when phoned helpline for other reason	1

9.6 Discussion

This study produced novel data showing first that patients are never symptom free but experience a wide range of daily symptoms that vary between and within patients; second that self-management is a constant necessity; third that definitions of flare vary within and between people and may not be purely defined by symptom severity; fourth that help-seeking decisions vary widely; and fifth that few patients experience early warnings for flare.

Study 3a identified that even on current, modern treatment regimes patients are never symptom free, even in daily life, which supports the findings from the free-form graphs completed by patients in Study 1 (Chapter 6.4.2). In fact some patients report higher symptoms in daily life than when they consider themselves in flare. The vast difference in reported symptom patterns by patients in daily life, intermittent flare and constant flares, highlight the individual nature of patients' experiences of RA. Only one patient reported symptoms that fit the expected pattern of RA, which anecdotal evidence suggests is used by clinicians as an illustration of RA to newly diagnosed patients (after sitting in on clinics, the researcher noted that all clinicians either draw a standard wavy line or wave their hands to indicate fluctuations, to explain to newly diagnosed patients what life will be like). This demonstrates the problem with the flare illustration by Stone *et al* (2008), which displayed four types of flare to patients with AS and asked them to pick which best fit their experience. Clinicians may not have a true picture of how patients' symptoms fluctuate daily and thus asking patients to pick one of four patterns produced by clinicians may not truly reflect how their disease fluctuates. Further, four patterns of symptoms appears to be too reductionist to enable this complex phenomenon to be fully appreciated.

Study 3 also found that patients use different levels of self-management, which do not necessarily relate to their level of symptoms. This supports the different patient groups identified in Study 2 (Q-methodology). Patients in study 3a who experience daily life as low symptoms with varying fluctuations report using a high number of self-management strategies every week. These patients seem to fit the Study 2 'taking active control' group (Factor A+), as they are self-managing their symptoms to a manageable level. Patients in Study 3a who reported daily life as high levels of symptoms and high fluctuation reported a moderate level of weekly self-management and appear to fit into the Study 2 'constant struggle' group (Factor B-). For some of these patients, their increase in self-management strategies did not relate to a drop in symptom severity and they therefore may not be identifying the correct types of self-management to control their symptoms, further supporting fit with the 'constant struggle' group. However, for other patients, as they increased the number of self-management strategies they used, their reported RA symptoms reduced. Thus it is possible that these are the Study 2 ‘putting RA in its place’ group (Factor C-) and do not always have time to consider self-management strategies, but when they do use them, they work.

Patients who experienced intermittent flares throughout the data collection period still used a moderate number of self-management strategies and some patients in a constant flare reported using all measured self-management strategies. Thus these patients appear to represent the Study 2 ‘constant struggle’ patients, being unable to self-manage their symptoms. However, these patients report self-managing as much as possible and thus could also be considered the Study 2 ‘taking active control’ group but who are no longer able to control their unmanageable flare symptoms. Thus even patients that are able to take control of their RA and maintain a balance in normal daily life, may still lose control when flare symptoms become overwhelming.

Study 3b identified that patients used a variety of self-management strategies before seeking medical help, including increasing their medication. These prospective, quantitative data support previous qualitative research (Hewlett *et al*, 2012), performed with patients who were asked to look back to a time when they were in a flare, and which proposed that failure of self-management strategies prompt patients’ help-seeking behaviours. A previous qualitative study (Kett *et al*, 2010), which addressed the self-management strategies used during flares in an ethnically diverse population had broadly similar findings, but with some specific cultural differences. Further, this increasing level of self-management prior to seeking help for an RA flare supports the Mediation Ladder developed in qualitative Study 1 (Chapter 6 Figure 6.23), confirming patients do use an additional level of self-management prior to help-seeking. It therefore appears that some, but not all, of the previous flare proposals generated from qualitative studies with patients not in flare, are supported by these quantitative exploratory data collected prospectively in patients in flare.

Study 3 identified that patients may all be using different criteria to define flare. It is also possible that patients who reported high symptoms, yet did not consider themselves to be in a flare at those times, may have accepted this high level of symptoms as normal for them. Nearly all patients who reported intermittent flares during the Study 3a data collection period reported days not in flare on which they recorded higher levels of symptoms than days in flare. Further, although patients who reported flares cancelled more plans on average than those not in flare, individual patients did not necessarily cancel more plans on the days they reported flares than the days they did not. Thus it is possible that patients are using more than just physical symptoms, emotions and impact on their lives to define themselves as in an RA flare. Patients may consider themselves in flare when they are no longer able to mediate the balance in their lives, with no single factor consistently contributing to this loss of balance. This idea is supported by Jane in Study 1 (Interviews):

> *"Stress can cause it, you know something that's worrying. I mean, when my son's marriage broke up that caused a flare-up"* (Jane, 65)

It is possible that stressful events do not always cause flare-ups *per se*, it may be that the stressful event tips the balance in patients' lives enough to cause them to reclassify their symptoms as a flare. Indeed, patients in Study 3b (Help-Seeking) did experience lower overall symptoms four weeks after their clinic appointment (when they were no longer in flare) indicating that seeking medical help for a flare does help to restore this balance, which supports the Fluctuating Balances Model developed in this thesis (Chapter 8, Figure 8.4).

The finding that there is a significant positive correlation between patients' self-reported pain and flare severity support findings from informal discussion groups with RA patients (Bingham *et al*, 2009b), which proposed that pain was a critical factor in patients' definition of flare. It is important to note that patients' self-reported flare severity did not significantly correlate with patients' self-reported swollen joints, which is the only RA symptom that is explicitly visible to clinicians.

These prospective, quantitative data from these patients at the time they consider they are in flare, suggest that they have a complex set of beliefs and tipping points that cause them to define their symptoms as an RA flare. This supports previous research (Hewlett *et al*, 2012), which claimed that increased symptoms and failure of self-management strategies led to patients defining themselves as in flare. However, the current study has demonstrated that even this may be too simplistic and the influence of inter-personal factors alongside socio-cultural factors in relation to patients' flare definitions need to be explored further, in order to better understand the individual context.

The help-seeking behaviours of patients in Study 3a who reported a flare support the types of flare help-seeking identified in Study 2. Some patients reported seeking help quickly ('definite decision': Factor A), whilst others waited up to seven weeks after identifying themselves as in a flare ('cautious indecision': Factor B). It is of note that not all patients in Study 3a who reported being in a flare sought medical help. Some of these were patients who reported being in flare for the 3 months of the study and of unknown duration prior to the study commencing. It is possible that these patients fit into the ‘cautious indecision’ type, and may eventually seek help. However, due to the length of time their flare has lasted without help-seeking, it is also possible that these patients form another group, who don’t ever seek help for their RA flares.

The majority of patients in Study 3b (Help-Seeking) reported low scores on (at least one of) being able to manage, being able to cope and maintaining their level of involvement. This supports the Fluctuating Balances Model (Chapter 8, Fig 8.4) developed in this thesis, which identified losing control as a tipping point for help-seeking. This prospective study with patients in flare identified that the most common tipping points for seeking help were unbearable pain and flare going on longer than expected. This supports the consensus for flare help-seeking identified in Study 2, which were intense pain, longevity of flare and loss of control. Further, these tipping points for help-seeking are similar to those identified in patients pre-diagnosis (Sheppard *et al*, 2008), which were symptom severity, impact on daily life and the patient’s interpretation and evaluation of their symptoms. The only tipping point not expressly measured was patients’ interpretation of their symptoms. However, all these patients considered themselves in a flare and thus had interpreted their symptoms in this way.

A further tipping point of note is that the majority of patients reported being prompted by a friend or family member to seek help. This could be due to patients needing external validation of their interpretation of their symptoms (Stoller *et al*, 1998). It is also possible that patients need this external permission to seek help, thus removing the responsibility of the patient possibly having made the wrong decision. This supports a previous qualitative study in acute myocardial infarction, which found that people were more likely to seek help if a friend or family member phoned for help as the patient reported feeling less guilty about the possibility of wasting the doctor’s time (Pattenden *et al,* 2002). Further, being prompted by a friend or family member to seek help may allow patients to retain their stoic identity, whilst still seeking help, by being able to claim they were coerced into seeking help. This indicates that patients are not alone in the decision-making process and thus family members of newly diagnosed patients may benefit from education along with patients.

Patients who sought help were asked how well they were coping, managing and able to be involved in activities. It was of note that these were not necessarily linked to each other, with some patients reporting being able to cope, but not to manage and vice versa. This supports previous qualitative research (Nicklin *et al*, 2010b), which found that patients make a clear distinction between managing and coping, with managing being related to practical issues and coping being concerned with emotions. This supports the psychological theory (Lazarus and Folkman, 1984) that claimed coping can be divided into problem-focused and emotion-focused. Thus some patients in this study may be able to cope emotionally, but not to manage in a practical way due to their symptoms, whilst others may be able to manage practical issues, but are not able to cope emotionally. It is possible that these different experiences could point to different types of flare, with one being related to physical restriction and another being related to patients becoming overwhelmed and losing their daily life balance.

In Study 3b (Flare Help-Seeking) only 3 out of 31 patients reported early warning signs of their flares and they reported that it was only with hindsight they were able to recognise these, thus these data were not reported. This contrasts with findings from a previous qualitative study (Hewlett *et al*, 2012), which found that some patients experience early warning signs of a flare such as flu-like symptoms, fatigue or symptoms in particular joints; and an international patient and professional Delphi study (Bartlett *et al*, 2012), which found that 77/148 (62%) patients identified early warning signs of a flare. It is possible that this difference is due to the small sample size in the current study and thus patients who experience early warning signs may not have been identified. Another explanation is that in the current study, the researcher was in the same room as the patient when they completed the early warning signs questionnaire, the participants therefore had the option to express to the researcher their feelings that they were only experiencing these with hindsight, whereas in the Delphi study (Bartlett *et al*, 2012) patients were either posted or emailed the study, and thus did not provide additional comments. It is of note that early warning signs were not retained in the Delphi study (Bartlett *et al*, 2012*)*, which may indicate that whilst experienced by some patients, these are not essential for a definition of flare and thus the idea of early warning signs may need further exploration.

This was also a feasibility study and thus the potential for a larger study will be addressed. The recruitment rate for Study 3a indicates that patients are willing to complete daily questionnaires for three months and the low attrition rate (14.8%) indicates that once patients have started the study they are likely to complete it. The option for patients to complete the daily measures online increased the likelihood of recruitment. However, there were a substantial proportion of missing data. Some patients reported the reasons for this, which were forgetting to complete and illness. The other participants may also have missed data for these reasons, or perhaps due to no longer wishing to complete questionnaires daily, being busy over the Christmas period or going on holiday without advising the researcher. Therefore this amount of missing data needs to be taken into account when calculating sample size for a larger study. Analysing the data visually through individual graphs was time-consuming, therefore to conduct this study on a multi-centre scale, a different method of analysis would be more practical (discussed in Chapter 10).

The recruitment rate for Study 3b (Flare Help-Seeking) at Site 1 was so low that based on this site alone it would not be possible to run the study on a larger scale. However, the 100% recruitment rate at site 2 indicates that this may be a local problem, potentially due to patients at Site 1 being over-researched. It is also possible that the high recruitment rate at Site 2 may have been due to a different definition of flare being used by the team there. Further, a number of the patients from Site 2 were managed with regular depomedrone injections, thus it is possible that these patients were calling for a routine injection and were incorrectly labelled as in flare by the person that recruited them from the Site 2 research team. It would therefore be advisable to use a large number of sites to recruit the numbers needed for this study to be powered. The Site 1 helpline audit identified that in a one month period only 16% of the callers with RA, were in a flare. This can be compared to a previous audit that was carried out on an RA helpline at a different Trust (Hughes *et al*, 2002), which found that 32% of calls were from patients reporting worsening symptoms. This study did not specify when patients were in flare, thus it is possible that not all patients who reported worsening symptoms were in flare. However, in the audit conducted in the current study only 19% of patients reported either flare or worsening symptoms, thus it appears as though fewer patients are contacting the helpline in an RA flare than they did ten years ago. This could be due to better control of RA or patients being better educated in how to self-manage and therefore having less need for crisis intervention.

9.6.1 Strengths and limitations

This study could be criticised for the small sample size, but it was an exploratory and feasibility study and therefore did not intend to be powered. The majority of patients in Study 3b came from one NHS Trust and therefore may not have represented a wide range of patients' experiences of flare when deciding to seek help. However, patients in Study 3a were recruited from three NHS Trusts with a range of age, gender, disease duration, disability and current flare status, thus providing a range of experiences of RA. Further, patients were offered both online and pen and paper response options, which also provided a diverse sample of patients.

This study did not define flare for patients, nor did it ask patients how they were defining flare, which means that all patients could have been using a different definition for flare. Further, in Study 3b the criterion was to recruit patients in a self-defined flare, but it is possible that the rheumatology specialist nurses made a judgement call and thus the definition of flare may have come from them.

Further possible limitations relate to the scales used. First, patients in Study 3a were asked whether they cancelled their plans, but not whether they avoided making plans. Thus patients may have been self-managing by not making plans when their RA symptoms were higher, which may indicate why there were not necessarily more plans cancelled when patients were in a flare. Alternatively, patients may have been keeping their plans due to weighing up the consequences and deciding that they would rather put up with their symptoms to achieve or complete something more important to them. For example, patients may decide that going shopping with friends provide more benefits, in terms of social support, than resting and withdrawing socially provides through minimising symptom severity, an interpretation supported by Study 1 (Interviews):

> *"I find sometimes um if you go out and you socialise it does take your mind off of it a bit"* (Jane, 65)

Second, some patients reported seeking medical help for more than one week running. It is unclear as to whether this is due to not being helped during their appointment, ticking the option weekly whilst waiting for an appointment, or study fatigue in which patients may have been ticking every self-management box by the end of the study. Thus this question should have been clearer or more detailed in order to unpick this.

The strengths of this study are that the content of the items used in the current study were developed from Study 1 and Study 2 and therefore reflected patients' views rather than being imposed by the researcher. Further, an open question was provided for patients in Study 3b in order to capture any tipping points that were not included in the other measures. This open question only identified one tipping point that had not been covered, which was the rheumatology specialist nurse prompting the patient to seek help when she phoned for another reason.

Study 3a was a prospective diary study, which captured symptoms daily and Study 3b captured patients whilst they were still in a flare. Thus neither of these studies were subject to retrospective bias. Daily measures of symptoms have not been previously measured in RA, which makes this study novel.

9.7 Summary

Patients report varying levels of symptoms in both daily life (not in flare) and when they are in flare, and these overlap. Patients therefore may be defining flare in very individual ways. Thus flare judgements made by patients may not always include the traditional professional views of high pain and swelling, this will be explored further in the discussion where all three Studies are considered together (Chapter 10). However, when patients do seek help the tipping points used by the majority of patients are pain, longevity of symptoms, lack of control and being prompted by a friend or family member.

The studies in this thesis have provided novel contributions to knowledge and have many implications for further research and clinical practice. These larger concepts will be explored in depth in Chapter 10.

Chapter 10: Discussion of the research findings, and the implications for research and clinical practice

Chapters 6 to 9 presented the results and discussed the individual findings of the three studies in this thesis. The current chapter discusses the combined findings of the three studies and considers the implications that these have for future research and clinical practice.

10.1 Thesis aims

The aims of this thesis were:

- To explore the individual experience and impact of RA in daily life and flare and how patients self-manage these
- To obtain consensus on patients' experiences of daily life with RA
- To obtain consensus on patients' help-seeking behaviours in an RA flare
- To characterise the level, variation and clustering of symptoms in daily life

Three studies were used to address these aims: qualitative interviews (Study 1), Q-methodology (Study 2) and two exploratory and feasibility surveys (Study 3).

10.2 Contributions to knowledge

The three studies used to meet the aims of this thesis have provided the following novel contributions to knowledge:

1. In normal daily life, even on current more aggressive treatments, RA patients are not symptom-free
2. Life with RA involves maintaining a delicate and fluctuating balance to mediate its impact
3. Patients employ a stepped approach to self-management, which increases as their symptoms increase and includes a baseline level of daily micro-management
4. Patients will seek help for their RA due to loss of control, longevity of the flare, pain severity, and feeling unable to cope or manage. However, there are also tipping points and barriers specific to subsets of patients based on personal beliefs
5. Patients may be using a definition of flare in a way that has not previously been identified.

As well as meeting the aims of this thesis, two novel issues were discovered:

6. Male RA patients have a more negative experience of RA than female patients
7. Patients use metaphors as a communication tool to express their RA symptoms and the impact it has on their lives

These contributions to knowledge will be addressed individually.

10.2.1 Daily life with RA

The findings from this thesis suggest that patients experience life with RA as unpredictable and uncertain, with their fluctuating symptoms making it difficult to predict how they will feel:

> *"Um, God it's really difficult, it's so different, I never know what I'm going to feel like when I wake up"* (Isabelle, 45, Study 1)

This supports previous qualitative research (Stenström, Bergman and Dahlgren, 1993), which reported uncertainty due to unpredictable exacerbations and remissions of RA, and its unpredictable long term course. However, Stenström's study is now 17 years old and therefore may not reflect experiences on current treatments. Further, this study used only 9 patients all of whom were female, therefore saturation of ideas may not have been reached.

Even on current more aggressive treatment regimes, which have been deemed more effective (Singh *et al*, 2010; Aaltonen *et al*, 2012) this thesis presents the novel finding that patients are never symptom-free, experiencing at least a baseline level of symptoms daily. Some patients in Study 3 even reported symptom levels as high as 8/10 (10 being worst symptoms imaginable), yet did not feel these symptoms constituted a flare and nor did they seek help. It is unclear as to why patients will accept these high levels of symptoms in daily life. It is possible that patients have learnt to live with this level of symptoms, or that they are reluctant to define themselves as in a flare as this would mean they would have to acknowledge and deal with their symptoms.

10.2.2 Fluctuating Balances

This thesis has proposed that patients experience life with RA as a continually fluctuating balance between living with their RA in the background and living with it in the foreground (Fig 8.4). Thus patients need to balance their physical and emotional RA symptoms with self-management techniques. Patients' RA symptoms are constantly fluctuating: even in normal daily life patients are rarely symptom free and report cancelling plans, and therefore employ self-management techniques to manage their RA even when they consider themselves to be doing well. Patients also balance the impact that RA has on aspects of their lives such as their identity and their independence, through making cognitive adjustments. The unpredictable and uncertain nature of RA and negative perceptions of RA can cause the delicate balance to tip, but patients are sometimes able to control this impact and restore the balance. However, at other times patients' RA symptoms become too much for them to control, which can prompt them to seek medical help (Section 10.2.4). It should also be noted that some patients, predominantly men, do not seem able to achieve a balance in their lives with RA and therefore often experience RA in the foreground of their lives (Section 10.2.6).

The Fluctuating Balances Model (Fig 8.4) builds on the Shifting Perspectives model of chronic illness (Paterson, 2001). This model claimed 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. 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, 1994). 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).

However, whilst this theory was developed through a metasynthesis of qualitative research studies and therefore was not based on primary data, the theory was not tested and refined through subsequent interviews. The Shifting Perspectives model (Paterson, 2001) had not previously been applied to the specific experiences of patients with RA but this study demonstrates that the Shifting Perspectives model of illness being either in the foreground or background of patients' lives may not adequately capture the experience of living with RA. In contrast, the Fluctuating Balances Model proposes that the fluctuating nature of RA symptoms coupled with patients' expert self-management techniques can mean that patients experience a third, dynamic stage in which their RA is moving into the foreground. At this point, RA is a potential threat but crucially, patients often hold the skills to manage their symptoms and balance the impact of RA and move it back in the background. Thus patients with RA seem to experience a fluctuation of their illness along a continuum of their RA being in the foreground or background, and one over which they can exert some control to regain balance, rather than Paterson's either/or model in which control is quickly lost.

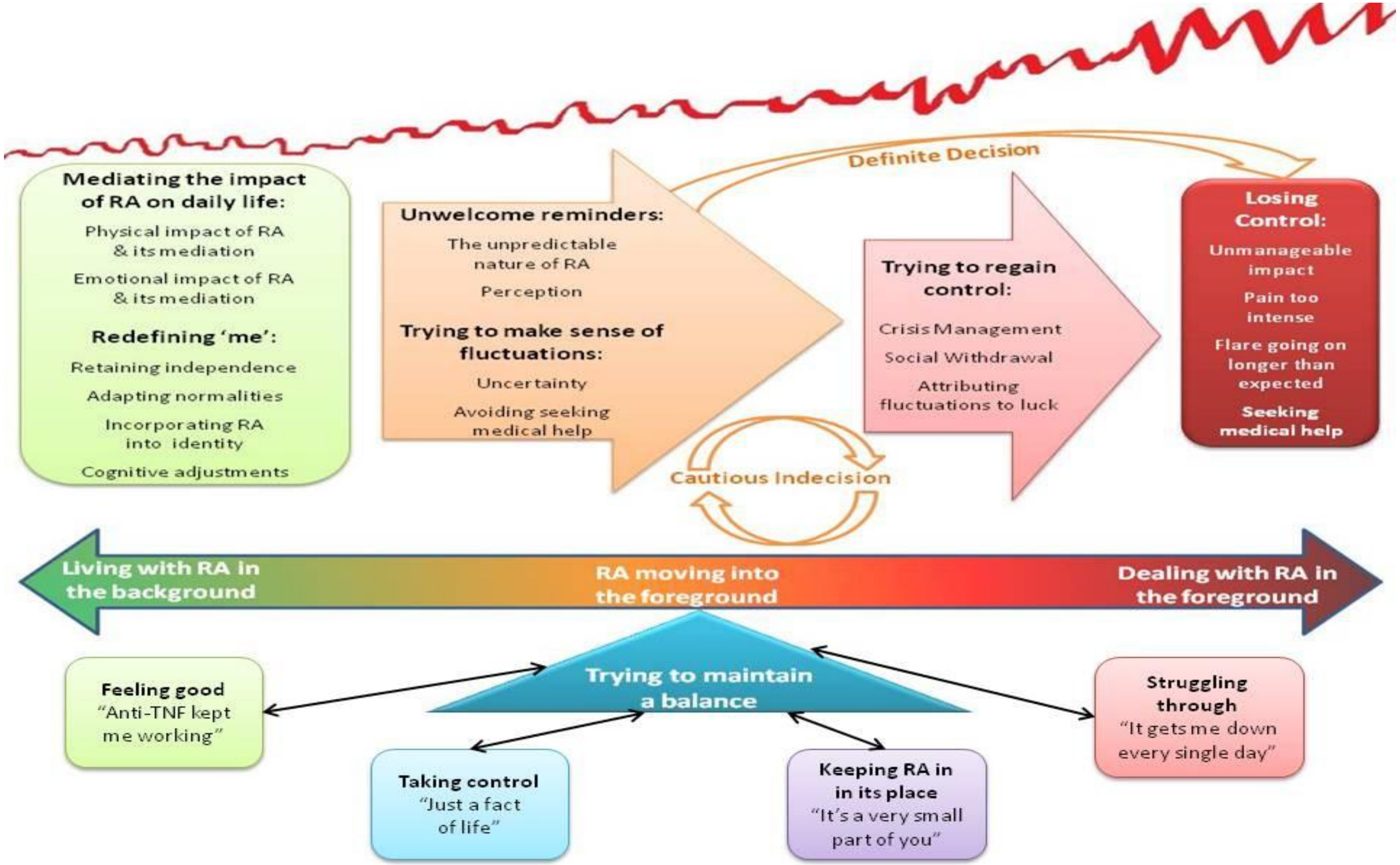

Figure 8.4: Final Fluctuating Balances Model

In addition, the Fluctuating Balances Model (FBM: Fig 8.4) has shown that RA in the background (wellness in the foreground) involves a more complex process than patients' abilities to reconcile their self-identity with their RA identity, which was proposed by Paterson. To keep their RA in the background patients need to balance their needs not only for self-identity, but also for independence and normality by using self-management of their symptoms to reduce the impact rather than simply a shift of perspective.

The finding that patients adapt their perspectives of normality in order to balance their lives with RA contributes to the existing literature. One study using nominal group technique (Sanderson *et al*, 2011a) found six different typologies of normality, which provides depth to the concept of normality, which was not specifically explored in this thesis. However, adapting normality is only one aspect of patients' experience of RA. It is therefore proposed that patients experience life with RA as a fluctuating condition, in which they need to employ constant but varying levels of self-management and coping in order to maintain the balance of their lives with RA. However, when patients experience severe symptoms, they are not always able to maintain this balance and some patients seem to struggle to achieve this balance at all.

The FBM has the potential to facilitate discussions between patients and health professionals. It could be used in discussions with newly diagnosed patients about what life with RA might be like for them. It could also be used in discussions with patients who need help coping with their RA, using the model to help patients understand where they fit within the model, where they would like to fit and how they could get to this point. However, the sections of the FBM relate to the themes that were identified in Studies 1 and 2, and therefore the language used may not be understood by all RA patients. The researcher has made an initial attempt at simplifying the language used in the FBM (Fig 10.1), but this needs testing with patients and clinicians to ensure the content can be easily understood and that none of the items pose a threat to patients, before recommending its use in clinical practice.

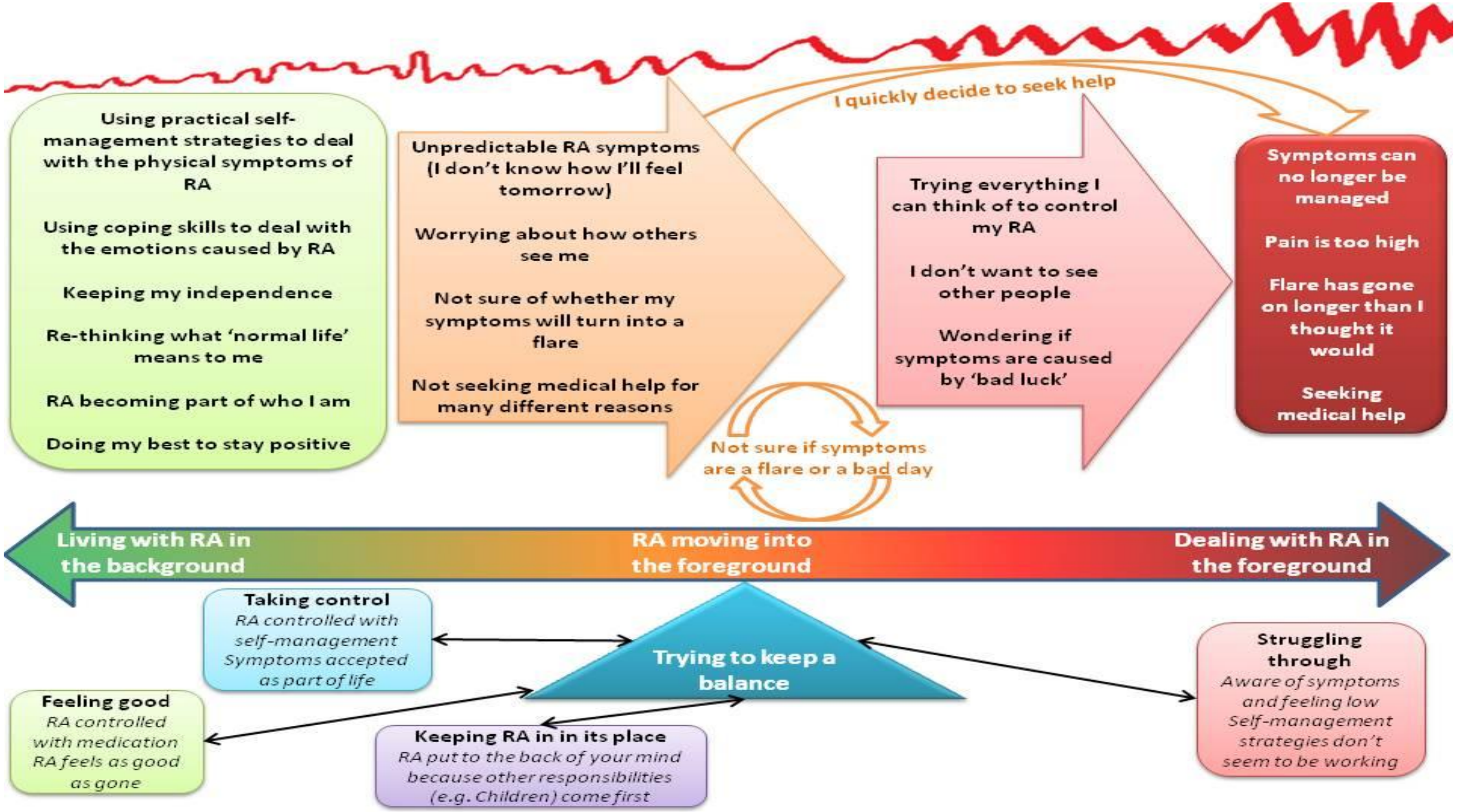

Figure 10.1: First attempt at Patient-Friendly Fluctuating Balances Model

10.2.3 Mediation Ladder

This thesis has proposed that patients use a stepped approach to manage their RA, or use a Mediation Ladder (Fig 6.23), whereby as patients' symptom severity increases, their self-management strategies also increase. This stepped approach to self-management means patients are often able to control their symptoms and can therefore step up or down depending on the impact and severity of their symptoms and their ability to manage them.

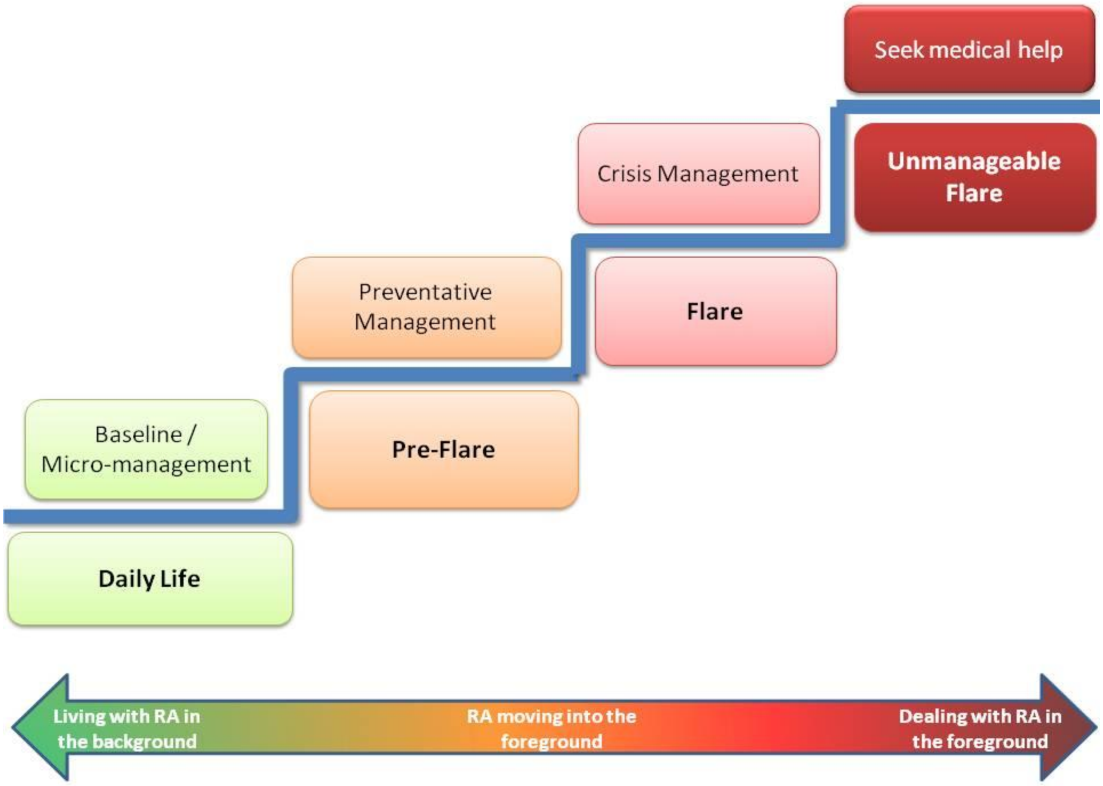

Figure 6.23: Mediation Ladder: Increasing steps of self-management

The RA literature reports that patients use pacing and planning, hot and cold packs, resting and exercise (Hammond, 1998) to control their RA. However, this study found that in addition patients use a baseline level of micro-management in daily life, even when they consider themselves to be well, a novel finding of preventative strategies. Thus patients are constantly aware of their RA, employing strategies to minimise the risk of initiating or aggravating their symptoms:

> *"If I was just printing something I will get up and go to the printer I won't just wait and print a whole load and then go up at one point or get someone else to get it for me, I will get up and move around and go for a coffee and yeah have a little wander round the office or something. I just find it helps a lot because otherwise you do seize up and that causes a lot more pain, a lot more trouble"* (Charlotte, 37, Study 1)

> *"This [making small adjustments to my day or activities constantly] is important as you need to be able to do this to manage your RA effectively"* (P1, Study 2).

When patients are in a flare, they step up their self-management strategies and employ crisis management in an attempt to reduce the physical symptoms and psychological factors associated with a flare. In addition to increasing their use of hot and cold therapies and resting, patients begin to increase their analgesics, increase their steroids, withdraw socially, reduce their activities, increase fluids and fast: in short, patients report that when they are in a flare they would be prepared to try anything to reduce their symptoms:

> *"I just try anything to, you know, try and defeat it really"* (Emma, 42, Study 1)

This contributes to the small body of previous literature that addresses patients' self-management techniques when in an RA flare. One qualitative study with an ethnically diverse population (Kett *et al,* 2010) identified that patients increase their rest time, apply heat to their joints, increase their analgesics, use distraction, use alternative therapies and avoid foods they believe will make their symptoms worse. This study conducted interviews in Punjabi, Urdu and Hindi as well as English and as the researcher spoke those languages they stated there was no need for a translator in the interviews. However, the authors do not explain how the interviews were translated for analysis: if they were translated by the researcher this has the potential for researcher-bias in terms of how they translated the data (Temple and Young, 2004) and there is no acknowledgement that the researcher may have paraphrased during interviewing.

This stepped approach to self-management supports a number of aspects of Crisis Theory (Chapter 3.1.1; Moos, 1982; Moos and Shaefer, 1986). Patients' self-management techniques increase (step up) as their symptoms increase and they perceive their RA as more threatening (*Illness-related factors*) and patients are more likely to seek help when they appraise their symptoms as constituting an RA flare (*cognitive appraisal*). Further, patients alter their *adaptive tasks* based on this appraisal, for example patients in daily life are trying to maintain a baseline level of RA symptoms, whereas patients in a flare are trying to reduce their symptoms to a manageable level. These different *adaptive tasks* would need different *coping skills*, which the Mediation Ladder (Fig 6.23) demonstrates. The final mediation step patients use to manage their RA flare is to seek help from the medical team.

10.2.4 Flare help-seeking

This thesis has identified consensus on tipping points for help-seeking in an RA flare as longevity of the flare, the pain becoming too intense and patients no longer feeling able to control their symptoms (Q methodology Study 2, Fig 8.2). However, two different types of help-seeking behaviours have been identified. One group (‘definite decision’) will seek help quickly, believing the medical team are there to help them. These patients are prompted to seek help quickly by worries about long term damage to their joints, feeling their flare needs to be controlled by new medication and affects on their quality of life. In contrast, another group of patients (‘cautious indecision’) will wait a long time as they hope the flare will go away and believe they should manage alone. These patients also worry more about wasting the rheumatology team’s time and sometimes need to be prompted by a friend or family member to seek medical help. A further group of patients was identified in the prospective data in Study 3, who whilst experiencing severe symptoms and defining themselves in a flare may never seek medical help.

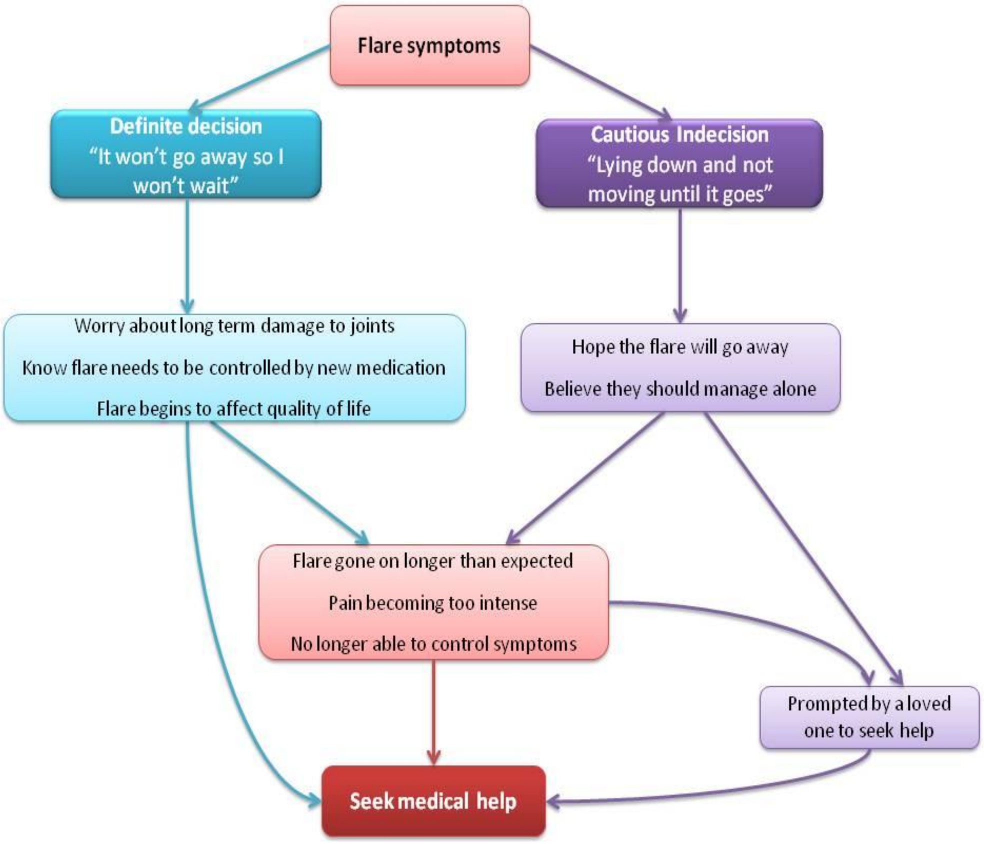

Figure 8.2: Decisions about seeking help in a flare

The finding that patients seek medical help when they are no longer able to control their symptoms supports a previous qualitative study (Hewlett *et al*, 2012), which claimed that patients seek help when their self-management strategies fail. However, this study did not identify patients' barriers to or final tipping points for seeking help. The finding that patients delay help-seeking due to worries about wasting the rheumatology team's time supports findings from another qualitative study (Kett *et al*, 2010). However, this study asked only one question about help-seeking in a study addressing self-management strategies and therefore the issue was not explored in depth. Thus help-seeking for RA flare has largely been overlooked in the literature and this thesis has explored this issue in depth through qualitative interviews (Study 1), identified typologies of help-seeking decision-making (Study 2) and has tested these for the first time by applying them prospectively to patients' behaviours when in a flare (Study 3).

All the behaviour change theories discussed in Chapter 4 have the potential to partly explain patients' help-seeking behaviours identified in this thesis. However, as hypothesised the illness perceptions associated with the Self-Regulatory Model (Moss-Morris *et al*, 2002) (Chapter 4.3.5) seem to best fit the help-seeking findings identified in this thesis. In terms of *cause,* patients who identified the cause of their flare as inflammation and therefore a need for a change in medication were more likely to seek help than those who could not identify a cause for their flare. In terms of *acute/chronic timeline*, patients reached consensus on seeking help when their flare had gone on longer than expected. In terms of *cyclical timeline,* the unpredictable nature of their RA left many patients uncertain as to whether their symptoms constituted a flare and therefore delayed help-seeking. In terms of *personal control*, patients who felt able to control their symptoms are less likely to seek help, as consensus was reached on being unable to manage symptoms as a tipping point for seeking help. In terms of *treatment control*, patients who felt the medical team were there to help them were more likely to seek help. In terms of *consequences* patients reported seeking help when the pain became too intense, or started to affect their quality of life. In terms of *emotional representations* patients who worry about the long term consequences are more likely to seek help. Finally, in terms of *Illness coherence*, patients who define their symptoms as an RA flare are more likely to seek help, whereas those who are uncertain about the cause of their symptoms will wait, hoping that their flare will go away on its own. Thus the revised illness perceptions (Moss-Morris *et al,* 2002) appear to effectively explain the decision-making process of patients in seeking help for an RA flare. However, the finding that some patients need to be prompted by a friend or family member to seek help indicates that illness perceptions cannot explain all aspects of help-seeking behaviours. This finding supports research in patients with pre-diagnosed RA that has found patients used friends and family as ‘lay consultants’ to seek advice and validation from before seeking help (Shaul, 1995; Sakalys, 1997). Patients may be waiting for friends or family to prompt them to seek help due to this removing the responsibility from them and thus causing them to worry less about wasting the rheumatology team’s time, which has previously been identified with acute myocardial infarction patients (Pattenden *et al*, 2002).

10.2.5 Flare definition

Patients in all three studies in this thesis use varying definitions of flare, which supports previous qualitative research that suggested patients use five different definitions of flare (Hewlett *et al,* 2012), all of which have been identified in this thesis: 1. Flare can be a single bad joint; 2. Flare can be self-induced; 3. Flare can be due to an external cause, such as food or the weather; 4. Flare can be a few bad days: 5. Flare that relates to uncontrollable symptoms prompting a request for medical help:

> *“Sometimes just my thumb or just my knee hurts”* (P1, Study 2)
>
> *“Most flares are self-inflicted”* (P14, Study 2)
>
> *“I mean they say food don’t give you flare-ups, I believe it do”* (Amelia, 67, Study 1)
>
> *“It does sometimes go away on its own after 3 or 4 days”* (P9, Study 2)
>
> *“I went into one [flare] and I was in agony and I couldn’t do anything and um, I contacted them [rheumatology team]”* (Chloe, 42, Study 1)

However, this thesis has identified an additional definition of flare, which relates to patients’ abilities to balance their lives with RA. Patients in prospective Study 3 reported increased symptoms that did not always correspond to defining themselves as in an RA flare. Further, some patients reported consistently high symptoms, yet still did not define themselves as in an RA flare. Thus it appears that an additional flare definition exists, which does not relate specifically to patients’ symptoms. It is therefore proposed that the type of flare that is uncontrollable and prompts a request for medical help (Hewlett *et al*, 2012) can be divided into ‘Inflammatory Flare’, which relates to patients’ symptoms and their ability to control them, and ‘Avalanche Flare’.

Avalanche flare occurs when patients feel they have lost control of all aspects of their lives and are no longer able to maintain a balance. Thus patients’ tipping points for defining themselves in an Avalanche Flare could be unrelated to their RA inflammation, but may be an internal factor (e.g. feeling low) or an external factor (e.g. going through a divorce) that tips the balance in their lives sufficiently for them to feel that they are no longer in control. This type of flare has been termed Avalanche Flare due to this cascading nature. This novel definition of Avalanche Flare may explain the differences between patient and physician perspectives of flare described by Bingham *et al* (2009b). Patients may need different support for an Avalanche Flare and therefore it is important for both clinicians and patients to be able to recognise the difference between this and an Inflammatory Flare.

One measure of Inflammatory Flare has been published since the studies in this thesis were conducted (Berthelot *et al*, 2012) and another is in the process of being developed, but only the flare domains have been selected so far (Bartlett *et al*, 2012). Both these studies used the Delphi method to identify items that patients and professionals deemed important enough to be included in a measure of flare. Domains that were consistent across both studies are joint swelling, stiffness, pain and participation, all of which were identified in Study 1 (Interviews). However, pain was the only patient-reported symptom that significantly correlated with patients' self-reported flare severity in Study 3b (Flare Help-Seeking survey). Function and tender joints were identified as domains by Bartlett *et al* (2012) while increased need for help, social withdrawal and increase in medication were domains identified by Berthelot *et al* (2012), all of which were also identified in Study 1. However, neither of these studies include a domain that relates to loss of control or feeling overwhelmed by issues other than RA, which has been identified in this thesis as an important element of Avalanche Flare. The Flare Assessment in Rheumatoid Arthritis (FLARE: Berthelot *et al*, 2012) does include items related to depression and irritability, and the core domains identified by Bartlett *et al* (2012) also include emotions (general emotional distress item). However, patients can experience loss of control without considering themselves depressed or irritable and emotional distress may be too vague to encompass such a complex process. Thus these measures and domains appear to relate to Inflammatory Flare as they include items relating to patients' symptom severity, but do not include items that might be important for a definition of Avalanche flare.

Delphi techniques were used by both studies that attempted to measure or define flare (Bartlett *et al*, 2012; Berthelot *et al*, 2012). Delphi is a technique that only considers items that reach a certain level of consensus (Jones and Hunter, 1995) and can be criticised for losing items that whilst not important to the majority, may still be worthy of attention. Further, both of these studies included patients who were not currently experiencing flare, which may affect how they perceive the experience of being in flare.

10.2.6 Men's experiences of RA

This thesis found that male patients have a more negative experience of RA than female patients. This raises the possibility that men could be less able to cope with their RA and do not find the current support that is offered useful:

> *The self help groups don't confront it enough, it might be all lovely-dovey but sometimes you have got to be quite hard about it"* (James, 47, Study 1)

This contributes to the small body of research that exists concerning men's experiences of RA. One qualitative study (Lack, Noddings and Hewlett, 2011) identified that RA threatens men's sense of power and control, which causes an impact on their masculinity. However, this study did not identify the support needs of men or the self-management strategies they used. Further, one small qualitative study (Hale *et al,* 2006) interviewed men and women with RA just before and one year after a self-management programme, and found that men sought practical coping skills in order to retain their masculinity. The courses consisted of predominantly female patients, which was a barrier that prevented men from engaging in the emotional support element of the course. The idea that men with RA have different support needs to women adds strength to these data suggesting that men are not coping as well with their RA as women. This is also supported by the wider masculinity literature, which shows that men have fewer social networks than women (Charmaz, 1994) and therefore do not experience the benefits of these. This indicates potential important gender differences in several coping strategies, which are not taken into consideration in current RA self-management programmes. Further, men are more likely to externalise their distress, such as anger directed at others (Branney and White, 2008), which supports the findings in this thesis:

> *"I get very frustrated with it, the problem is then I get irritated and take it out on the wife"* (P9, Study 2)

It is therefore possible that male RA patients have different support needs to women, which may not be taken into consideration by current self-management interventions. Thus it is possible that men's health needs may be better served by more tailored support. The specific needs of male RA patients is an area that would benefit from further detailed research to ascertain whether an intervention targeting the specific needs of men is needed.

10.2.7 Metaphors as a communication tool

One novel finding from qualitative Study 1 is that patients use metaphors to explain their experiences of RA, which has not previously been explored. The naturally occurring use of metaphor in the interviews indicates that patients often use this method of communication, therefore the use or awareness of metaphors in clinic may enable better communication between patients and clinicians. This contributes to the wider literature, not previously applied to RA, which suggests that the shared language of metaphors can aid the therapeutic relationship by providing understanding of clinical reality (Reisfield and Wilson, 2004, Whaley, 2000) and can also help family members understand patients' experiences (Mastergeorge, 1999).

Further, patients in Study 1 used the question *"If your RA were an animal what would it be?"* to express ideas that they had not previously voiced in the interview or to summarise issues that were important to them, indicating this question could be a useful communication tool. The animal attribution technique has been successfully used in family therapy to assist children with behavioural disorders (Arad, 2004), but has not previously been used with adults. Patients in Study 1 enjoyed participating in the animal question and reported that it enabled them to think differently about their RA. Thus this technique can be effective with adults, providing a way for them to discuss their thoughts and concerns about RA. It is therefore proposed that metaphors are a valuable communication tool for patients with RA to use with their friends, family and clinicians.

10.3 Implications for research

10.3.1 The use of Q-methodology in rheumatology research

Q-methodology has been used in a wide-range of health conditions including chronic pain (Eccleston *et* al, 1997) and irritable bowel syndrome (Stenner, Dancey and Watts, 2000), but only one study has previously used Q-methodology within rheumatology (Nikolaus *et al,* 2010), which explored patients' perspectives of RA fatigue. However, this study did not embrace the Gestalt nature of Q-methodology as only the statements sorted in the +6, +5, +4, -4, -5, -6 (highest and lowest) positions were included in the analysis, thus the full meaning of the statement configurations may have been overlooked (Watts and Stenner, 2012). Further, this study did not invite patients to complete comments booklets, thus the intended meaning of the statement positions may not have been captured.

Q-methodology is a practical task for participants as it requires them to move cards across a fixed grid. This could be potentially problematic for RA patients due to not being able to reach across the grid or not being able to grip the cards to move them. In Study 2 the grid on which patients sorted the statements was A3 in size, which the majority of patients were able to reach across. However, some patients found the continual reaching required by Q-methodology was strenuous. Whilst some patients were happy for the researcher to place the cards for them, others preferred to walk around the table to place the cards themselves. Thus it is recommended that future Q-studies with RA patients are conducted with the sorting grid placed on a table that has space to walk around it. Further, in Study 2 Velcro was placed on the cards and on the grid. This served two purposes: firstly, it ensured that the statements could not be knocked off the grid and secondly, the Velcro on the cards raised them up from the table, which enabled patients to grip them. The use of Velcro would therefore be recommended for future Q-studies with RA patents. These issues highlight the usefulness of Q-methodology but identify that in RA patients a pilot run is critical, and patient partners would provide an ideal collaboration to test out practicalities.

The majority of patients in Study 2 easily understood what was being asked of them and reported that they enjoyed the Q-sorting task, although one man did not. Thus it should be noted that Q-methodology cannot be understood by everyone. Further, sorting statements will exclude people who are illiterate, but Q-methodology can be conducted with images instead of words (Fairweather and Swaffield, 2002), which would remove this limitation.

The Study 2 Q-sorting task provided a discussion point between the participants and the researcher, with many providing powerful insights into their experiences of RA and reasons for sorting the cards. Patients also completed comments booklets, which enabled more detailed analysis. However, the patients in Study 2 did not record everything that they verbalised to the researcher, in their comments booklets. Thus it is suggested that future Q-studies with RA patients are digitally-recorded to capture such informal discussions and further enrich the analysis.

In Q-methodology participants concentrate on sorting individual cards in relation to other cards across a grid. It is difficult for participants to perceive the overall story they are telling by looking at their statement configurations, thus people are able to be more open with their responses. This was particularly important for male participants as men tend to provide a discourse that protects their masculinity, drawing on and reproducing idealised masculine expectations (Knight *et al*, 2012), but also for other patients who might be attempting to portray a particular identity. Further, patients are sorting statements that have been generated from interviews with other patients. They may therefore feel able to agree with a statement due to feeling it has been validated by being included in the study, which they may not have felt able to raise themselves in an interview (e.g. *“I get angry due to my RA”*).

Q-methodology was chosen for Study 2 rather than a consensus method such as NGT or Delphi due to its ability to retain the individual context (Chapter 5.5.2). This was effective in Study 2, as four different experiences of daily life and two different ways in which people decide to seek help for their RA flares were discovered. These experiences are so diverse it is difficult to see how they could have been combined into one consensus, which supports the argument that consensus techniques may produce a bland averaging of opinions or beliefs (Rennie, 1981).

It is therefore suggested that Q-methodology is an under-used method in rheumatology research, which could provide insights and experiences that may not be reached by qualitative methods or consensus methods alone. However, it would be important to analyse the entire configuration of sorted statements, along with comment booklets and digital-recording of the discussion to provide a full explanation of patients’ experiences.

10.3.2 Future research

There are many aspects of patients’ experiences of RA identified in these studies that deserve further exploration. Three specific areas suggested for further research are detailed here.

10.3.2.1 Daily variation and patterns

This thesis identified that patients have very different experiences of their RA in daily life, although broad categories of experience could still be identified (Chapter 9). Study 3 identified that a multi-centre study measuring patients’ symptoms daily for three months would be possible. This would enable detailed analysis of patients’ daily patterns of symptoms and a larger number of participants may enable the discovery of common patterns across patients. Further, a larger number of participants may enable the statistical identification of differences in patients’ symptoms when they are in and out of both Inflammatory and Avalanche Flare.

It is suggested that the scales used in Study 3 are tested for clarity of wording before applying them to a multi-centre study. The weekly self-management questions in Study 3 were potentially problematic as it was unclear why patients chose particular options, and cognitive interviewing would be an ideal methodology (Drennen, 2003). Reliability and sensitivity to change should also be established. Further, the method of visual analysis used in Study 3 would be time-consuming with a larger number of participants and statistical conclusions cannot be drawn. It is therefore suggested that time-series analysis (McCleary *et al*, 1980) is used with a larger version of this study, but this was beyond the remit of this thesis, which aimed to gather preliminary data and see whether a larger study would be possible. Time-series analysis is the analysis of quantitative data, recorded at successive time intervals, with a view to projecting this experience of the past to predict what will happen in the (uncertain) future (McCleary *et al*, 1980). Thus time-series analysis has the potential to predict patterns of RA symptoms based on previous symptom patterns.

10.3.2.2 Avalanche Flare

The novel separation of patient-perceived flare into Inflammatory and Avalanche Flare was identified in Study 3 of this thesis. An Avalanche Flare seems to prompt patients to seek medical help, but does not necessarily involve patients' highest reported symptoms. Thus future research is needed to unpick the difference between an Avalanche Flare and an Inflammatory Flare in order to support patients effectively. As Avalanche Flare was only identified through Study 3, which involved patients who were in flare, it is proposed that future research into this type of flare is conducted with patients who are in flare at the time of the study. It is necessary to explore the differences at the time of flare, between Avalanche Flare and Inflammatory Flare in depth (qualitative research) and also to discover how frequently these different definitions occur (quantitative research). Data on patients' symptoms, emotions, life events and other items identified by qualitative research should be collected prospectively from patients who are in a self-defined flare and factor analysis could be used to see if the differences between Inflammatory Flare and Avalanche Flare could be explained differently by different factors (e.g. stronger emotions in an Avalanche Flare and stronger swollen joints in an Inflammatory Flare). This could lead to developing and testing information or an education programme to educate patients or to train staff, as appropriate and to develop and test a measure or single item relating to Avalanche Flare to add to the developing flare questionnaires. Further, the difference between Avalanche Flare and Inflammatory Flare has the potential to explain the difference in flare definitions used by patients and professionals, which should be further explored.

10.3.2.3 Men, masculinity and rheumatoid arthritis

The finding that men have a more negative experience of RA than women has not previously been explored in detail. There is a lack of understanding as to how men experience their RA, how it impacts on their lives and the types of support that they require from their medical team. As more women (70%) than men have

RA, studies of support needs have been biased towards the female viewpoint. Thus to provide care that meets men’s specific needs it is necessary to explore male patients’ needs in depth (qualitative research) and to discover how widespread the issues are (quantitative research) and then develop and test an appropriate intervention through collaboration with a male patient research partner.

10.4 Implications for clinical practice

Clinicians should be aware that for the majority of RA patients, even on current medication regimes, normal daily life is never symptom free. Patients must employ a constant level of micro-management to control their symptoms or prevent exacerbation, which they increase in steps as their symptoms increase. Further, in normal daily life patients still report cancelling plans due to their RA. These are important points to consider when informing newly diagnosed patients about what life with RA is likely to be like. Clinicians should also be aware that there are at least four ways in which patients experience life with RA: 'Feeling Good', 'Taking Active Control', 'Keeping RA in its Place' and 'Struggling Through' and these patients would require different levels and types of support. Some patients manage well due to low symptoms or expert self-management and therefore appear to need little intervention from the medical team. The Patient-Friendly Fluctuating Balances Model and Mediation Ladder can be used in clinical discussions with patients and visually represented in patient information materials to help educate newly diagnosed patients.

Clinicians need to be aware that patients use the word flare to explain a variety of different experiences. Thus it may be necessary to further unpick the terminology that an individual patient is using in clinic in order to inform treatment discussions and improve understanding and concordant decisions. Further, it is important to ensure patients feel that it is valid to ask for help in an Avalanche Flare, as patients may worry about seeking help for symptoms that do not specifically constitute an Inflammatory Flare. In fact, whilst some patients will seek help quickly due to beliefs that the medical team are there to help them, other patients delay in help-seeking for their flares due to being uncertain as to whether they are in a flare, beliefs they should manage alone and worries about wasting the rheumatology team's time. These patients sometimes needed to be prompted by a friend or family member to seek help. This indicates the need for patient education programmes to ensure patients are aware of when to seek help for their RA flares.

Cognitive Behavioural Therapies (CBT) (Sheldon, 2011) are growing in application within the UK health care system. In rheumatology, positive results have been found for tailored CBT interventions among patients with systemic lupus erythematosus (SLE) (Goodman *et al,* 2005) and RA. In RA CBT interventions have facilitated the reduction of depression, helplessness, fatigue and enhanced the use of active coping strategies (Evers *et al,* 2002; Hewlett *et al*, 2011; Dures *et al,* 2012). Thus based on the findings of this thesis, one subset of patients may benefit from clinicians addressing psychological issues to empower them to seek help even if they are uncertain of whether their symptoms constitute an Inflammatory or Avalanche Flare. A CBT intervention might be used to facilitate patients' skills in self-managing an Avalanche Flare.

One group of patients of particular note are male RA patients, who appear to have a more negative experience of RA than female patients. These male patients focus on their symptoms, experience negative thoughts and feelings and do not seem able to identify effective self-management techniques. This has an important clinical implication for the way in which men with RA are supported. These male patients may benefit from a tailored intervention, but their specific support needs require further research before an effective intervention can be designed (Section 10.3.2.1).

A further consideration is that patients use metaphors to explain their RA, and thus adopting these metaphors in clinic may facilitate better communication between the patient and clinician. Clinicians should listen for the metaphors patients are using and respond to these. Asking patients *"If your RA were an animal what would it be?"* provided insight into the issues that appeared to be most salient to the patient (based on the content of the preceding interview) and issues that they had not previously voiced. The use of metaphors in clinic may help clinicians and patients differentiate between Avalanche Flare and Inflammatory Flare.

10.5 Strength and limitations

The strengths and limitations relevant to the individual studies have been addressed in their respective results chapters. The most important were the small number of male patients recruited in all three studies and the lack of validated scales. The main strengths of these studies were the critical and careful approach with each study building on the previous, the use of mixed methodologies and support from patient research partners. It is of particular note that the Partner (PR) who reviewed the Fluctuating Balances Model and Mediation Ladder could fully identify with these as encapsulating what her daily life is like, and helped make minor adjustments to the wording of the model. The findings from this thesis have already begun to be disseminated (Appendix T: Flurey *et al* 2012a; 2012b; 2012c; *In Press*).

10.6 Thesis summary

Patients with RA experience varying levels of symptoms in daily life even on the best available treatment regimes. They employ a stepped approach to self-management (Mediation Ladder) in order to maintain a balance in their lives. Thus patients experience a Fluctuating Balance of life with RA:

> *"It's sort of a balancing job really. If I use more than my share of energy for one day, it will affect the next"* (Debbie, 44, Study 1)

Patients use many definitions of flare, one of which (Avalanche Flare) has not previously been acknowledged in the literature and involves tipping points for patients defining themselves as in flare that relate to more than their inflammatory symptoms:

> *"Stress can cause it, you know something that's worrying. I mean, when my son's marriage broke up that caused a flare-up"* (Jane, 65, Study 1)

Patients often see seeking help for their flares as a last resort, having tried everything they can think of first and prompted by loss of control. However, clinicians should be aware that some patients will wait a long time before seeking help due to worries about wasting the rheumatology team's time and beliefs they should manage alone. When the balance has tipped and patients are no longer in control of their flare symptoms then it's *"Game over"*:

> *"It isn't the pain really it's the immobility, what it [flare] makes you feel is, it's just on top of the restriction you've got, it's like a 'Game Over'"* (Isabelle, 45, Study 1)

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Appendices

Appendix A1: Study 1 patient information sheet

University of the
West of England
BRISTOL

University Hospitals Bristol NHS
NHS Foundation Trust

Rheumatology Research
Faculty of Health and Life Sciences
Based at:
Academic Rheumatology
Bristol Royal Infirmary
BRISTOL BS2 8HW

Patients' individual experiences of high disease activity in rheumatoid arthritis

Patient information sheet

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 read the following information carefully and discuss it with friends and relatives if you wish. Ask us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is asking you to take part?
I am Caroline Flurey, a PhD student at the University of the West of England. This research study is the first of three research studies which will form my PhD. The results from this study will assist with the designing the next two research studies, as well as providing important information to help clinicians understand what daily life with RA is really like.

What is the purpose of the study?
The aim of medication in rheumatoid arthritis (RA) is to help control inflammation. From time to time, people with RA have episodes of inflammation or high disease activity. Sometimes, this high disease activity makes the patient and the doctor wonder if the RA drugs are not working well enough, and should be changed. Usually, the patient and the doctor decide this together.

However, some early research suggests that patients and health professionals think about different symptoms when they discuss inflammation. We don't really know what it is that patients experience when they have inflammation. We don't even have a common term for this bad inflammation. Some people call it a 'flare' but this may mean different things to different people. It is important to understand more about what patients experience during these episodes of inflammation, and how they decide that it is time they discussed their medication with their doctors. This research study aims to explore the patient's experience of inflammation – what are the symptoms they get? How do patients decide their drugs may need changing? If we knew this, it would help avoid misunderstandings when treatment decisions are made.

We would also like to find out what daily life is like with RA and how patients manage their symptoms. At the moment doctors describe daily life with RA to newly diagnosed patients as unpredictable and will often either draw wavy lines to explain this or wave their hands to indicate ups and downs! However, we don't really know what makes a good day or a bad day with RA. Having a better understanding of daily life with RA would help doctors to give newly diagnosed patients a better understanding of RA, what life will be like and how to manage their symptoms.

Why have I been chosen?
You have been invited to take part because you have RA, and have experienced an episode of high disease activity at some point. We are inviting about 20-25 patients to take part within Bristol from both the Bristol Royal Infirmary and Cossham Hospital.

What will I be asked to do if I take part?
You will be invited to take part in a one-on-one interview with a researcher. In the interview you will be asked questions which will enable you to discuss what it feels like to have high disease activity – the symptoms, how you manage them and how you would decide that this is different from your daily symptoms. You can say as much or as little as you like, and there's no such thing as a wrong answer - we are looking for your own individual experience. The discussion will last between an hour and an hour and a half and will be held in the Rheumatology Outpatient Department at the Bristol Royal Infirmary. We will offer you refreshments and will be happy to pay your travel costs to attend.

We will tape record the discussion, type it up and then analyse it. This means that we will examine the typed transcripts for different themes about inflammation and daily life. To check our findings, we will ask two other project members to review several transcripts. These project members include a patient representative. As the discussions will be typed up they will be completely anonymous to the other project members. The only person who will know who the interview transcript belongs to would be you and the researcher interviewing you.

We will put the findings from these interviews together with findings from the other one-on-one interviews being conducted. The findings from the interviews will also be put together with findings from focus groups (group discussions) conducted across 5 countries (UK, the USA, Canada, Germany and Australia) and look at whether there are any differences between the individual and the group results.

A report will be written on what it means to have high disease activity and we will be happy to send you a copy of the final report.

The findings from the interviews will also be used in the second stage of the PhD research project. This will involve asking people to put the themes which came out of the interviews into the order of most importance to them.

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 to

keep. If you 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 care you receive will not be affected.

What are my responsibilities?
We would be grateful if you could attend the clinic for the interview if you agree to take part. We would also like you to complete a brief questionnaire about your arthritis, so that we can make sure we have a wide range of patients taking part.

What are the possible side effects of taking part?
We do not believe that talking about your experience of high disease activity in an interview will have any side effects. However, if it makes you feel worried about your arthritis, the researcher will be able to arrange for you to see a nurse or doctor from the Rheumatology team.

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 understand more about a common problem and how patients and doctors can discuss it better. Once we understand what high disease activity really means to patients, we will develop a definition that both patients and doctors can agree on. This should be useful in everyday clinical practice, in clinical research trials, and in helping educate people about how to manage their RA.

Will my taking part in this study be kept confidential?
Yes. When the tape is typed up, your name will be replaced with a code. No one will be able to identify you from the typed discussion. Although the report will include quotations from the interviews, no names will be used. The tapes will be kept securely for 6 years and then destroyed, in accordance with good practice guidelines.
The analysis of the transcripts will be led by Caroline Flurey in the University of the West of England, Bristol.

Will my GP be informed that I am taking part in this study?
That is up to you. The researchers will be happy to send a letter to your GP to explain this study if you require.

What will happen to the results of the research study?
The research will take about one year. The results will be reported in professional publications and conferences (but patients will not be identified by name). The results will also be reported in the PhD thesis produced by Caroline Flurey. The results will help inform the design of the following two stages of the PhD research project which in total will take three years to complete.

Who is funding the study and who has reviewed the research?
The research has been funded by Arthritis Research Campaign (arc). The study has been peer reviewed by the UWE Research Degrees Committee and has been approved by the North Somerset and South Bristol Research Ethics Committee and the Research Department of the Bristol Royal Infirmary. The University of the West of England will take responsibility for the conduct of the study.

What do I do now?
Thank you for considering taking part in this research. Please complete the slip if you are interested and either hand it to the clinic nurse, or return it in the reply-paid envelope. A researcher will then contact you with further information.

If you have any concerns about participating in this study and would like to receive free independent advice please contact PALS (Patient Advise and Liaison Service) on 0800 0851 067.

Researcher details:

Caroline Flurey MSc
University of the West of England, Bristol, UK
PhD Student, Bristol Royal Infirmary
0117 928 4972
Caroline2.Flurey@uwe.ac.uk

Study Team
Caroline Flurey MSc, PhD Student, UWE Bristol
Sarah Hewlett PhD MA RN, arc Professor of Rheumatology Nursing, UWE Bristol
Marianne Morris PhD MSc, Principal Lecturer in Health Psychology, UWE Bristol
John Pollock, PhD, Reader in Epidemiology, UWE Bristol
Rod Hughes MD, Rheumatologist, Chertsey
Pam Richards – Patient Partner
Angela Knight – Patient Partner

Appendix A2: Study 1 reply slip

University of the West of England
BRISTOL

University Hospitals Bristol NHS
NHS Foundation Trust

Patients' individual experiences of high disease activity in rheumatoid arthritis

Please complete the following and return this sheet of paper in the envelope provided. The researcher will contact you in the next few days to talk about the study and arrange a time to meet up.

I agree to be contacted by the researcher to discuss the research study

Signature ……………………………………………………………………………………

Name ……………………………………………………………………………………

Address ……………………………………………………………………………………

……………………………………………………………………………………

Preferred contact telephone Number ………………………………………………

Preferred contact time ……………………………………………………………………

Many Thanks

Caroline Flurey, Research PhD Student
University of the West of England
Tel No: 0117 3424972
Email: Caroline2.Flurey@uwe.ac.uk

Appendix B: Study 1 participant consent form

UWE BRISTOL
University of the
West of England

University Hospitals Bristol NHS
NHS Foundation Trust

Rheumatology Research
Faculty of Health and Life Sciences
Based at:
Academic Rheumatology
Bristol Royal Infirmary
BRISTOL BS2 8HW

Patients' individual experiences of high disease activity in rheumatoid arthritis

Consent form for research study

Please initial each box

1 I confirm that I have read and understand the information sheet dated 17th March 2010 for the above study ☐

2 I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected ☐

3 I understand that relevant sections of my medical notes will be looked at by a member of the clinical team. I give permission for these individuals to have access to my records. ☐

4 I am willing for the interview to be audio-recorded ☐

5 I understand that anonymised quotes from the interview may be used in publications, conference presentations and a PhD thesis. ☐

6 I agree to take part in the above study ☐

____________________	____________	________________
Name of patient	Date	Signature
____________________	____________	________________
Name of researcher	Date	Signature

Appendix C1: Demographic and clinical questionnaire

Participant No.____________

Pre-Interview Questionnaire

1. Please state your age: ☐ years

2. Are you employed? If so, what is your current role?

   ....

   ....

3. Do you have anyone at home who helps you? *Please delete as applicable:*
   Husband / Wife / Partner / Grown-up child / Young Carer / No-one / Other
   If other, please state:
   …………………………………………………………………….......................

4. Do you have anyone at home who relies on you? If so, what is their relationship to you?
   e.g. Child / Parent
   ....

5. How long ago was your RA diagnosed?...

6. What medication are you currently taking for your RA? ....

   ………………………………………………………………………………………..

   ....

7. If any of these are new in the last 6 months, please say which and what you were previously taking in its place

   ....

   ....

8. Have you experienced a period of high disease activity whilst having RA?

   Yes ☐ No ☐

9. How often, would you say, that you experience bad patches with your RA?

   ....

10. Considering all the ways your arthritis affects you, please mark on the line below how well you are doing:

VERY WELL VERY BADLY

Appendix C2: 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
.... Walking Frame
.... Crutches
.... Wheelchair
.... Devices used for dressing (button hook, zipper pull, long handled shoe horn etc
.... Built-up or special utensils
.... Special or built-up chair

Other(specify): ....

Please tick any categories for which you usually need help from another person:

.... Dressing and grooming
.... Rising
.... Eating
.... Walking

5 **HYGIENE** Are you able to:	**Without ANY difficulty**	**With SOME difficulty**	**With MUCH difficulty**	**Unable to do**
- 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?	__________	__________	__________	__________

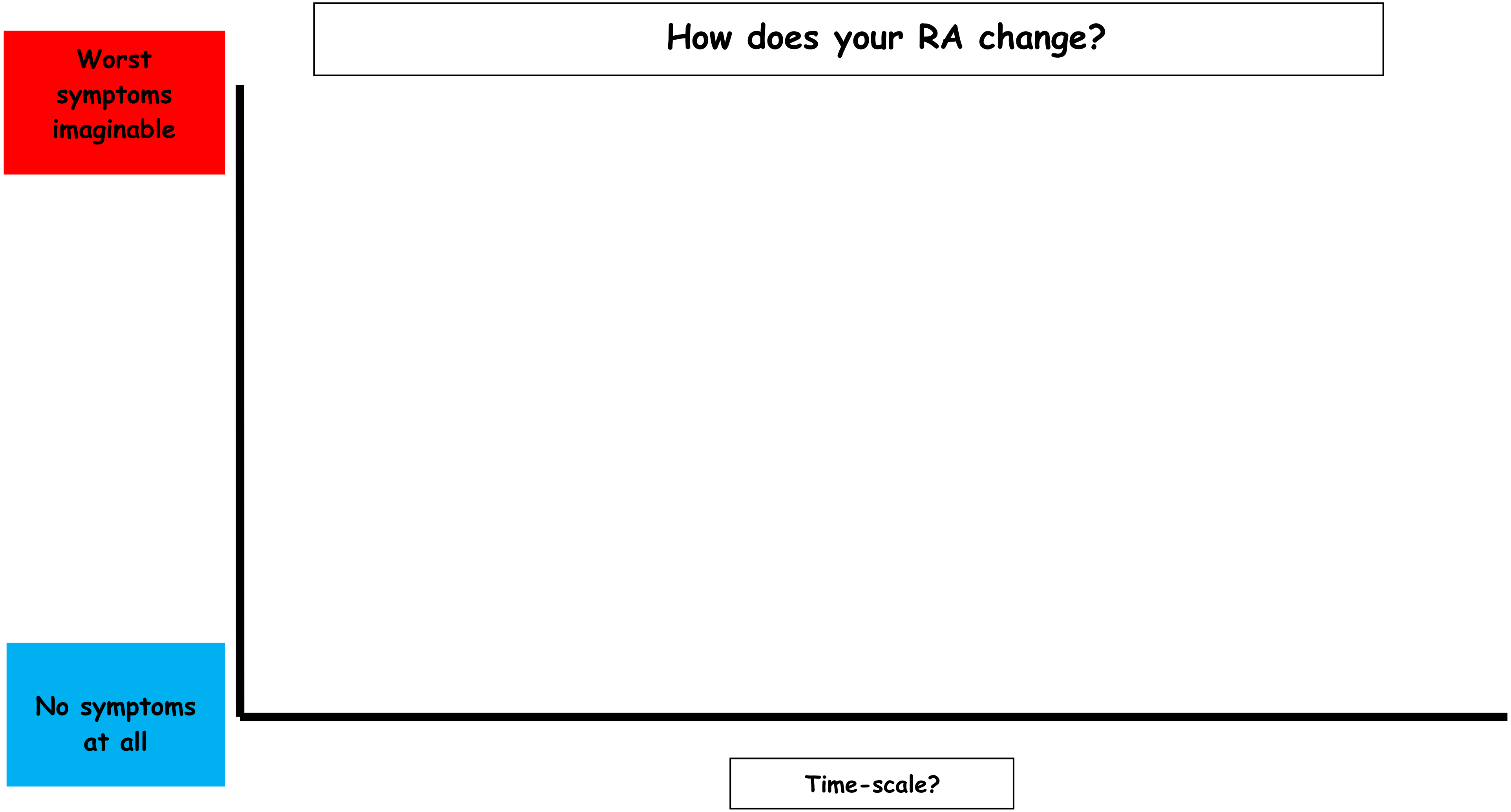
Please tick any aids or devices that you usually use for any of these activities:

.... Raised toilet seat
.... Bath seat
.... Jar opener (for jars previously opened)
.... Bath rail
.... Long handled appliances for reach

Other (specify)...

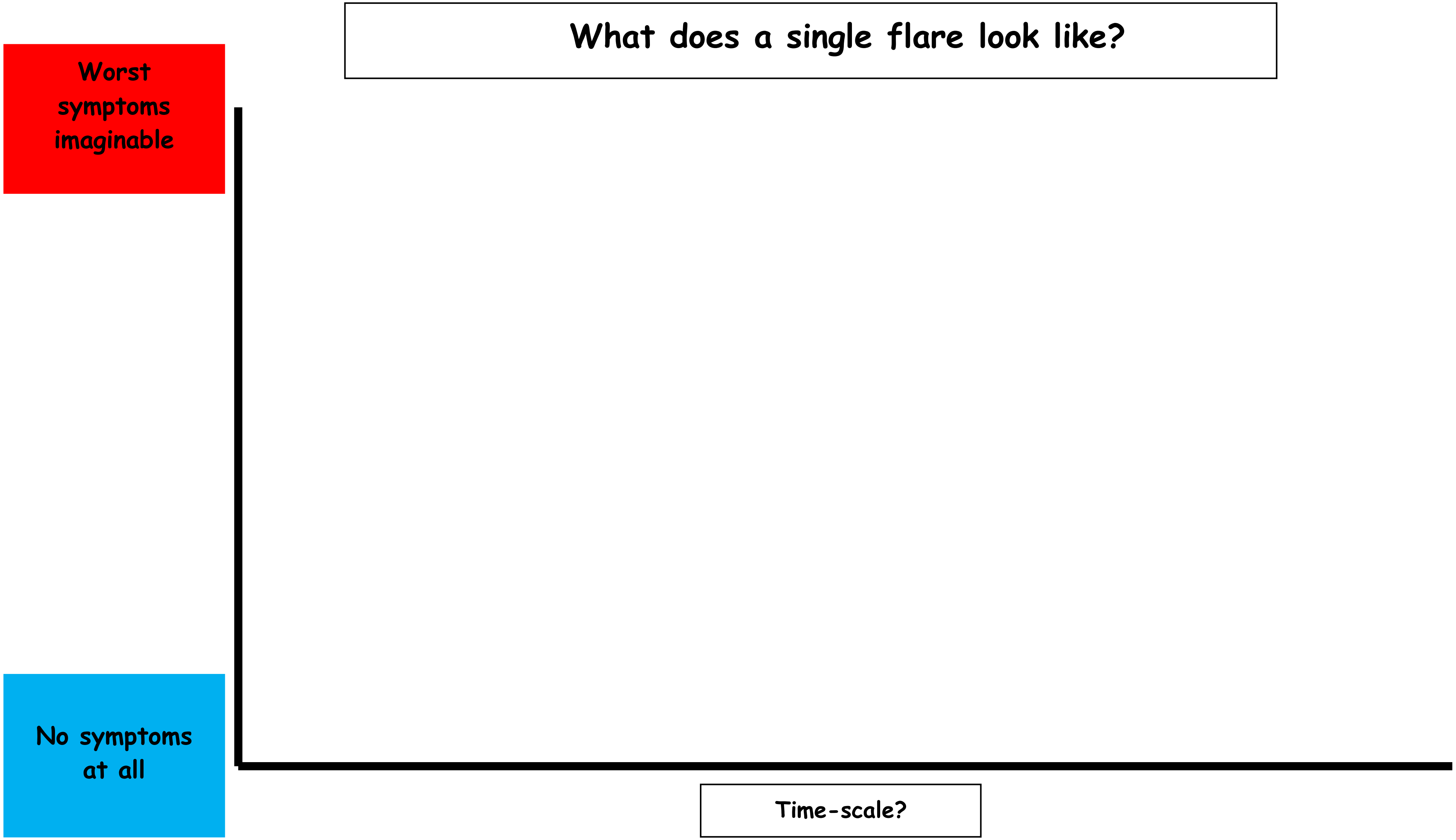
Please tick any categories for which you usually need help from another person:

.... Hygiene
.... Reach
.... Gripping and opening things
.... Errands and housework



Appendix D1: Study 1 daily life blank free-form

Appendix D2: Study 1 flare blank free-form graph



Appendix E: List of rheumatoid arthritis drug names

NSAIDs

Ibuprofen
Nabumetone
Meloxicam
Diclofenac
Clelbrex

DMARDs

Methotrexate
Gold
Lefunomide
Sulphasalazine
Hydroxychloriquine
Cyclosporin

Anti-TNF / Biologics

Rituximab
Adulimamab
Infliximab
Remicide
Embrel

Steroids

Prednisolone

Appendix F1: Study 2 patient information sheet

University of the West of England
BRISTOL

University Hospitals Bristol NHS
NHS Foundation Trust

Rheumatology Research
Faculty of Health and Life Sciences
Based at:
Academic Rheumatology
Bristol Royal Infirmary
BRISTOL BS2 8HW

A Q-methodology research study. What is life like with rheumatoid arthritis?

Patient information sheet

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 read the following information carefully and discuss it with friends and relatives if you wish. Ask us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is asking you to take part?
I am Caroline Flurey, a PhD student at the University of the West of England. This research study is the second of three research studies which will form my PhD.

What is the purpose of the study?
We would like to find out what daily life is like with Rheumatoid Arthritis (RA) and how patients manage their symptoms. At the moment doctors describe daily life with RA to newly diagnosed patients as unpredictable and will often either draw wavy lines to explain this or wave their hands to indicate ups and downs! However, we don't really know what makes a good day or a bad day with RA. Having a better understanding of daily life with RA would help doctors to give newly diagnosed patients a better understanding of RA, what life will be like and how to manage their symptoms.

In addition to this, some early research suggests that patients and health professionals think about different symptoms when they discuss periods of high disease activity. It is important to understand more about what patients experience during these episodes of high disease activity, and how they decide that it is time to discuss their medication with their doctors. We would like to explore your experience of high disease activity – what symptoms do you get? And how do you decide your drugs may need changing? If we knew this, it might help avoid misunderstandings when treatment decisions are made.

Why have I been chosen?
You have been invited to take part because you have RA, and have experienced an episode of high disease activity at some point. We are inviting between 20 and 50 patients to take part from Bristol hospitals and from Ashford and St. Peter's Hospital, Cherstey.

What will I be asked to do if I take part?

You will be invited to take part in a study called a Q-sort. This means you will be given cards with statements on them, which may or may not relate to your experience of living with RA. The statements will cover aspects of your daily life and how you manage when you have high disease activity (when your RA is particularly bad). You will be invited to sort the statements according to how much you agree or disagree with them.

There is no right or wrong way of sorting these statements - we are looking for your own individual understanding of high disease activity and normal daily life. The study will last about an hour and you will have the choice of coming to the Rheumatology Outpatient Department at the Bristol Royal Infirmary, or for the researcher to visit you at home. If you choose to come to the Bristol Royal Infirmary we will offer you refreshments and will be happy to pay your travel costs to attend.

The way that you sort the statements will be recorded and then your method of sorting will be compared with other patients. In doing this we will be able to show a number of ways in which patients experience and manage their RA. To check our findings, we will ask two other project members to review our analysis. These project members include a patient representative.

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 to keep. If you 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 care you receive will not be affected.

What are the possible side effects of taking part?
Talking about your experience of high disease activity in an interview should not produce any side effects. However if it makes you feel worried about your arthritis the researcher will arrange for you to see a member of the clinical team.

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 understand more about a common problem and how patients and doctors can discuss it better.

Will my taking part in this study be kept confidential?
Yes. When the card sort is typed up your name will be replaced with a code. No one will be able to identify you from your card-sort. The anonymised data will be kept securely for 6 years and then destroyed, in accordance with good practice guidelines. The analysis will be led by Caroline Flurey in the University of the West of England, Bristol.

What will happen to the results of the research study?
The research will take about one year. The results will be reported in professional publications and conferences (but patients will not be identified by name). The results will also be reported in the PhD thesis produced by Caroline Flurey. A summary of the results will be sent to you once the study is complete. The results will help inform the design of the final stage of the PhD research project which in total will take three years to complete.

Who is funding the study and who has reviewed the research?
The research has been funded by Arthritis Research UK. The study has been peer reviewed by the UWE Research Degrees Committee and has been approved by South West 4 Research Ethics Committee and the Research Department of the Bristol Royal Infirmary. The University of the West of England will take responsibility for the conduct of the study.

What do I do now?
Thank you for considering taking part in this research. Please complete the slip if you are interested and either hand it to the clinic nurse, or return it in the reply-paid envelope. A researcher will then contact you with further information.

If you have any concerns about participating in this study and would like to receive free independent advice please contact PALS (Patient Advise and Liaison Service) on 0800 0851 067.

Researcher details:

Caroline Flurey MSc
University of the West of England, Bristol, UK
PhD Student, Bristol Royal Infirmary
0117 342 4972
Caroline2.Flurey@uwe.ac.uk

Study Team
Caroline Flurey MSc, PhD Student, UWE Bristol
Sarah Hewlett PhD MA RN, Arthritis Research UK, Professor of Rheumatology Nursing, UWE Bristol
Marianne Morris PhD MSc, Principal Lecturer in Health Psychology, UWE Bristol
Jon Pollock, PhD, Reader in Epidemiology, UWE Bristol
Rod Hughes MD, Rheumatologist, Chertsey
Pam Richards – Patient Partner

Appendix F2: Study 2 reply slip

University of the West of England
BRISTOL

University Hospitals Bristol NHS
NHS Foundation Trust

A Q-methodology research study. What is life like with rheumatoid arthritis?

Please complete the following and return this sheet of paper in the envelope provided. The researcher will contact you in the next few days to talk about the study and arrange a time to meet up.

I agree to be contacted by the researcher to discuss the research study

Signature ………………………………………………………………………

Name ………………………………………………………………………

Address ………………………………………………………………………

………………………………………………………………………

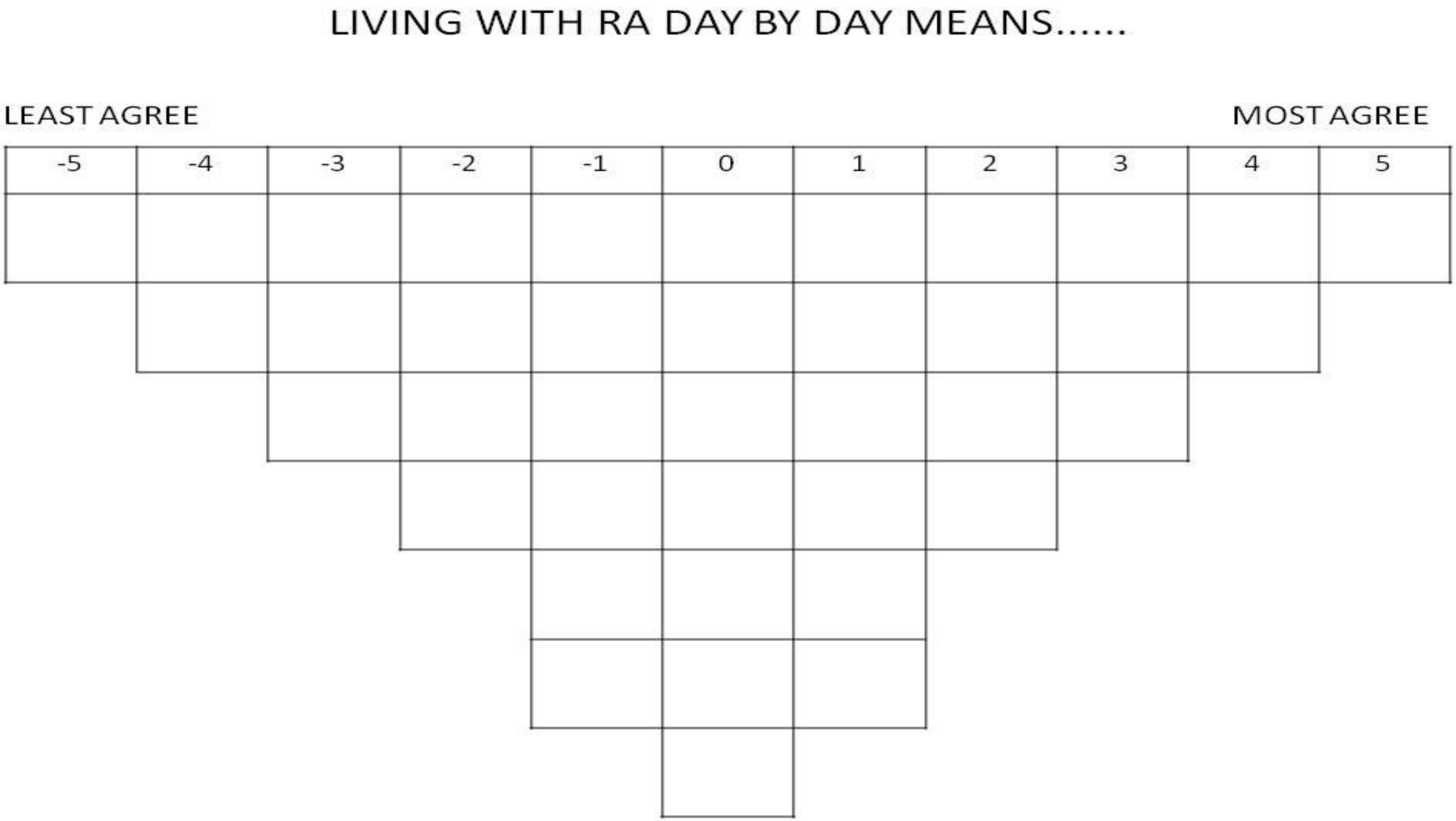
Preferred contact telephone Number ……………………………………………

Preferred contact time ………………………………………………………………………

Many Thanks

Caroline Flurey, Research PhD Student
University of the West of England
Tel No: 0117 3424972
Email: Caroline2.Flurey@uwe.ac.uk

Appendix G1: Study 2 daily life blank Q-sorting grid



Appendix G2: Study 2 flare blank Q-sorting grid

WHEN I AM IN A FLARE......

LEAST AGREE

MOST AGREE

-4	-3	-2	-1	0	1	2	3	4

Appendix H: Study 2 participant consent form

University of the West of England
BRISTOL

University Hospitals Bristol NHS
NHS Foundation Trust

Rheumatology Research
Faculty of Health and Life Sciences
Based at:
Academic Rheumatology
Bristol Royal Infirmary
BRISTOL BS2 8HW

A Q-methodology study. What is life like with rheumatoid arthritis?

Consent form for research study

Please initial each box

1	I confirm that I have read and understand the information sheet dated 26th Oct 2010 for the above study	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected	☐
3	I understand that relevant sections of my medical notes may be looked at by a member of the clinical team. I give permission for these individuals to have access to my records.	☐
4	I understand that anonymised card sort data collected during the study may be used in publications, conference presentations and a PhD thesis.	☐
5	I agree to take part in the above study	☐

Name of patient	Date	Signature
Name of researcher	Date	Signature

1 Copy to Participant *1 Copy to Researcher* *1 Copy for Notes*

Appendix I1: Study 3a patient information sheet

University of the West of England
BRISTOL

University Hospitals Bristol NHS
NHS Foundation Trust

Rheumatology Research
Faculty of Health and Life Sciences
Based at:
Academic Rheumatology
Bristol Royal Infirmary
BRISTOL BS2 8HW

Capturing Daily Fluctuations in Rheumatoid Arthritis

Patient information sheet

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 read the following information carefully and discuss it with friends and relatives if you wish. Ask us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is asking you to take part?

I am Caroline Flurey, a PhD student at the University of the West of England. This research study is the third of three research studies which will form my PhD.

What is the purpose of the study?

We would like to find out what daily life is like with Rheumatoid Arthritis (RA) and how patients manage their symptoms. At the moment doctors describe daily life with RA to newly diagnosed patients as unpredictable and will often either draw wavy lines to explain this or wave their hands to indicate ups and downs! However, we don't really know what makes a good day or a bad day with RA. Having a better understanding of daily life with RA would help doctors to give newly diagnosed patients a better understanding of RA, what life will be like and how to manage their symptoms.

Why have I been chosen?

You have been invited to take part because you have RA, and have experienced a Flare of your RA at some point. We are inviting 30 patients to take part from Bristol hospitals and from Ashford and St. Peter's Hospital, Cherstey.

What will I be asked to do if I take part?

You will be invited to take part in a daily diary study. This will involve completing 10 simple questions about your RA symptoms every day and 10 short questions about your experiences weekly (a copy of each questionnaire is attached). You will be asked to do this for 3 months.

You can choose how to answer the questions. You can complete them on paper and post this back to the researcher each week, or the researcher could phone you daily for your responses (which should take about 10 minutes), or you can complete your responses daily online on a secure website. It's up to you!

There are no right or wrong answers, we would like to know how your individual symptoms vary from day to day.

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 to keep. If you 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 care you receive will not be affected.

What are the possible side effects of taking part?
Recording your daily symptoms should not produce any side effects. However if it makes you feel worried about your arthritis the researcher will arrange for you to see a member of the clinical team.

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 understand more about a common problem and how patients and doctors can discuss it better. If you would like a copy of your daily scores, to assist in discussions with your doctor, the researcher will provide this for you.

Will my taking part in this study be kept confidential?
Yes. When your responses are input into the computer your name will be replaced with a code. No one will be able to identify you from your responses. The anonymised data will be kept securely for 6 years and then destroyed, in accordance with good practice guidelines.
The analysis will be led by Caroline Flurey in the University of the West of England, Bristol.

What will happen to the results of the research study?
The research will take about one year. The results will be reported in professional publications and conferences (but patients will not be identified by name). The results will also be reported in the PhD thesis produced by Caroline Flurey. A summary of the results will be sent to you once the study is complete.

Who is funding the study and who has reviewed the research?
The research has been funded by Arthritis Research UK. The study has been peer reviewed by the UWE Research Degrees Committee and has been approved by South West 5 Research Ethics Committee and the Research Department of the Bristol Royal Infirmary. The University of the West of England will take responsibility for the conduct of the study.

What do I do now?
Thank you for considering taking part in this research. Please complete the attached reply slip if you are interested and either hand it to the clinic nurse, or return it in the pre-paid reply envelope. A researcher will then contact you with further information.

Helpful Contact Numbers:
If you have any concerns about participating in this study and would like to receive free independent advice please contact PALS (Patient Advise and Liaison Service) on 0117 342 3571. If you have any complaints about this research please contact the Patient Complaints Manager on 0117 342 3604.

Researcher details:

Caroline Flurey MSc
University of the West of England, Bristol, UK
PhD Student, Bristol Royal Infirmary
0117 342 4972
Caroline2.Flurey@uwe.ac.uk

Study Team
Caroline Flurey MSc, PhD Student, UWE Bristol
Sarah Hewlett PhD MA RN, Arthritis Research UK, Professor of Rheumatology Nursing, UWE
Marianne Morris PhD MSc, Principal Lecturer in Health Psychology, UWE Bristol
Jon Pollock, PhD, Reader in Epidemiology, UWE Bristol
Rod Hughes MD, Rheumatologist, Chertsey
Pam Richards – Patient Partner

Appendix I2: Study 3a reply slip

UWE BRISTOL University of the West of England

University Hospitals Bristol NHS
NHS Foundation Trust

Capturing Daily Fluctuations in Rheumatoid Arthritis

Please complete the following and return this sheet of paper in the envelope provided. The researcher will contact you in the next few days to talk about the study and arrange a time to meet up.

I agree to be contacted by the researcher to discuss the research study

Signature ....

Name ....

Address ....

....

Preferred contact telephone Number ....

Preferred contact time ....

Many Thanks

Caroline Flurey, Research PhD Student
University of the West of England
Tel No: 0117 3424972
Email: Caroline2.Flurey@uwe.ac.uk

Apendix J: Study 3b patient information sheet

UWE
University of the West of England
BRISTOL

University Hospitals Bristol NHS
NHS Foundation Trust
Rheumatology Research
Faculty of Health and Life Sciences
Based at:
Academic Rheumatology
Bristol Royal Infirmary
BRISTOL BS2 8HW

Seeking Help for Flares in Rheumatoid Arthritis

Patient information sheet

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 read the following information carefully and discuss it with friends and relatives if you wish. Ask us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is asking you to take part?

I am Caroline Flurey, a PhD student at the University of the West of England. This research study is the third of three research studies which will form my PhD.

What is the purpose of the study?

It is important to understand more about what people with Rheumatoid Arthritis (RA) experience during a Flare, and how they decide that it is time to seek help or discuss their medication with their doctors. We would like to explore your current experience Flare – what symptoms do you have? And how did you decide to come to the Rheumatology team for help? We would also like to understand the differences between a Flare and normal daily symptoms.

Why have I been chosen?

You have been invited to take part because you have RA, and have contacted the Direct Access helpline to make an appointment due to currently experiencing a Flare. We are inviting 15 patients to take part from the Bristol Royal Infirmary and 15 patients from Ashford & St Peter’s Hospital, Chertsey.

What will I be asked to do if I take part?

You will be invited to complete a short questionnaire when you come to the clinic for your appointment. The questionnaire is about your current symptoms and the period that led up to you contacting the helpline. You will also be sent a further short questionnaire about your symptoms, which will be sent to you four weeks after your appointment and you will be asked to return this in a pre-paid envelope.

The information you provide will be used to help us understand what motivates people to seek help, or what causes them to wait. The symptoms scores will provide useful information about the severity of your symptoms when you are experiencing a Flare

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 to keep. If you 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 care you receive will not be affected.

What are the possible side effects of taking part?
Filling in a questionnaire about your symptoms and motivations for seeking help should not produce any adverse effects. However, if it makes you feel worried about your arthritis the researcher will arrange for you to see a member of the clinical team.

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 understand more about a common problem and how patients and doctors can discuss it better.

Will my taking part in this study be kept confidential?
Yes. When the questionnaires are input into the computer your name will be replaced with a code. No one will be able to identify you from your responses. The anonymised data will be kept securely for 6 years and then destroyed, in accordance with good practice guidelines.
The analysis will be led by Caroline Flurey in the University of the West of England, Bristol.

What will happen to the results of the research study?
The research will take about one year. The results will be reported in professional publications and conferences (but patients will not be identified by name). The results will also be reported in the PhD thesis produced by Caroline Flurey. A summary of the results will be sent to you once the study is complete.

Who is funding the study and who has reviewed the research?
The research has been funded by Arthritis Research UK. The study has been peer reviewed by the UWE Research Degrees Committee and has been approved by South West 5 Research Ethics Committee and the Research Department of the Bristol Royal Infirmary. The University of the West of England will take responsibility for the conduct of the study.

What do I do now?
Thank you for considering taking part in this research. If you are interested in taking part, please hand the attached slip into reception when you attend clinic for your appointment. If you are no longer interested in taking part, there's nothing more you need to do.

Helpful Contact Numbers:
If you have any concerns about participating in this study and would like to receive free independent advice please contact PALS (Patient Advise and Liaison Service) on 0117 342 3571. If you have any complaints about this research please contact the Patient Complaints Manager on 0117 342 3604.

Researcher details:

Caroline Flurey MSc
University of the West of England, Bristol, UK
PhD Student, Bristol Royal Infirmary
0117 342 4972
Caroline2.Flurey@uwe.ac.uk

Study Team
Caroline Flurey MSc, PhD Student, UWE Bristol
Sarah Hewlett PhD MA RN, Arthritis Research UK, Professor of Rheumatology Nursing, UWE
Marianne Morris PhD MSc, Principal Lecturer in Health Psychology, UWE Bristol
Jon Pollock, PhD, Reader in Epidemiology, UWE Bristol
Rod Hughes MD, Rheumatologist, Chertsey
Pam Richards – Patient Partner

Appendix K1: Daily symptoms questionnaire

ID ……………………………

Today's date: ______________________________

Please circle the appropriate number from 0-10 (none to worst) for each item, based on your RA symptoms for <u>THE PAST 24 HOURS</u>

1) How much pain do you have?

0 1 2 3 4 5 6 7 8 9 10

No pain at all **Worst possible pain**

2) What is your average level of fatigue?

0 1 2 3 4 5 6 7 8 9 10

No Fatigue **Totally Exhausted**

3) How much joint swelling do you have?

0 1 2 3 4 5 6 7 8 9 10

No swelling at all **Worst possible swelling**

4) How much joint stiffness do you have?

0 1 2 3 4 5 6 7 8 9 10

No stiffness at all **Worst possible stiffness**

5) How much time today did you spend being frustrated by your RA?

0 1 2 3 4 5 6 7 8 9 10

None of the time **All of the time**

6) How much time today did you spend being angry about your RA?

0 1 2 3 4 5 6 7 8 9 10

None of the time **All of the time**

7) How much time today was your RA a worry in your life?

0 1 2 3 4 5 6 7 8 9 10

None of the time **All of the time**

8) Is your Rheumatoid Arthritis in a Flare condition today? **Yes** ☐ **No** ☐

Appendix K2: Weekly impact and management questionnaire

ID ....

Today's date: ________________________________

Self-Management

Please answer these questions in relation to the PAST WEEK

1) How many times (if at all) have you had to cancel/change your plans due to your RA? ☐

2) Over the past week, what things have you tried to help you deal with your arthritis?

	Activity	**Please ✓ if you have used this in the last week**
a)	Avoided or altered doing the things that might cause pain	________
b)	Gave myself permission to leave a task half-finished	________
c)	Distracted myself from my symptoms	________
d)	Asked for help with the difficulties of everyday tasks	________
e)	Made small adjustments to my day to deal with the difficulties of everyday tasks	________
f)	Made time for socialising	________
g)	Allocated time for relaxation	________
h)	Managed my medication (knowing when and how to take it)	________
i)	Contacted my doctor or other health professional	________

Please see overleaf for 2 questions relating to your overall feelings

Overall Feelings

3) Considering your arthritis overall, how would you rate your level of physical well-being during the past week? Circle the number that best describes your level of physical well-being.

0 1 2 3 4 5 6 7 8 9 10
Very Good Very Bad

4) Considering your arthritis overall, how would you rate your level of emotional well-being during the past week? Circle the number that best describes your level of emotional well-being.

0 1 2 3 4 5 6 7 8 9 10
Very Good Very Bad

Appendix L: Study 3a participant consent form

University of the
West of England
BRISTOL

University Hospitals Bristol NHS
NHS Foundation Trust

Rheumatology Research
Faculty of Health and Life Sciences
Based at:
Academic Rheumatology
Bristol Royal Infirmary
BRISTOL BS2 8HW

Capturing Daily Fluctuations in Rheumatoid Arthritis

Consent form for research study

Please initial each box

1	I confirm that I have read and understand the information sheet dated 27th May 2011 for the above study	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected	☐
3	I understand that relevant sections of my medical notes may be looked at by a member of the clinical team. I give permission for these individuals to have access to my records.	☐
4	I understand that anonymised data collected during the study may be used in publications, conference presentations and a PhD thesis.	☐
5	I agree to take part in the above study	☐

______________________	____________	______________________
Name of patient	Date	Signature
______________________	____________	______________________
Name of researcher	Date	Signature

1 Copy to Participant *1 Copy to Researcher* *1 Copy for Notes*

Appendix M1: Daily symptoms questionnaire

ID ....

Today's date: ________________________________

Please circle the appropriate number from 0-10 (none to worst) for each item, based on your RA symptoms for <u>THE PAST 24 HOURS</u>

1) How much pain do you have? **0 1 2 3 4 5 6 7 8 9 10**

No pain at all **Worst possible pain**

2) What is your average level of fatigue? **0 1 2 3 4 5 6 7 8 9 10**

No Fatigue **Totally Exhausted**

3) How much joint swelling do you have? **0 1 2 3 4 5 6 7 8 9 10**

No swelling at all **Worst possible swelling**

4) How much joint stiffness do you have? **0 1 2 3 4 5 6 7 8 9 10**

No stiffness at all **Worst possible stiffness**

5) How much time today did you spend being frustrated by your RA?

0 1 2 3 4 5 6 7 8 9 10

None of the time **All of the time**

6) How much time today did you spend being angry about your RA?

0 1 2 3 4 5 6 7 8 9 10

None of the time **All of the time**

7) How much time today was your RA a worry in your life?

0 1 2 3 4 5 6 7 8 9 10

None of the time **All of the time**

8) Is your Rheumatoid Arthritis in a Flare condition today? **Yes** ☐ **No** ☐

Appendix M2: Flare help-seeking questionnaire

ID ....

Today's date: ________________________________

1) Please circle the number that describes the severity of your RA flare:

0 1 2 3 4 5 6 7 8 9 10
Usual RA symptoms **Extremely bad**

2) Considering your normal ability to run or manage your life (at work or home), please circle the number that describes how you are currently managing:

0 1 2 3 4 5 6 7 8 9 10
Unable to manage **Able to manage as normal**

3) Considering your ability to take part in social and/or pleasurable activities that are normal for you, please circle the number that describes your current level of involvement:

0 1 2 3 4 5 6 7 8 9 10
No Involvement **Full Involvement**

4) Considering your arthritis overall, please circle how well you coped with your disease during the last week?

0 1 2 3 4 5 6 7 8 9 10
Coped Not At All Well **Coped Very Well**

5) As a result of this flare, what did you do? *(Tick as many boxes as apply)*

☐ I didn't do anything different
☐ I reduced the amount of activities I did
☐ I increased my rest time
☐ I avoided doing activities I had planned to do
☐ I asked for help with everyday tasks
☐ I tried to distract myself from my symptoms
☐ I took more painkillers or extra anti-inflammatory medications (NSAIDS)
☐ I took more steroid tablets

6) What finally caused you to decide to contact the medical team?

Please see overleaf for final question

7) Do any of the following apply to you? *(Tick as many boxes as apply)*

☐ I avoided seeking medical help as I didn't want to be given any more medication
☐ I waited until the Flare had lasted longer than I expected before seeking help
☐ I waited until I had more than one Flare symptom before seeking medical help
☐ I was prompted by a family member/friend to seek medical help

Appendix M3: Flare early warning signs questionnaire

ID ....

Today's date: ________________________________

1) Did you get any early warning signs that this flare was about to start?

Yes ☐ No ☐

2) Thinking back to when your flare started, did you experience any of the following early warning signs?

Early Warnings of a Flare	**Yes**	**No**
'Flu-like' symptoms		
Increased pain		
Symptoms in a single joint that warned you about a flare starting		
Increased fatigue		
Became more aware of your physical body		
Realised that you needed to ask for help		
Realised that you had been taking extra painkillers		
Realised that you had been using more self-management strategies than usual		
People close to you noticed warning signs of the flare		
Just 'knew' that a flare was coming		
Didn't want to be touched because everything is so tender		

Appendix N: Study 3b participant consent form

UWE BRISTOL University of the West of England

University Hospitals Bristol NHS
NHS Foundation Trust

Rheumatology Research
Faculty of Health and Life Sciences
Based at:
Academic Rheumatology
Bristol Royal Infirmary
BRISTOL BS2 8HW

Seeking Help for Flares in Rheumatoid Arthritis

Consent form for research study

Please initial each box

1 I confirm that I have read and understand the information sheet dated 27th May 2011 for the above study ☐

2 I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected ☐

3 I understand that relevant sections of my medical notes may be looked at by a member of the clinical team. I give permission for these individuals to have access to my records. ☐

4 I understand that anonymised data collected during the study may be used in publications, conference presentations and a PhD thesis. ☐

5 I agree to take part in the above study ☐

Name of patient ____________ Date ____________ Signature ____________

Name of researcher ____________ Date ____________ Signature ____________

1 Copy to Participant *1 Copy to Researcher* *1 Copy for Notes*

Appendix O1: Daily life comments booklet

Living with RA day by day means........

Number	Statement	Comment
1	I sometimes have to cancel plans due to my RA	
2	Being more spontaneous with life	
3	Struggling to do certain things	
4	Choosing my clothes according to how easy they are to put on and take off	

5	I am able to predict how bad my symptoms will be each day	
6	Taking longer to get things done than I think it should	
7	Finding different ways of doing the things I want to	
8	Giving myself permission to leave a task half finished	

9	Using tools or devices to aid me in daily tasks	
10	Finding a balance between asking for help and remaining independent	
11	Doing what I want to do regardless of the consequences	
12	Choosing to prioritise pleasurable activities against chores	

13	Not letting my RA get me down	
14	Relying on support from my family / friends / other	
15	Talking to other people with RA who are similar to me helps	
16	Using alternative medicines / therapies to manage my RA symptoms	

17	Distracting myself from my symptoms	
18	Trying not to eat certain foods	
19	I am cautious of gaining weight and putting extra stress on my joints	
20	Exercising as much as I can	

21	Making small adjustments to my day or activities constantly because of my RA	
22	Taking my medication exactly as prescribed	
23	Planning rest time into my week	
24	Feeling lucky in comparison to others	

25	I have periods of being completely symptom free	
26	Dealing with the severity of my symptoms going up and down	
27	Getting frustrated due to my RA	
28	Feeling guilty about holding others back due to my RA	

29	Feeling that my body has let me down	
30	Trying to forget that I have RA	
31	Worrying because of my RA	
32	Repetitive tasks make my RA symptoms worse	

33	Being determined not to allow my RA to interfere with my responsibilities	
34	Being angry because of my RA	
35	Experiencing unexplainable fatigue / exhaustion daily	
36	Experiencing pain daily	

37	Experiencing swelling daily	
38	Experiencing stiffness daily	
39	Struggling to explain to family and friends what life is like for me	

Appendix O2: Flare comments booklet

When I am in a Flare.....

Number	Statement	Comment
1	I feel the Flare will last until I seek medical help	
2	I will contact the medical team as soon as possible	
3	I am reluctant to seek medical help as I worry about wasting the Rheumatology Team’s time	
4	I am more reluctant to seek medical help when I think I’ve caused the Flare	

5	I am reluctant to seek medical help as I don't think the Dr can do anything to help	
6	I am reluctant to seek medical help as I hope it'll go away on its own	
7	I avoid seeking medical help as I don't like taking drugs	
8	I seek help from the medical team once flare starts to affect my quality of life too much	

9	I know I don't have to manage my flare alone	
10	Easy access to the medical team is part of my decision to seek help for my flare	
11	A loved one tells me I ought to seek help	
12	I don't like admitting that I need to ask for help	

13	I am reluctant to seek medical help as I don’t get on well with my Rheumatology Team	
14	I manage my symptoms until the flare stops	
15	I seek help from the medical team as I worry about long term damage to my joints	
16	I seek help from the medical team when the pain becomes too intense	

17	I wait until my next scheduled appointment with the Rheumatologist before seeking help	
18	I am reluctant to seek medical help as I don’t want to waste my own time	
19	I seek help from the medical team when I know my Flare needs to be controlled by new medication	
20	I control my Flare symptoms with medication before contacting the medical team	

21	I seek help from the medical team when my symptoms become uncontrollable	
22	I seek help from the medical team when the Flare has gone on longer than I expected	
23	I wait until I have more than one Flare symptoms before seeking medical help	

Appendix P1: Initial list of Daily Life Q-statements

1. I often have to cancel my plans due to my RA
2. I have had to become more spontaneous
3. There are certain things I always struggle with
4. I choose my clothes according to how easy they will be to take on and off
5. I have adapted my home to fit my needs
6. Sometimes I can do daily chores on my own, but at other times I need help
7. It takes me longer to get things done than I think it should
8. I’ve lost confidence in my ability to do the things I want to
9. I have had to give up something important to me because of my RA
10. It’s important to me that I keep working despite having RA
11. I modify my life around my RA
12. I often have to ask for help from my friends and/or family
13. I like to remain as independent as possible
14. I find different ways of doing things so that my RA doesn’t stop me
15. I give myself permission to leave a task half finished
16. I use tools or devices to aid me in daily life
17. I find other things to do to replace the activities that I can no longer manage
18. I try to find a balance between asking for help and remaining independent
19. I try to find a balance between being active and resting
20. Before I act I always consider the consequences of how I will feel the next day
21. I prioritise pleasurable activities over household chores
22. If I want to do something, I do it. Even if that means I’m pain in the next day.
23. I have to work hard not to let my RA get me down
24. Having RA has turned my life upside down
25. I feel lucky compared with other people who have RA
26. I think my Rheumatologist knows best about how to manage my RA
27. Having control over my RA is important to me
28. Having RA is part of my identity now
29. I have to work hard to remain positive
30. My family and/or friends are understanding and support me
31. I think a supportive medical team is important
32. Talking to other people with RA who are similar to me helps
33. It gets me down to talk to other people who have RA
34. I use alternative medicines/therapies to manage my RA symptoms
35. I try to distract myself when I am having a bad day

36. I try to rest as much as possible throughout a normal day
37. I try not to eat certain foods in case they trigger a Flare
38. I am careful of what I eat as I don’t want to put on weight
39. I exercise as much as I can
40. I build small tasks into my working day to keep my symptoms at bay
41. I do my best to avoid any activity that may lead to a Flare
42. I plan a ‘rest-day’ into my week
43. When I have a task to do I pace myself; I do a little bit then stop for a rest, then do a bit more
44. On a normal day I would consider myself to be completely symptom free
45. Throughout a normal day, the severity of my symptoms go up and down
46. I consider myself unlucky to have RA
47. The medication I take controls my symptoms well
48. I am reluctant to take medication for my RA
49. I always take my medication as it has been prescribed
50. I often get frustrated due to my RA
51. I feel guilty when I feel that I am holding others back due to my RA
52. I feel that my body has let me down
53. I now have a new definition of ‘normal’ for me
54. Other people can’t understand what it’s like to have RA
55. If I want to do something I will push through the pain
56. I won’t let my RA stop me doing anything
57. I want people to believe I have a disability. I don’t want to have to explain myself.
58. I want to be treated the same as everyone else
59. I try to forget that I have RA
60. I avoid telling people that I have RA
61. My RA symptoms are completely unpredictable
62. I have no idea how I will feel when I wake up in the morning
63. I can’t work because of my RA
64. I worry that I can’t keep up with my colleagues at work
65. I find that repetitive tasks make my RA symptoms worse
66. I don’t like to have time off work due to my RA
67. I won’t allow my RA to interfere with my responsibilities
68. I am angry that I have RA

Appendix P2: Initial list of Flare Q-statements

1. A ‘flare’ means having a couple of swollen joints
2. I find that a ‘flare’ that I can’t explain is worse than one I can explain
3. A ‘flare’ can be pain that lasts no more than a few minutes
4. A ‘flare’ effects your entire body
5. A ‘flare’ is when my symptoms are out of my control
6. When I am in a ‘flare’ I worry that the disease is getting worse
7. I get irritable when I’m in a ‘flare’
8. The emotional aspect of a ‘flare’ is worse than the physical symptoms
9. If I do a repetitive task I will end up in a ‘flare’
10. Overdoing it can cause a ‘Flare’
11. Stress causes a ‘flare’
12. I have ‘flares’ regularly
13. I increase my medication to control a ‘flare’
14. I try to distract myself from ‘flare’ symptoms
15. I rest as much as possible when I’m in a ‘flare’
16. If I have a ‘flare’ I will have to cancel any plans I have
17. I slow down if I feel a ‘flare’ up coming to try and prevent it developing
18. When I have a ‘flare’ I struggle to move
19. When I have a ‘flare’ my symptoms are similar to having the Flu
20. When I am in a ‘flare’ I can’t get comfortable as I am in so much pain
21. My joints get swollen and hot when I am in a ‘flare’
22. When I am in a ‘flare’ I have no energy
23. My ‘flare’ will last until I seek medical help
24. When I have a ‘flare’ I just want to hibernate
25. When I have a ‘flare’ I have no choice but to ask for help
26. When I have a ‘flare’ it feels like the RA is winning
27. I don’t have any motivation when I’m in a ‘flare’
28. When I am in a ‘flare’ I wait as long as possible before contacting the medical team
29. I wait to contact the medical team for assistance as I worry that I will be wasting their time
30. I am more reluctant to seek medical help for a ‘flare’ if I think I’ve caused it
31. I don’t like to see other patients with RA, so I avoid coming to clinic
32. I don’t come for medical help when I am in a ‘flare’ as I don’t think the Dr can do anything to help
33. I don’t seek help for a ‘flare’ straight away as I hope it’ll go away on its own

34. I’m not always certain that my symptoms are related to RA
35. I don’t like taking drugs, so I avoid seeking medical help when I am in a ‘flare’
36. I seek help from the medical team for a ‘flare’ when it starts to effect my quality of life
37. I know I don’t have to manage alone when I am in a ‘flare’
38. If my clinic appointment’s coming up I will wait to seek help for my ‘flare’
39. I can tell the difference between daily fluctuation and a ‘flare’
40. I can tell whether my ‘flare’ needs to be controlled by medication or not
41. When I am in a flare I worry about long term damage to my joints
42. Easy access to the medical team is important to me
43. I always try to think of a reason for my ‘flare’
44. I don’t like admitting that I need to ask for help
45. A ‘flare’ comes out of the blue
46. Having a ‘flare’ means game-over
47. I can sometimes manage my ‘flare’ myself
48. I have to be encouraged to seek help for my ‘flare’ by a family member
49. I seek help from the medical team when my ‘flare’ has gone on too long
50. I increase my medication before contacting the medical team when I am in a ‘flare’

Appendix Q1: Daily life Q-study 5-factor solution

```
===============================================================================================================
Factor scores                            Living with RA day by day means.sty
===============================================================================================================
Living with RA day by day means.sty file name
30 sorts
39 items
11 piles
5 centroids
1 2 3 4 6 7 6 4 3 2 1  frequencies
5.43589743589744 variance

scores edited scores edited     4:01:02 PM,7/6/2012
factored factored          4:02:00 PM,7/6/2012
varimax
last opened at last opened at     4:00:49 PM,7/6/2012

===============================================================================================================
Summary (varimax)
===============================================================================================================
23 sorts have been accounted for in 5 factors.
  n    fac    sorts contributing to each factor
---------------------------------------------------------------------------------------------------------------
[ 8]  A  |  3  7 16 18 21 23 25 28
[ 4]  B  | 12 17 19 20
[ 6]  C  |  1  2  5  8  9 14
[ 2]  D  | 10 30
[ 3]  E  |  4 26 29
---------------------------------------------------------------------------------------------------------------
```

```
Factors
 have no loadings greater or equal to 41
---------------------------------------------------------------------------------------------------------------
[ 1]      Confounded: 13,
[ 6] Not significant:  6,11,15,22,24,27,
===============================================================================================================
Factor A for Living with RA day by day means.sty (varimax)
===============================================================================================================

 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 18  15  16   1   4   5   8  13   3   6  33
     19  25   2   9  14  10  27   7  35
         39  12  20  26  11  28  36
             24  22  29  17  38
                 23  30  21
                 31  32  37
                     34

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI61MBL                     3  0.48          COSS79FGK                    7  0.44
CH72FEH                     16  0.70          CH61MSB                     18  0.58
BRI55MAA                    21  0.46          COSS55FDH                   23  0.43
BRI52MMH                    25  0.63          BRI46FGB                    28  0.49
```

```
===============================================================================================================
Factor B for Living with RA day by day means.sty (varimax)
===============================================================================================================


 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 34  35  31   5   3   1   7   4   2  11  20
     36  32  27   6   8  12  16  18  13
         38  29  15   9  26  17  25
             39  19  10  28  24
                 21  14  30
                 37  22  33
                     23

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
CH50MLC                     12  0.62          CH63FMN                     17 -0.59
COSS51FKP                   19 -0.78          COSS41FCS                   20 -0.83


===============================================================================================================
Factor C for Living with RA day by day means.sty (varimax)
===============================================================================================================

 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 33  13  19  11   7   2   1   6  12   4   9
     24  20  22  16   3  15   8  23  14
         30  27  17   5  21  18  28
             35  26  10  31  34
                 36  25  32
```

```
                 38  29  39
                     37
Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI63FJE                     1 -0.50          COSS33FHJ                    2 -0.63
COSS30FSB                    5 -0.48          COSS39FKK                    8 -0.41
CH50FJM                      9 -0.69          CH39FDV                     14 -0.46


===============================================================================================================
Factor D for Living with RA day by day means.sty (varimax)
===============================================================================================================

 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 22   6   4  19   1  12   3   2  16  11  25
     13   7  24   5  17   8  18  36  34
         33  27   9  21  10  30  37
             29  15  31  14  32
                 20  35  23
                 26  38  28
                     39

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
CH66FOM                     10 -0.68          BRI65FVV                    30 -0.52
```

```
===============================================================================================================
Factor E for Living with RA day by day means.sty (varimax)
===============================================================================================================



 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 29  11  16  18   3   1   4   7   8  12  22
     28  31  25   6   2   5   9  10  21
         34  27  33  13  14  20  23
             39  35  15  17  26
                 37  19  24
                 38  30  32
                     36

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI67FJF                     4  0.77          BRI50BD                     26  0.42
BRI60FSY                    29  0.66


===============================================================================================================
Item scores  (varimax)
===============================================================================================================
                                                Factors  A    B    C    D    E
                                                        ---- ---- ---- ---- ----
  1.I sometimes have to cancel plans due to my RA         -2    0    1   -1    0
  2.Being more spontaneous with life                      -2    3    0    2    0
  3.Struggling to do certain things                        3   -1    0    1   -1
  4.Choosing my clothes according to how easy they        -1    2    4   -3    1
    are to put on and take off
  5.I am able to predict how bad my symptoms will be       0   -2    0   -1    1
    each day
```

6.Taking longer to get things done than I think it should	4	-1	2	-4	-1
7.Finding different ways of doing things	3	1	-1	-3	2
8.Giving myself permission to leave a task half finished	1	0	2	1	3
9.Using tools or devices to aid me in daily tasks	-1	0	5	-1	2
10.Finding a balance between asking for help and remaining independent	1	0	0	1	3
11.Doing what I want to do regardless of the consequences	1	4	-2	4	-4
12.Choosing to prioritise pleasurable activities against chores	-2	1	3	0	4
13.Not letting my RA get me down	2	4	-4	-4	0
14.Relying on support from my family / friends / other	0	0	4	1	1
15.Talking to other people with RA who are similar to me helps	-4	-1	1	-1	0
16.Using alternative medicines / therapies to manage my RA symptoms	-3	2	-1	3	-3
17.Distracting myself from my symptoms	1	2	-1	0	1
18.Trying not to eat certain foods	-5	3	2	2	-2
19.I am cautious of gaining weight and putting extra stress on my joints	-4	-1	-3	-2	0
20.Exercising as much as I can	-1	5	-3	-1	2
21.Making small adjustments to my day or activities constantly because of my RA	1	-1	1	0	4
22.Taking my medication exactly as prescribed	-1	0	-2	-5	5
23.Planning rest time into my week	-1	0	3	1	3
24.Feeling lucky in comparison to others	-2	2	-4	-2	1
25.I have periods of being completely symptom free	-3	3	0	5	-2
26.Dealing with the severity of my symptoms going up and down	0	1	-1	-1	2
27.Getting frustrated due to my RA	2	-2	-2	-2	-2
28.Feeling guilty about holding others back due to	2	1	3	1	-4

```
    my RA
 29.Feeling that my body has let me down                   0   -2    0   -2   -5
 30.Trying to forget that I have RA                        0    1   -3    2    0
 31.Worrying because of my RA                             -1   -3    1    0   -3
 32.Repetitive tasks make my RA symptoms worse             0   -3    1    2    1
 33.Being determined not to allow my RA to interfere       5    1   -5   -3   -1
    with my responsibilities
 34.Being angry because of my RA                           0   -5    2    4   -3
 35.Experiencing unexplainable fatigue / exhaustion        4   -4   -2    0   -1
    daily
 36.Experiencing pain daily                                3   -4   -1    3    0
 37.Experiencing swelling daily                            1   -1    0    3   -1
 38.Experiencing stiffness daily                           2   -3   -1    0   -1
 39.Struggling to explain to family and friends what      -3   -2    1    0   -2
    life is like for me

===============================================================================================================
Consensus statements  (varimax)
===============================================================================================================
---------------------------------------------------------------------------------------------------------------
          There are no consensus item for Living with RA day by day means.sty Q-study
---------------------------------------------------------------------------------------------------------------

===============================================================================================================
Differentiating statements   (varimax)
===============================================================================================================
  3 items distinguish Factor A from all other factors
---------------------------------------------------------------------------------------------------------------
                                                Factors  A   B   C   D   E
                                                        --- --- --- --- ---
 27.Getting frustrated due to my RA                        2  -2  -2  -2  -2
 33.Being determined not to allow my RA to interfere       5   1  -5  -3  -1
 35.Experiencing unexplainable fatigue / exhaustion        4  -4  -2   0  -1
```

```
------------------------------------------------------------------------------------------------------------------
  No items distinguish Factor B
------------------------------------------------------------------------------------------------------------------

------------------------------------------------------------------------------------------------------------------
  No items distinguish Factor C
------------------------------------------------------------------------------------------------------------------

------------------------------------------------------------------------------------------------------------------
No items distinguish Factor D
------------------------------------------------------------------------------------------------------------------

------------------------------------------------------------------------------------------------------------------
  2 items distinguish Factor E from all other factors
------------------------------------------------------------------------------------------------------------------
                                                Factors  A   B   C   D   E
                                                        --- --- --- --- ---
 22.Taking my medication exactly as prescribed           -1   0  -2  -5   5
 28.Feeling guilty about holding others back due to       2   1   3   1  -4


==================================================================================================================
Factor correlations   (varimax)
==================================================================================================================
------------------------------------------------------------------------------------------------------------------
        Factors  A   B   C   D   E
------------------------------------------------------------------------------------------------------------------
             A   0 -26 -23 -19  -2
             B -26   0 -19  -5  13
             C -23 -19   0  20   8
             D -19  -5  20   0 -33
             E  -2  13   8 -33   0
------------------------------------------------------------------------------------------------------------------
 reliabilities  96  94  95  88  92   std. errors  40  56  46  77  64
```

Appendix Q2: Daily Life Q-study 4-factor solution

```
===============================================================================================================
Factor scores
===============================================================================================================
Living with RA day by day means.sty file name
30 sorts
39 items
11 piles
4 centroids
1 2 3 4 6 7 6 4 3 2 1  frequencies
5.43589743589744 variance

scores edited scores edited     4:01:02 PM,7/6/2012
factored factored          4:03:58 PM,7/6/2012
varimax
last opened at last opened at     4:00:49 PM,7/6/2012

===============================================================================================================
Summary (varimax)
===============================================================================================================
23 sorts have been accounted for in 4 factors.
  n    fac    sorts contributing to each factor
---------------------------------------------------------------------------------------------------------------
[ 9]  A  |  3  7 16 18 21 23 25 26 28
[ 3]  B  | 17 19 20
[ 6]  C  |  1  2  5  9 13 14
[ 5]  D  |  4 10 15 29 30
---------------------------------------------------------------------------------------------------------------
Factors
 have no loadings greater or equal to 41
---------------------------------------------------------------------------------------------------------------
[ 2]      Confounded:  8,12,
```

```
[ 5] Not significant:  6,11,22,24,27,
==============================================================================================================
Factor A for Living with RA day by day means.sty (varimax)
==============================================================================================================
 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 18  19  15   1   4   5  10  13   3   6  33
     25  16   2  22   8  14  17   7  35
         39  12  23   9  27  28  21
             24  29  11  30  36
                 31  20  37
                 34  26  38
                     32

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI61MBL                     3  0.48          COSS79FGK                    7  0.47
CH72FEH                     16  0.73          CH61MSB                     18  0.54
BRI55MAA                    21  0.44          COSS55FDH                   23  0.42
BRI52MMH                    25  0.62          BRI50BD                     26  0.42
BRI46FGB                    28  0.48

==============================================================================================================
Factor B for Living with RA day by day means.sty (varimax)
==============================================================================================================

 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 35  34   5  27   6   1  12   4   2  11  20
     36  31  29   8   3  14  18  13  25
         32  38  15   7  17  24  16
             39  19   9  26  28
                 22  10  30
                 37  21  33
```

```
                     23

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
CH63FMN                     17 -0.57          COSS51FKP                   19 -0.80
COSS41FCS                   20 -0.80

===============================================================================================================
Factor C for Living with RA day by day means.sty (varimax)
===============================================================================================================

 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 24  13  19   5   3   2   1  15  12   4   9
     33  30  22   7  10   6  18  14  28
         35  27  11  17   8  34  23
             38  16  21  25  39
                 20  29  31
                 26  36  32
                     37

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI63FJE                     1 -0.50          COSS33FHJ                    2 -0.62
COSS30FSB                    5 -0.46          CH50FJM                      9 -0.68
CH43FNS                     13 -0.57          CH39FDV                     14 -0.47



===============================================================================================================
Factor D for Living with RA day by day means.sty (varimax)
```

```
 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 22   7  12   8   1   4   2  18  25  11  16
     13  20   9   6   5   3  29  28  34
         24  17  10  14  27  36  37
             21  19  15  31  39
                 23  26  35
                 32  30  38
                     33

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI67FJF                     4 -0.59          CH66FOM                     10 -0.59
CH72MDP                     15 -0.56          BRI60FSY                    29 -0.68
BRI65FVV                    30 -0.45

===============================================================================================================
Item scores  (varimax)
===============================================================================================================
                                                Factors  A    B    C    D
                                                        ---- ---- ---- ----
  1.I sometimes have to cancel plans due to my RA         -2    0    1   -1
  2.Being more spontaneous with life                      -2    3    0    1
  3.Struggling to do certain things                        3    0   -1    1
  4.Choosing my clothes according to how easy they        -1    2    4    0
    are to put on and take off
  5.I am able to predict how bad my symptoms will be       0   -3   -2    0
    each day
  6.Taking longer to get things done than I think it       4   -1    1   -1
   should
  7.Finding different ways of doing things                 3    0   -1   -4
  8.Giving myself permission to leave a task half          0   -1    1   -2
    finished
```

9. Using tools or devices to aid me in daily tasks	0	0	5	-2
10. Finding a balance between asking for help and remaining independent	1	0	0	-1
11. Doing what I want to do regardless of the consequences	0	4	-1	4
12. Choosing to prioritise pleasurable activities against chores	-2	1	3	-3
13. Not letting my RA get me down	2	3	-4	-4
14. Relying on support from my family / friends / other	1	1	3	0
15. Talking to other people with RA who are similar to me helps	-3	-1	2	0
16. Using alternative medicines / therapies to manage my RA symptoms	-3	3	-1	5
17. Distracting myself from my symptoms	2	1	0	-2
18. Trying not to eat certain foods	-5	2	2	2
19. I am cautious of gaining weight and putting extra stress on my joints	-4	-1	-3	-1
20. Exercising as much as I can	0	5	-1	-3
21. Making small adjustments to my day or activities constantly because of my RA	3	0	0	-2
22. Taking my medication exactly as prescribed	-1	-1	-2	-5
23. Planning rest time into my week	-1	0	3	-1
24. Feeling lucky in comparison to others	-2	2	-5	-3
25. I have periods of being completely symptom free	-4	4	1	3
26. Dealing with the severity of my symptoms going up and down	0	1	-1	0
27. Getting frustrated due to my RA	1	-2	-2	1
28. Feeling guilty about holding others back due to my RA	2	2	4	3
29. Feeling that my body has let me down	-1	-2	0	2
30. Trying to forget that I have RA	1	1	-3	0
31. Worrying because of my RA	-1	-3	1	1
32. Repetitive tasks make my RA symptoms worse	0	-3	1	-1

```
 33.Being determined not to allow my RA to interfere       5    1   -4    0
    with my responsibilities
 34.Being angry because of my RA                          -1   -4    2    4
 35.Experiencing unexplainable fatigue / exhaustion        4   -5   -3    1
    daily
 36.Experiencing pain daily                                2   -4    0    2
 37.Experiencing swelling daily                            1   -1    0    3
 38.Experiencing stiffness daily                           1   -2   -2    1
 39.Struggling to explain to family and friends what      -3   -2    2    2
    life is like for me

==============================================================================================================
Consensus statements  (varimax)
==============================================================================================================
--------------------------------------------------------------------------------------------------------------
          There are no consensus item for Living with RA day by day means.sty Q-study
--------------------------------------------------------------------------------------------------------------

==============================================================================================================
Differentiating statements   (varimax)
==============================================================================================================
--------------------------------------------------------------------------------------------------------------
  3 items distinguish Factor A from all other factors
--------------------------------------------------------------------------------------------------------------
                                                Factors  A   B   C   D
                                                        --- --- --- ---
 18.Trying not to eat certain foods                      -5   2   2   2
 25.I have periods of being completely symptom free      -4   4   1   3
 33.Being determined not to allow my RA to interfere      5   1  -4   0

--------------------------------------------------------------------------------------------------------------
```

```
3 items distinguish Factor B from all other factors

                                                Factors  A   B   C   D
                                                        --- --- --- ---
 20.Exercising as much as I can                            0   5  -1  -3
 24.Feeling lucky in comparison to others                 -2   2  -5  -3
 36.Experiencing pain daily                                2  -4   0   2

---------------------------------------------------------------------------------------------------------------
  2 items distinguish Factor C from all other factors
---------------------------------------------------------------------------------------------------------------
                                                Factors  A   B   C   D
                                                        --- --- --- ---
  9.Using tools or devices to aid me in daily tasks        0   0   5  -2
 33.Being determined not to allow my RA to interfere       5   1  -4   0

---------------------------------------------------------------------------------------------------------------
  No items distinguish Factor D
---------------------------------------------------------------------------------------------------------------

===============================================================================================================
Factor correlations   (varimax)
===============================================================================================================
---------------------------------------------------------------------------------------------------------------
        Factors  A   B   C   D
---------------------------------------------------------------------------------------------------------------
             A   0 -20 -26 -19
             B -20   0   0  -8
             C -26   0   0  17
             D -19  -8  17   0
---------------------------------------------------------------------------------------------------------------
reliabilities  97  92  95  95
   std. errors  38  64  46  50
```

Appendix Q3: Daily Life Q-study 3-factor solution

```
===============================================================================================================
Factor scores
===============================================================================================================
Living with RA day by day means.sty file name
30 sorts
39 items
11 piles
4 centroids
1 2 3 4 6 7 6 4 3 2 1  frequencies
5.43589743589744 variance

scores edited scores edited     4:01:02 PM,7/6/2012
factored factored          4:32:59 PM,7/6/2012
varimax
last opened at last opened at     4:32:53 PM,7/6/2012

===============================================================================================================
Summary (varimax)
===============================================================================================================
23 sorts have been accounted for in 4 factors.
  n    fac    sorts contributing to each factor
---------------------------------------------------------------------------------------------------------------
[ 9]  A  |  3  7 16 18 21 23 25 26 28
[ 3]  B  | 17 19 20
[ 6]  C  |  1  2  5  9 13 14
[ 5]  D  |  4 10 15 29 30
---------------------------------------------------------------------------------------------------------------
Factors
 have no loadings greater or equal to 41
---------------------------------------------------------------------------------------------------------------
[ 2]      Confounded:  8,12,
```

```
[ 5] Not significant:  6,11,22,24,27,
===============================================================================================================
Factor A for Living with RA day by day means.sty (varimax)
===============================================================================================================
 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 18  19  15   1   4   5  10  13   3   6  33
     25  16   2  22   8  14  17   7  35
         39  12  23   9  27  28  21
             24  29  11  30  36
                 31  20  37
                 34  26  38
                     32

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI61MBL                     3  0.48          COSS79FGK                    7  0.47
CH72FEH                     16  0.73          CH61MSB                     18  0.54
BRI55MAA                    21  0.44          COSS55FDH                   23  0.42
BRI52MMH                    25  0.62          BRI50BD                     26  0.42
BRI46FGB                    28  0.48

===============================================================================================================
Factor B for Living with RA day by day means.sty (varimax)
===============================================================================================================

 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 35  34   5  27   6   1  12   4   2  11  20
     36  31  29   8   3  14  18  13  25
         32  38  15   7  17  24  16
             39  19   9  26  28
                 22  10  30
                 37  21  33
```

```
                     23

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
CH63FMN                     17 -0.57          COSS51FKP                   19 -0.80
COSS41FCS                   20 -0.80

===============================================================================================================
Factor C for Living with RA day by day means.sty (varimax)
===============================================================================================================

 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 24  13  19   5   3   2   1  15  12   4   9
     33  30  22   7  10   6  18  14  28
         35  27  11  17   8  34  23
             38  16  21  25  39
                 20  29  31
                 26  36  32
                     37

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI63FJE                     1 -0.50          COSS33FHJ                    2 -0.62
COSS30FSB                    5 -0.46          CH50FJM                      9 -0.68
CH43FNS                     13 -0.57          CH39FDV                     14 -0.47


===============================================================================================================
Factor D for Living with RA day by day means.sty (varimax)
===============================================================================================================
```

```
 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 22   7  12   8   1   4   2  18  25  11  16
     13  20   9   6   5   3  29  28  34
         24  17  10  14  27  36  37
             21  19  15  31  39
                 23  26  35
                 32  30  38
                     33

Sort with significant loadings:
--label-------------------sort--load         --label-------------------sort--load
BRI67FJF                     4 -0.59         CH66FOM                     10 -0.59
CH72MDP                     15 -0.56         BRI60FSY                    29 -0.68
BRI65FVV                    30 -0.45


==================================================================================================================
Item scores  (varimax)
==================================================================================================================
                                                Factors  A    B    C    D
                                                        ---- ---- ---- ----
  1.I sometimes have to cancel plans due to my RA        -2    0    1   -1
  2.Being more spontaneous with life                     -2    3    0    1
  3.Struggling to do certain things                       3    0   -1    1
  4.Choosing my clothes according to how easy they       -1    2    4    0
    are to put on and take off
  5.I am able to predict how bad my symptoms will be      0   -3   -2    0
    each day
  6.Taking longer to get things done than I think it      4   -1    1   -1
    should
  7.Finding different ways of doing things                3    0   -1   -4
  8.Giving myself permission to leave a task half         0   -1    1   -2
```

finished				
9. Using tools or devices to aid me in daily tasks	0	0	5	-2
10. Finding a balance between asking for help and remaining independent	1	0	0	-1
11. Doing what I want to do regardless of the consequences	0	4	-1	4
12. Choosing to prioritise pleasurable activities against chores	-2	1	3	-3
13. Not letting my RA get me down	2	3	-4	-4
14. Relying on support from my family / friends / other	1	1	3	0
15. Talking to other people with RA who are similar to me helps	-3	-1	2	0
16. Using alternative medicines / therapies to manage my RA symptoms	-3	3	-1	5
17. Distracting myself from my symptoms	2	1	0	-2
18. Trying not to eat certain foods	-5	2	2	2
19. I am cautious of gaining weight and putting extra stress on my joints	-4	-1	-3	-1
20. Exercising as much as I can	0	5	-1	-3
21. Making small adjustments to my day or activities constantly because of my RA	3	0	0	-2
22. Taking my medication exactly as prescribed	-1	-1	-2	-5
23. Planning rest time into my week	-1	0	3	-1
24. Feeling lucky in comparison to others	-2	2	-5	-3
25. I have periods of being completely symptom free	-4	4	1	3
26. Dealing with the severity of my symptoms going up and down	0	1	-1	0
27. Getting frustrated due to my RA	1	-2	-2	1
28. Feeling guilty about holding others back due to my RA	2	2	4	3
29. Feeling that my body has let me down	-1	-2	0	2
30. Trying to forget that I have RA	1	1	-3	0
31. Worrying because of my RA	-1	-3	1	1

```
 32.Repetitive tasks make my RA symptoms worse           0   -3    1   -1
 33.Being determined not to allow my RA to interfere     5    1   -4    0
    with my responsibilities
 34.Being angry because of my RA                        -1   -4    2    4
 35.Experiencing unexplainable fatigue / exhaustion      4   -5   -3    1
    daily
 36.Experiencing pain daily                              2   -4    0    2
 37.Experiencing swelling daily                          1   -1    0    3
 38.Experiencing stiffness daily                         1   -2   -2    1
 39.Struggling to explain to family and friends what    -3   -2    2    2
    life is like for me

===============================================================================
Consensus statements  (varimax)
===============================================================================
-------------------------------------------------------------------------------
There are no consensus item for Living with RA day by day means.sty Q-study
-------------------------------------------------------------------------------

===============================================================================
Differentiating statements   (varimax)
===============================================================================
-------------------------------------------------------------------------------
  3 items distinguish Factor A from all other factors
-------------------------------------------------------------------------------
                                                Factors  A   B   C   D
                                                        --- --- --- ---
 18.Trying not to eat certain foods                     -5   2   2   2
 25.I have periods of being completely symptom free     -4   4   1   3
 33.Being determined not to allow my RA to interfere     5   1  -4   0

-------------------------------------------------------------------------------
3 items distinguish Factor B from all other factors
-------------------------------------------------------------------------------
```

```
Factors  A   B   C   D
                                                        --- --- --- ---
 20.Exercising as much as I can                           0   5  -1  -3
 24.Feeling lucky in comparison to others                -2   2  -5  -3
 36.Experiencing pain daily                               2  -4   0   2

---------------------------------------------------------------------------------------------------------------
  2 items distinguish Factor C from all other factors
---------------------------------------------------------------------------------------------------------------
                                                Factors   A   B   C   D
                                                        --- --- --- ---
  9.Using tools or devices to aid me in daily tasks       0   0   5  -2
 33.Being determined not to allow my RA to interfere      5   1  -4   0

---------------------------------------------------------------------------------------------------------------
  No items distinguish Factor D
---------------------------------------------------------------------------------------------------------------


===============================================================================================================
Factor correlations   (varimax)
===============================================================================================================
---------------------------------------------------------------------------------------------------------------
        Factors  A   B   C   D
---------------------------------------------------------------------------------------------------------------
             A   0 -20 -26 -19
             B -20   0   0  -8
             C -26   0   0  17
             D -19  -8  17   0
---------------------------------------------------------------------------------------------------------------
reliabilities  97  92  95  95
   std. errors   38  64  46  50
```

Appendix Q4: Daily Life Q-Study 2-factor solution

```
===============================================================================================================
Factor scores
===============================================================================================================
Living with RA day by day means.sty file name
30 sorts
39 items
11 piles
2 centroids
1 2 3 4 6 7 6 4 3 2 1  frequencies
5.43589743589744 variance

scores edited scores edited     4:01:02 PM,7/6/2012
factored factored          4:04:54 PM,7/6/2012
varimax
last opened at last opened at     4:00:49 PM,7/6/2012

===============================================================================================================
Summary (varimax)
===============================================================================================================
18 sorts have been accounted for in 2 factors.
  n    fac    sorts contributing to each factor
---------------------------------------------------------------------------------------------------------------
[ 9]  A  |  1  8  9 13 15 16 28 29 30
[ 9]  B  |  3 12 17 18 19 20 21 22 25
---------------------------------------------------------------------------------------------------------------
Factors
 have no loadings greater or equal to 41
---------------------------------------------------------------------------------------------------------------
[ 0]      Confounded:
[12] Not significant:  2, 4, 5, 6, 7,10,11,14,23,24,26,27,
```

```
================================================================================================================
Factor A for Living with RA day by day means.sty (varimax)
================================================================================================================

 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 34  18  16   4   1   2   3  10   7  33  13
     25  28  11   9   8   5  19  22  35
         39  14  12  15   6  21  24
             37  23  26  17  38
                 31  27  20
                 32  29  30
                     36

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI63FJE                     1  0.63          COSS39FKK                    8  0.45
CH50FJM                      9  0.47          CH43FNS                     13  0.69
CH72MDP                     15  0.49          CH72FEH                     16  0.53
BRI46FGB                    28  0.52          BRI60FSY                    29  0.49
BRI65FVV                    30  0.45

================================================================================================================
Factor B for Living with RA day by day means.sty (varimax)
================================================================================================================
 -5  -4  -3  -2  -1   0   1   2   3   4   5
--------------------------------------------
 34  35   5   3  10   1   9   4   2  18  20
     36  27   6  21   7  15  11  13  25
         31  32  28   8  17  12  16
             38  29  14  22  24
                 37  19  23
                 39  26  30
                     33
```

```
 Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI61MBL                     3 -0.48          CH50MLC                     12  0.72
CH63FMN                     17 -0.47          CH61MSB                     18 -0.51
COSS51FKP                   19 -0.70          COSS41FCS                   20 -0.86
BRI55MAA                    21 -0.52          BRI60MCS                    22 -0.44
BRI52MMH                    25 -0.43


===============================================================================================================
Item scores  (varimax)
===============================================================================================================
                                                Factors  A    B
                                                        ---- ----
  1.I sometimes have to cancel plans due to my RA         -1    0
  2.Being more spontaneous with life                       0    3
  3.Struggling to do certain things                        1   -2
  4.Choosing my clothes according to how easy they        -2    2
    are to put on and take off
  5.I am able to predict how bad my symptoms will be       1   -3
    each day
  6.Taking longer to get things done than I think it       1   -2
    should
  7.Finding different ways of doing things                 3    0
  8.Giving myself permission to leave a task half          0    0
    finished
  9.Using tools or devices to aid me in daily tasks       -1    1
 10.Finding a balance between asking for help and          2   -1
    remaining independent
 11.Doing what I want to do regardless of the             -2    2
    consequences
 12.Choosing to prioritise pleasurable activities         -1    2
    against chores
 13.Not letting my RA get me down                          5    3
```

14.Relying on support from my family / friends / other	-2	0
15.Talking to other people with RA who are similar to me helps	0	1
16.Using alternative medicines / therapies to manage my RA symptoms	-3	3
17.Distracting myself from my symptoms	1	1
18.Trying not to eat certain foods	-4	4
19.I am cautious of gaining weight and putting extra stress on my joints	2	0
20.Exercising as much as I can	1	5
21.Making small adjustments to my day or activities constantly because of my RA	2	-1
22.Taking my medication exactly as prescribed	3	1
23.Planning rest time into my week	-1	1
24.Feeling lucky in comparison to others	3	2
25.I have periods of being completely symptom free	-4	4
26.Dealing with the severity of my symptoms going up and down	0	0
27.Getting frustrated due to my RA	0	-3
28.Feeling guilty about holding others back due to my RA	-3	-1
29.Feeling that my body has let me down	0	-1
30.Trying to forget that I have RA	1	1
31.Worrying because of my RA	-1	-3
32.Repetitive tasks make my RA symptoms worse	-1	-2
33.Being determined not to allow my RA to interfere with my responsibilities	4	0
34.Being angry because of my RA	-5	-5
35.Experiencing unexplainable fatigue / exhaustion daily	4	-4
36.Experiencing pain daily	0	-4
37.Experiencing swelling daily	-2	-1
38.Experiencing stiffness daily	2	-2

```
 39.Struggling to explain to family and friends what      -3   -1
    life is like for me

===============================================================================================================
Consensus statements  (varimax)
===============================================================================================================
---------------------------------------------------------------------------------------------------------------
          There are 11 consensus item for Living with RA day by day means.sty Q-study
---------------------------------------------------------------------------------------------------------------
                                                Factors  A   B
                                                        --- ---
  1.I sometimes have to cancel plans due to my RA        -1   0
  2.Giving myself permission to leave a task half         0   0
  3.Talking to other people with RA who are similar       0   1
  4.Distracting myself from my symptoms                   1   1
  5.Feeling lucky in comparison to others                 3   2
  6.Dealing with the severity of my symptoms going up     0   0
  7.Feeling that my body has let me down                  0  -1
  8.Trying to forget that I have RA                       1   1
  9.Repetitive tasks make my RA symptoms worse           -1  -2
 10.Being angry because of my RA                         -5  -5
 11.Experiencing swelling daily                          -2  -1
===============================================================================================================
Differentiating statements   (varimax)
===============================================================================================================
---------------------------------------------------------------------------------------------------------------
  11 items distinguish Factor A from all other factors
                                                Factors  A   B
                                                        --- ---
  4.Choosing my clothes according to how easy they       -2   2
  5.I am able to predict how bad my symptoms will be      1  -3
 11.Doing what I want to do regardless of the            -2   2
 16.Using alternative medicines / therapies to manage    -3   3
 18.Trying not to eat certain foods                      -4   4
```

```
 20.Exercising as much as I can                         1   5
 25.I have periods of being completely symptom free    -4   4
 33.Being determined not to allow my RA to interfere    4   0
 35.Experiencing unexplainable fatigue / exhaustion     4  -4
 36.Experiencing pain daily                             0  -4
 38.Experiencing stiffness daily                        2  -2

----------------------------------------------------------------------------------------------------------------
  11 items distinguish Factor B from all other factors
----------------------------------------------------------------------------------------------------------------
                                               Factors  A   B
                                                       --- ---
  4.Choosing my clothes according to how easy they     -2   2
  5.I am able to predict how bad my symptoms will be    1  -3
 11.Doing what I want to do regardless of the          -2   2
 16.Using alternative medicines / therapies to manage  -3   3
 18.Trying not to eat certain foods                    -4   4
 20.Exercising as much as I can                         1   5
 25.I have periods of being completely symptom free    -4   4
 33.Being determined not to allow my RA to interfere    4   0
 35.Experiencing unexplainable fatigue / exhaustion     4  -4
 36.Experiencing pain daily                             0  -4
 38.Experiencing stiffness daily                        2  -2

================================================================================================================
Factor correlations   (varimax)
================================================================================================================
----------------------------------------------------------------------------------------------------------------
        Factors  A   B
----------------------------------------------------------------------------------------------------------------
             A   0  -7
             B  -7   0
----------------------------------------------------------------------------------------------------------------
reliabilities  97  97   std. errors  38  38
```

Appendix R1: Flare Help-Seeking Q-study 4-factor solution

```
===============================================================================================================
Factor scores
===============================================================================================================
Seeking help for RA flares.sty file name
29 sorts
23 items
9 piles
4 centroids
1 2 3 3 5 3 3 2 1  frequencies
4.26086956521739 variance

scores edited scores edited     11:44:38 AM,7/20/2011
factored factored          4:07:47 PM,7/6/2012
varimax
last opened at last opened at     4:05:51 PM,7/6/2012

===============================================================================================================
Summary (varimax)
===============================================================================================================
20 sorts have been accounted for in 4 factors.
  n    fac    sorts contributing to each factor
---------------------------------------------------------------------------------------------------------------
[13]  A  |  1  3  6  7  8 10 11 13 17 19 26 27 28
[ 4]  B  |  2 16 20 23
[ 2]  C  | 14 25
[ 1]  D  |  4
---------------------------------------------------------------------------------------------------------------
Factors
 have no loadings greater or equal to 54
---------------------------------------------------------------------------------------------------------------
[ 1]      Confounded: 12,
```

```
[ 8] Not significant:  5, 9,15,18,21,22,24,29,
=================================================================================================================
Factor A for Seeking help for RA flares.sty (varimax)
=================================================================================================================

 -4  -3  -2  -1   0   1   2   3   4
------------------------------------
 13   3   5   4   1   2   9  16   8
     17   6   7  11  10  15  21
         18  12  14  19  22
                 20
                 23

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI63FJE                     1  0.77          CH50FJM                      3  0.73
CH50MLC                      6  0.87          CH43FNS                      7  0.71
CH39DDV                      8  0.75          CH63FMN                     10  0.77
CH61MSB                     11  0.71          COSS62MRC                   13  0.75
BRI67FJF                    17  0.80          COSS41FCS                   19  0.84
BRI46FGB                    26  0.58          BRI68MDP                    27  0.79
BRI65FVV                    28  0.80

=================================================================================================================
Factor B for Seeking help for RA flares.sty (varimax)
=================================================================================================================

 -4  -3  -2  -1   0   1   2   3   4
------------------------------------
  6  10  11   8  15   2   5   1  13
     12  14   9  18   3  17   4
         20  16  21   7  19
                 22
                 23
```

```
 Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
COSS33FHJ                    2 -0.64          BRI61MBL                    16 -0.77
COSS55FDH                   20 -0.63          BRI52MMH                    23 -0.64


===============================================================================================================
Factor C for Seeking help for RA flares.sty (varimax)
===============================================================================================================

 -4  -3  -2  -1   0   1   2   3   4
------------------------------------
 13  11   4   5   1   2   3  10   9
     18   7   6  12  16  21  17
         15   8  14  19  22
                 20
                 23

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
COSS79FGK                   14  0.67          COSS48FDN                   25  0.56


===============================================================================================================
Factor D for Seeking help for RA flares.sty (varimax)
===============================================================================================================

 -4  -3  -2  -1   0   1   2   3   4
------------------------------------
  3  21   6  17   1   4  10   2  13
     22  11  18   5  14  15   8
         16  23   7  20  19
                  9
                 12
```

```
 Sort with significant loadings:
--label-------------------sort--load
CH66FOM                      4 -0.86


===============================================================================================================
Item scores  (varimax)
===============================================================================================================
                                                Factors  A    B    C    D
                                                        ---- ---- ---- ----
  1.I feel the flare will last until I seek medical        0    3    0    0
    help
  2.I will contact the medical team as soon as             1    1    1    3
    possible
  3.I m reluctant to seek medical help as I worry         -3    1    2   -4
    about wasting the Rheumatology Team's time
  4.I am more reluctant to seek medical help when I       -1    3   -2    1
    think I've caused the flare
  5.I am reluctant to seek medical help as I don't        -2    2   -1    0
    think the Dr can do anything to help
  6.I am reluctant to seek medical help as I hope         -2   -4   -1   -2
    it'll go away on its own
  7.I avoid seeking medical help as I don't like          -1    1   -2    0
    taking drugs
  8.I seek help from the medical team once flare           4   -1   -1    3
    starts to affect my quality of life too much
  9.I know I don't have to manage my flare alone           2   -1    4    0
 10.Easy access to the medical team is part of my          1   -3    3    2
    decision to seek help for my flare
 11.A loved one tells me I ought to seek medical help      0   -2   -3   -2
 12.I don't like admitting that I need to ask for         -1   -3    0    0
    help
 13.I am reluctant to seek medical help as I don't        -4    4   -4    4
    get on well with my Rheumatology team
```

```
 14.I manage my symptoms until the flare stops            0   -2    0    1
 15.I seek help from the medical team as I worry          2    0   -2    2
    about long term damage to my joints
 16.I seek help from the medical team when the pain       3   -1    1   -2
    becomes too intense
 17.I wait until my next scheduled appointment with      -3    2    3   -1
    the Rheumatologist before seeking help
 18.I am reluctant to seek medical help as I don't       -2    0   -3   -1
    want to waste my own time
 19.I seek help from the medical team when I know my      1    2    1    2
    Flare needs to be controlled by new medication
 20.I control my flare symptoms with medication           0   -2    0    1
    before contacting the medical team
 21.I seek help from the medical team when my             3    0    2   -3
    symptoms become uncontrollable
 22.I seek help from the medical team when the flare      2    0    2   -3
    has gone on longer than expected
 23.I wait until I have more than one flare symptoms      0    0    0   -1
    before seeking medical help

==============================================================================================================
Consensus statements  (varimax)
==============================================================================================================
--------------------------------------------------------------------------------------------------------------
          There are 2 consensus item for Seeking help for RA flares.sty Q-study
--------------------------------------------------------------------------------------------------------------
                                                     Factors  A   B   C   D
                                                             --- --- --- ---
  1.I seek help from the medical team when I know my      1   2   1   2
  2.I wait until I have more than one flare symptoms      0   0   0  -1
```

```
===============================================================================================================
Differentiating statements   (varimax)
===============================================================================================================
---------------------------------------------------------------------------------------------------------------
  No items distinguish Factor A
---------------------------------------------------------------------------------------------------------------

---------------------------------------------------------------------------------------------------------------
  1 item distinguishes Factor B from all other factors
---------------------------------------------------------------------------------------------------------------
                                                Factors  A   B   C   D
                                                        --- --- --- ---
 10.Easy access to the medical team is part of my         1  -3   3   2

---------------------------------------------------------------------------------------------------------------
  No items distinguish Factor C
---------------------------------------------------------------------------------------------------------------

---------------------------------------------------------------------------------------------------------------
  No items distinguish Factor D
---------------------------------------------------------------------------------------------------------------

===============================================================================================================
Factor correlations   (varimax)
===============================================================================================================
---------------------------------------------------------------------------------------------------------------
        Factors  A   B   C   D
---------------------------------------------------------------------------------------------------------------
             A   0 -32  34   5
             B -32   0 -17  20
             C  34 -17   0 -28
             D   5  20 -28   0
---------------------------------------------------------------------------------------------------------------
 reliabilities  98  94  88  80      std. errors  28  50  68  92
```

Appendix R2: Flare Help-Seeking Q-Study 3-factor solution

```
==================================================================================================================
Factor scores
==================================================================================================================
Seeking help for RA flares.sty file name
29 sorts
23 items
9 piles
4 centroids
1 2 3 3 5 3 3 2 1  frequencies
4.26086956521739 variance

scores edited scores edited     11:44:38 AM,7/20/2011
factored factored          4:07:47 PM,7/6/2012
varimax
last opened at last opened at     4:05:51 PM,7/6/2012

==================================================================================================================
Summary (varimax)
==================================================================================================================
20 sorts have been accounted for in 4 factors.
  n    fac    sorts contributing to each factor
------------------------------------------------------------------------------------------------------------------
[13]  A  |  1  3  6  7  8 10 11 13 17 19 26 27 28
[ 4]  B  |  2 16 20 23
[ 2]  C  | 14 25
[ 1]  D  |  4
------------------------------------------------------------------------------------------------------------------
Factors
 have no loadings greater or equal to 54
------------------------------------------------------------------------------------------------------------------
[ 1]      Confounded: 12,
```

```
[ 8] Not significant:  5, 9,15,18,21,22,24,29,
==================================================================================================
Factor A for Seeking help for RA flares.sty (varimax)
==================================================================================================

 -4  -3  -2  -1   0   1   2   3   4
------------------------------------
 13   3   5   4   1   2   9  16   8
     17   6   7  11  10  15  21
         18  12  14  19  22
                 20
                 23

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI63FJE                     1  0.77          CH50FJM                      3  0.73
CH50MLC                      6  0.87          CH43FNS                      7  0.71
CH39DDV                      8  0.75          CH63FMN                     10  0.77
CH61MSB                     11  0.71          COSS62MRC                   13  0.75
BRI67FJF                    17  0.80          COSS41FCS                   19  0.84
BRI46FGB                    26  0.58          BRI68MDP                    27  0.79
BRI65FVV                    28  0.80

==================================================================================================
Factor B for Seeking help for RA flares.sty (varimax)
==================================================================================================
 -4  -3  -2  -1   0   1   2   3   4
------------------------------------
  6  10  11   8  15   2   5   1  13
     12  14   9  18   3  17   4
         20  16  21   7  19
                 22
                 23
```

```
Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
COSS33FHJ                    2 -0.64          BRI61MBL                    16 -0.77
COSS55FDH                   20 -0.63          BRI52MMH                    23 -0.64


===============================================================================================================
Factor C for Seeking help for RA flares.sty (varimax)
===============================================================================================================

 -4  -3  -2  -1   0   1   2   3   4
------------------------------------
 13  11   4   5   1   2   3  10   9
     18   7   6  12  16  21  17
         15   8  14  19  22
                 20
                 23

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
COSS79FGK                   14  0.67          COSS48FDN                   25  0.56


===============================================================================================================
Factor D for Seeking help for RA flares.sty (varimax)
===============================================================================================================

 -4  -3  -2  -1   0   1   2   3   4
------------------------------------
  3  21   6  17   1   4  10   2  13
     22  11  18   5  14  15   8
         16  23   7  20  19
                  9
                 12
```

```
Sort with significant loadings:
--label-------------------sort--load
CH66FOM                      4 -0.86


===============================================================================================================
Item scores  (varimax)
===============================================================================================================
                                                Factors  A    B    C    D
                                                        ---- ---- ---- ----
  1.I feel the flare will last until I seek medical        0    3    0    0
    help
  2.I will contact the medical team as soon as             1    1    1    3
    possible
  3.I m reluctant to seek medical help as I worry         -3    1    2   -4
    about wasting the Rheumatology Team's time
  4.I am more reluctant to seek medical help when I       -1    3   -2    1
    think I've caused the flare
  5.I am reluctant to seek medical help as I don't        -2    2   -1    0
    think the Dr can do anything to help
  6.I am reluctant to seek medical help as I hope         -2   -4   -1   -2
    it'll go away on its own
  7.I avoid seeking medical help as I don't like          -1    1   -2    0
    taking drugs
  8.I seek help from the medical team once flare           4   -1   -1    3
    starts to affect my quality of life too much
  9.I know I don't have to manage my flare alone           2   -1    4    0
 10.Easy access to the medical team is part of my          1   -3    3    2
    decision to seek help for my flare
 11.A loved one tells me I ought to seek medical help      0   -2   -3   -2
 12.I don't like admitting that I need to ask for         -1   -3    0    0
    help
 13.I am reluctant to seek medical help as I don't        -4    4   -4    4
```

```
    get on well with my Rheumatology team
 14.I manage my symptoms until the flare stops            0   -2    0    1
 15.I seek help from the medical team as I worry          2    0   -2    2
    about long term damage to my joints
 16.I seek help from the medical team when the pain       3   -1    1   -2
    becomes too intense
 17.I wait until my next scheduled appointment with      -3    2    3   -1
    the Rheumatologist before seeking help
 18.I am reluctant to seek medical help as I don't       -2    0   -3   -1
    want to waste my own time
 19.I seek help from the medical team when I know my      1    2    1    2
    Flare needs to be controlled by new medication
 20.I control my flare symptoms with medication           0   -2    0    1
    before contacting the medical team
 21.I seek help from the medical team when my             3    0    2   -3
    symptoms become uncontrollable
 22.I seek help from the medical team when the flare      2    0    2   -3
    has gone on longer than expected
 23.I wait until I have more than one flare symptoms      0    0    0   -1
    before seeking medical help

==============================================================================================================
Consensus statements  (varimax)
==============================================================================================================
--------------------------------------------------------------------------------------------------------------
          There are 2 consensus item for Seeking help for RA flares.sty Q-study
--------------------------------------------------------------------------------------------------------------
                                                         Factors  A   B   C   D
                                                                 --- --- --- ---
  1.I seek help from the medical team when I know my      1   2   1   2
  2.I wait until I have more than one flare symptoms      0   0   0  -1
```

```
===============================================================================================================
Differentiating statements   (varimax)
===============================================================================================================
---------------------------------------------------------------------------------------------------------------
  No items distinguish Factor A
---------------------------------------------------------------------------------------------------------------

---------------------------------------------------------------------------------------------------------------
  1 item distinguishes Factor B from all other factors
---------------------------------------------------------------------------------------------------------------
                                                Factors  A   B   C   D
                                                        --- --- --- ---
 10.Easy access to the medical team is part of my         1  -3   3   2

---------------------------------------------------------------------------------------------------------------
  No items distinguish Factor C
---------------------------------------------------------------------------------------------------------------

---------------------------------------------------------------------------------------------------------------
  No items distinguish Factor D
---------------------------------------------------------------------------------------------------------------

===============================================================================================================
Factor correlations   (varimax)
===============================================================================================================
---------------------------------------------------------------------------------------------------------------
Factors  A   B   C   D
---------------------------------------------------------------------------------------------------------------
             A   0 -32  34   5
             B -32   0 -17  20
             C  34 -17   0 -28
             D   5  20 -28   0
---------------------------------------------------------------------------------------------------------------
 reliabilities  98  94  88  80      std. errors  28  50  68  92
```

Appendix R3: Flare Help-Seeking Q-study 2-factor solution

```
===============================================================================================================
Factor scores
===============================================================================================================
Seeking help for RA flares.sty file name
29 sorts
23 items
9 piles
2 centroids
1 2 3 3 5 3 3 2 1  frequencies
4.26086956521739 variance

scores edited scores edited     11:44:38 AM,7/20/2011
factored factored          5:41:34 PM,7/6/2012
varimax
last opened at last opened at     5:41:26 PM,7/6/2012

===============================================================================================================
Summary (varimax)
===============================================================================================================
22 sorts have been accounted for in 2 factors.
  n    fac    sorts contributing to each factor
---------------------------------------------------------------------------------------------------------------
[16]  A  |  1  5  6  7  8 10 11 13 17 18 19 22 24 26 27 28
[ 6]  B  |  2  4 12 16 23 29
---------------------------------------------------------------------------------------------------------------
Factors
 have no loadings greater or equal to 54
---------------------------------------------------------------------------------------------------------------
[ 0]      Confounded:
[ 7] Not significant:  3, 9,14,15,20,21,25,
===============================================================================================================
```

```
Factor A for Seeking help for RA flares.sty (varimax)
===============================================================================================================

 -4  -3  -2  -1   0   1   2   3   4
------------------------------------
 13   3   7   4   1   2   9  16   8
      5  17   6  11  10  19  21
         18  12  14  15  22
                 20
                 23

Sort with significant loadings:
--label-------------------sort--load          --label-------------------sort--load
BRI63FJE                     1  0.90          CH53FSC                      5  0.55
CH50MLC                      6  0.86          CH43FNS                      7  0.67
CH39DDV                      8  0.78          CH63FMN                     10  0.78
CH61MSB                     11  0.60          COSS62MRC                   13  0.76
BRI67FJF                    17  0.86          COSS51FKP                   18  0.58
COSS41FCS                   19  0.76          BRI55MAA                    22  0.57
BRI50FBD                    24  0.62          BRI46FGB                    26  0.70
BRI68MDP                    27  0.81          BRI65FVV                    28  0.89

===============================================================================================================
Factor B for Seeking help for RA flares.sty (varimax)
===============================================================================================================

 -4  -3  -2  -1   0   1   2   3   4
------------------------------------
  6  16  11   8   3   5   4   1  13
     21  12   9  10  15   7   2
         22  14  18  17  19
                 20
                 23
Sort with significant loadings:
```

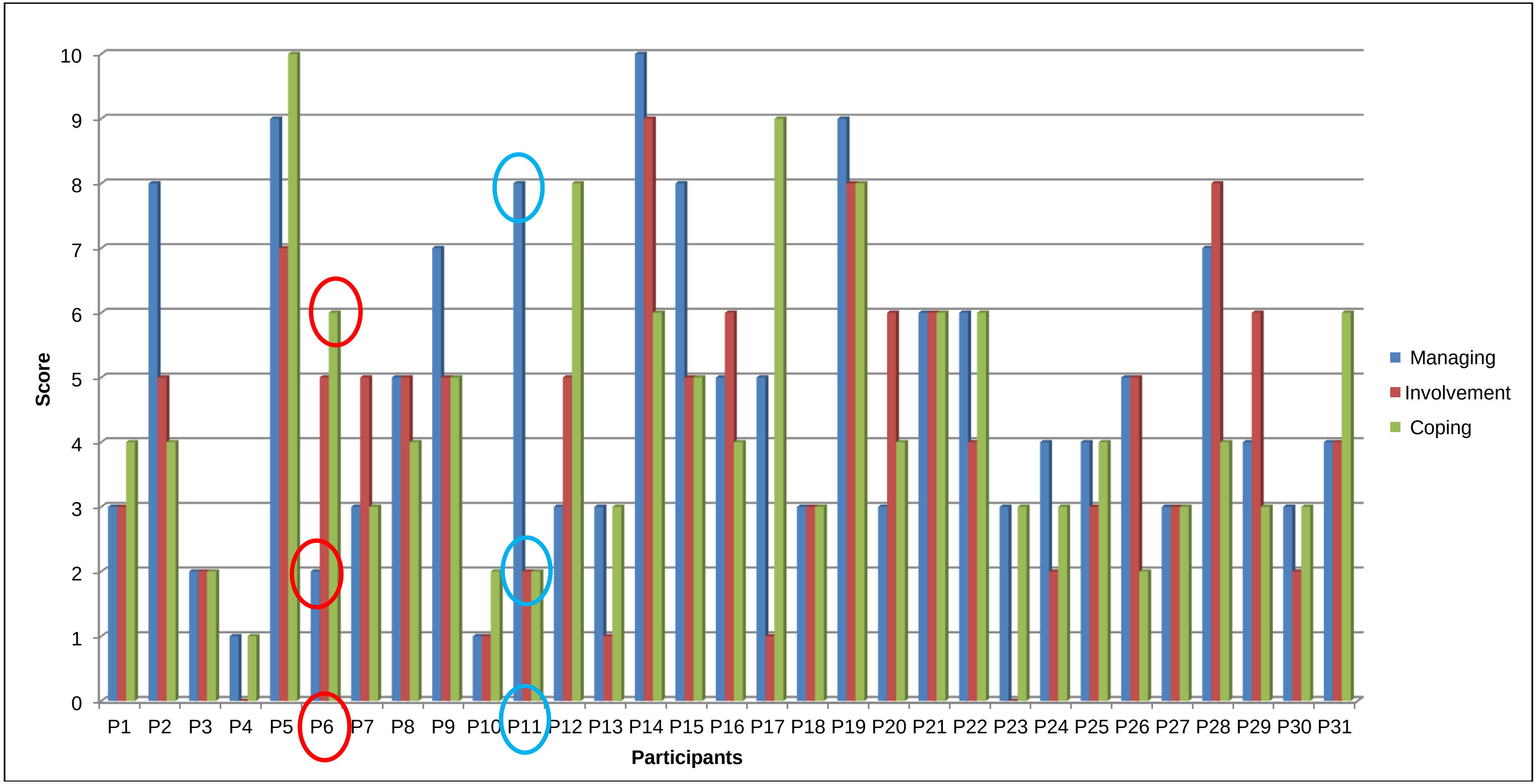
```
--label-------------------sort--load         --label-------------------sort--load
COSS33FHJ                    2 -0.60         CH66FOM                      4 -0.70
COSS30FSB                   12 -0.71         BRI61MBL                    16 -0.72
BRI52MMH                    23 -0.63         BRI61FHD                    29 -0.59


==============================================================================================================
Item scores  (varimax)
==============================================================================================================
                                                            Factors  A    B
                                                                   ---- ----
  1.I feel the flare will last until I seek medical                   0    3
    help
  2.I will contact the medical team as soon as                        1    3
    possible
  3.I m reluctant to seek medical help as I worry                    -3    0
    about wasting the Rheumatology Team's time
  4.I am more reluctant to seek medical help when I                  -1    2
    think I've caused the flare
  5.I am reluctant to seek medical help as I don't                   -3    1
    think the Dr can do anything to help
  6.I am reluctant to seek medical help as I hope                    -1   -4
    it'll go away on its own
  7.I avoid seeking medical help as I don't like                     -2    2
    taking drugs
  8.I seek help from the medical team once flare                      4   -1
    starts to affect my quality of life too much
  9.I know I don't have to manage my flare alone                      2   -1
 10.Easy access to the medical team is part of my                     1    0
    decision to seek help for my flare
 11.A loved one tells me I ought to seek medical help                 0   -2
 12.I don't like admitting that I need to ask for                    -1   -2
    help
 13.I am reluctant to seek medical help as I don't                   -4    4
```

```
    get on well with my Rheumatology team
 14.I manage my symptoms until the flare stops            0   -1
 15.I seek help from the medical team as I worry          1    1
    about long term damage to my joints
 16.I seek help from the medical team when the pain       3   -3
    becomes too intense
 17.I wait until my next scheduled appointment with      -2    1
    the Rheumatologist before seeking help
 18.I am reluctant to seek medical help as I don't       -2    0
    want to waste my own time
 19.I seek help from the medical team when I know my      2    2
    Flare needs to be controlled by new medication
 20.I control my flare symptoms with medication           0    0
    before contacting the medical team
 21.I seek help from the medical team when my             3   -3
    symptoms become uncontrollable
 22.I seek help from the medical team when the flare      2   -2
    has gone on longer than expected
 23.I wait until I have more than one flare symptoms      0    0
    before seeking medical help

==============================================================================================================
Consensus statements  (varimax)
==============================================================================================================
--------------------------------------------------------------------------------------------------------------
          There are 7 consensus item for Seeking help for RA flares.sty Q-study
--------------------------------------------------------------------------------------------------------------
                                                Factors  A   B
                                                        --- ---
  1.Easy access to the medical team is part of my        1   0
  2.I don't like admitting that I need to ask for       -1  -2
  3.I manage my symptoms until the flare stops           0  -1
  4.I seek help from the medical team as I worry         1   1
  5.I seek help from the medical team when I know my     2   2
```

```
  6.I control my flare symptoms with medication           0   0
  7.I wait until I have more than one flare symptoms      0   0

==================================================================================================================
Differentiating statements   (varimax)
==================================================================================================================
------------------------------------------------------------------------------------------------------------------
  7 items distinguish Factor A from all other factors
------------------------------------------------------------------------------------------------------------------
                                                Factors  A   B
                                                        --- ---
  5.I am reluctant to seek medical help as I don't       -3   1
  7.I avoid seeking medical help as I don't like         -2   2
  8.I seek help from the medical team once flare          4  -1
 13.I am reluctant to seek medical help as I don't       -4   4
 16.I seek help from the medical team when the pain       3  -3
 21.I seek help from the medical team when my             3  -3
 22.I seek help from the medical team when the flare      2  -2

------------------------------------------------------------------------------------------------------------------
  7 items distinguish Factor B from all other factors
------------------------------------------------------------------------------------------------------------------
                                                Factors  A   B
                                                        --- ---
  5.I am reluctant to seek medical help as I don't       -3   1
  7.I avoid seeking medical help as I don't like         -2   2
  8.I seek help from the medical team once flare          4  -1
 13.I am reluctant to seek medical help as I don't       -4   4
 16.I seek help from the medical team when the pain       3  -3
 21.I seek help from the medical team when my             3  -3
 22.I seek help from the medical team when the flare      2  -2


==================================================================================================================
```

```
Factor correlations   (varimax)
===============================================================================================================
---------------------------------------------------------------------------------------------------------------
Factors  A   B
---------------------------------------------------------------------------------------------------------------
             A   0 -41
             B -41   0
---------------------------------------------------------------------------------------------------------------
 reliabilities  98  95
   std. errors  25  41
```

Appendix S: Graph displaying Study 3b patients' individual coping, managing and involvement scores



Appendix T: Dissemination of this thesis

This includes

T1 List of events where this thesis has been disseminated

and the following peer reviewed abstracts:

T2 Flurey, C. A. (2010) Capturing the patient perspective: Characterising daily fluctuations, 'flare' and self-management in rheumatoid arthritis [abstract]. OMERACT10, Kota Kinabalu

T3 Flurey, C. A. (2011) The patient experience of Daily Life and 'Flare' with Rheumatoid Arthritis [abstract]. *Rheumatology*, 50 (Suppl. 3): iii9-iii10, IP44

T4 Flurey, C. A. (2012) "It gets me down every single day": Are men with RA getting the support they need? [abstract]. Arthritis Research UK Fellows Meeting, Loughborough

T5 Flurey, C.A., Morris, M., Pollock, J., Hughes, R., Richards, P., Hewlett, S. (2012a) Will I waste your time? Delays in help seeking for RA flares [abstract] *Annals of the Rheumatic Diseases*, 71 (Suppl. 3), p737

Flurey, C.A., Morris, M., Pollock, J., Hughes, R., Richards, P., Hewlett, S. (2012b) Will I waste your time? Delays in help seeking for RA flares [abstract] *Rheumatology*, 51 (Suppl. 3): iii19-iii26

T6 Flurey, C.A., Morris, M., Pollock, J., Hughes, R., Richards, P., Hewlett, S. (2012c) "You make your own luck" Three different perceptions of living with RA: A Q-methodological study [abstract]. *Rheumatology*, 51 (Suppl. 3): iii52-iii92

T7 Flurey, C.A., Morris, M., Pollock, J., Hughes, R., Richards, P., Hewlett, S. (*In Press*) "A Computer Virus...An Endless Loop That Won't Stop": Making sense of the inexplicable [abstract] *British Pychological Society Division of Health Psychology Annual Conference*. Liverpool 2012

Appendix T1: List of dissemination events

Bristol rheumatology post-graduate seminar, 2009: Oral presentation and discussion, “Characterising daily fluctuations, flare and self-management in rheumatoid arthritis: The patient perspective”

OMERACT 10 Conference, 2010: Poster presentation, “Capturing the patient perspective: Characterising daily fluctuations, flare and self-management in rheumatoid arthritis” (Abstract in Appendix S2)

UWE H&SC research student training and support day, 2010: Oral presentation and discussion, “What is it like to live with rheumatoid arthritis?”

Bristol rheumatology post-graduate seminar, 2011: Oral presentation and discussion, “PhD research update: Methods and Phase 1 results”

Arthritis Research UK fellows annual meeting, 2011: Poster presentation, “Daily life, flare and self-management in rheumatoid arthritis: The patient perspective”

British Society for Rheumatologists (BSR) and British Society for Rheumatology Health Professionals (BHPR) annual conference, 2011: Invited talk, “The patient experience of daily life and flare with rheumatoid arthritis” (Abstract in Appendix S3)

South West Rheumatology Nurses training day, 2011: Oral presentation and discussion, “Using metaphors to explore patients’ experiences of rheumatoid arthritis”

UWE H&SC research student training and support day, 2011: Oral presentation and discussion, “Using Q-methodology to explore patients’ experiences of rheumatoid arthritis

Bristol rheumatology post-graduate seminar, 2012: Oral presentation and discussion, ““It gets me down every single day”: Are men with RA getting the support they need?”

Arthritis Research UK fellows annual meeting, 2012: Oral presentation (*Won prize for best oral presentation: PhD Student*), ““It gets me down every single day”: Are men with RA getting the support they need?” (Abstract in Appendix S4)

BSR/BHPR annual conference, 2012: Plenary presentation (“Jewels in the crown”), “Will I waste your time? Delays in help-seeking for RA flares” (Abstract in Appendix S5)

BSR/BHPR annual conference, 2012: Poster presentation (*Won the Chris Moran poster prize*), “”You make your own luck”: Three different perspectives of living with RA: A Q-methodological study” (Abstract in Appendix S6)

European League Against Rheumatology (EULAR) annual conference, 2012: Poster presentation, “Will I waste your time? Delays in help-seeking for RA flares” (Abstract in Appendix S5)

Division of Health Psychology (DHP) annual conference, 2012: Poster presentation, ““A computer virus...an endless loop that won’t stop”: Making sense of the inexplicable in rheumatoid arthritis” (Abstract in Appendix S7)

Appendix T2: Flurey, C. A. (2010) Capturing the patient perspective: Characterising daily fluctuations, ‘flare’ and self-management in rheumatoid arthritis [abstract]. OMERACT10, Kota Kinabalu

Background: OMERACT 9 identified that patient’s experience of symptoms associated with flare differs from the traditional inflammatory paradigm of number of painful, swollen joints. This series of studies will apply novel methodologies capturing the patient perspective in the management of ‘flare’ in order to explore new outcome measures.

Aims: This doctorate aims to identify the nature and effect of daily symptoms experienced in RA, how patients manage these, how patients differentiate the important symptom differences between daily fluctuation and ‘flare,’ and the level, variation and clustering of symptoms that patients experience as both daily life and ’flare’.

Methods: ***<u>Phase 1</u>*** will use interviews with RA patients, to qualitatively explore the patient perspective of daily symptoms and flare symptoms. Interpretative Phenomenology will be utilized to understand the lived experience of RA, and also patients’ visual representations (drawings) of disease patterns for different symptoms, to understand their complexity and nature. The use of ‘Framework’ allows exploration of emerging collective themes (tabulated in rows) but also personal schema of symptoms (cross-tabulated in columns), thus preserving the individual context that is lost in focus group methodology. These data will highlight flare symptoms or symptom clusters - potential domains for flare and daily life measures.

<u>Phase 2</u> will comprise Q-sort methodology with patients as experts. In Q-sort methodology patients rank the symptoms generated in Phase I (forced into a normal distribution) and the resulting item scores are analysed to produce the best clusters. The clusters are then interpreted against the characteristics of the patients in each cluster. These data will be compared with the data emerging from the OMERACT patient focus group study on flare, and their Delphi technique, which explores clinicians’ and patients’ views on flare. A set of key domains will be proposed from Phase II data.

Also in this Phase an expert patient group will design simple numerical rating scales (NRS) for any symptoms arising in Phase 1 which do not have existing measures (e.g. flare prodrome).

<u>Phase 3</u> will provide preliminary data on the patient’s perspective of the frequency and severity of daily symptoms, flare and flare prodrome (from Phases I and II). 100 patients will be sampled to represent patients in ‘flare’ and not in ‘flare’, with predictable ‘flares’ and those with frequent but unpredictable ‘flares’. NRS emerging from Phases I and II will be completed each night to describe the preceding 24 hours for 3 months. Novel methods of data capture may be trialled, such as PDAs, a secure website, email or mail. Qualitative diaries will also be completed once a week for the same 3 months. Patients will be asked to comment on their symptoms, thoughts, feelings and actions, to help clarify cognitions around their decision making on the important difference between daily variation and flare. Longitudinal analysis of the frequency and intensity of daily and ‘flare’ symptoms will be performed, plus analyses to explore symptom groupings and patterns using hierarchical statistical techniques (multidimensional scaling and cluster analysis). A form of qualitative analysis will be used to analyse the qualitative diaries.

Appendix T3: Flurey, C. A. (2011) The patient experience of daily life and ‘flare’ with rheumatoid arthritis [abstract]. Rheumatology, 50 (Suppl. 3): iii9-iii10, IP44

‘Flare’ underpins requests for help and treatment decisions, with potentially significant impact on outcome, yet it has not been defined. Informal work suggests a serious mismatch between patient and clinician perception of ‘flare,’ with patients perceiving a range of ‘flare’ symptoms and even early warning signs, of which clinicians are unaware. Little is known about daily variation in symptoms within current treatment regimens, how patients self-manage these, patient language for ‘flare,’ how they differentiate ‘flare’ from normal daily variation, what prompts patients to seek help, nor how these relate to adaptation to and experience of RA. If we can identify these features we may be able to improve explanations to newly-diagnosed patients and clarify discussions regarding ‘flare’ and reduce distress of delayed help seeking. The results from Phase 1 of a 3-Phase PhD will be presented.

20 semi-structured interviews were conducted. RA patients who have experienced a ‘flare’ during their RA trajectory were purposefully sampled to reflect a range of age, gender, disease duration, disability, current therapies and current ‘flare’ status. The selection criteria included patients who have had a diagnosis of RA (Arnett et al 1990) for at least 2 years and who have experienced an RA ‘flare’ during their disease duration, who are over 18 and who speak English as a first language. 11 patients were sampled from The Bristol Royal Infirmary where Direct Access (Hewlett et al 2005) is being used, whereby patients initiate their own medical reviews when in ‘flare’. 9 patients were sampled from Cossham Hospital which uses the traditional method of Rheumatologist-initiated reviews. The interviews were analysed using Inductive Thematic Analysis.

The results of the interviews will be presented. These will cover how patients experience daily life, how they manage their day-to-day symptoms, how patients decide they are in a 'flare' and distinguish this from a 'bad day', how patients manage their 'flare' symptoms and how they decide it is time to seek help from the Rheumatology team.

Patients' experiences of daily life will provide professionals with real examples to assist them in explaining what life will be like to newly diagnosed patients. Understanding why patients wait to seek help has the potential for creating an intervention to encourage help seeking. A contribution to a global definition of 'Flare' would have the potential to improve communication between Clinicians and patients and to improve clarity in RCT outcomes. Further research is necessary, this research will be continued with a further 2 studies as part of the PhD project.

Appendix T4: Flurey, C. A. (2012) "It gets me down every single day": Are men with RA getting the support they need? [abstract]. Arthritis Research UK Fellows Meeting, Loughborough

Background: Daily life with RA has been explained as unpredictable and full of uncertainty. However, most research about daily life with RA was conducted before current more aggressive medications.

Objectives: To explore daily life on modern therapies.

Methods: 30 RA patients sorted 39 statements (generated in previous qualitative interviews) about daily life with RA across a forced distribution, in ranked order of agreement. Data were analysed using centroid factor analysis with varimax rotation (i.e. the participants and not the items are the variables). Demographic and clinical data were collected and patients completed comments booklets about their rationale for sorting the statements.

Results: Three factors were generated, which explained 33% of the study variance and accounted for 23 of the 30 participants. None of the Q-sorts were confounded (loading on more than one factor). A participant loading of 0.41 reached significance at p<.01 Factors A & B have been reported elsewhere and therefore only the descriptive statistics are presented:

Factor A: Taking Control: "Just a fact of life":Seven participants: mean disease duration 22.7yrs (SD 10.8), age 61.7yrs (SD 10.3), HAQ score 2.0 (SD 0.6), patient global 3.1 (SD 1.7), 86% female, 71% on biologic therapies.

Factor B: Keeping RA in its place: "It's a very small part of you":Seven participants: mean disease duration 9.9yrs (SD 10.1), age 42.4yrs (SD 11.2), HAQ score 0.5 (SD 0.5), patient global 1.7 (SD 1.0), 100% female, 71% employed, 86% mothers, 43% on biologic therapies.

Factor C: Struggling Through: "It gets me down every single day":Eight participants: mean disease duration 15.3yrs (SD 14.3), age 55.5yrs (SD 7.1), HAQ score 1.3 (SD 0.9), patient global 4.8 (SD 2.5), 63% Male, 50% on biologic therapies.
These predominantly male patients are never symptom free, experiencing pain and fatigue daily: *"It's like feeling ill all the time"* and describing fatigue as *"the worst symptom".* They worry and get angry and frustrated about their RA. It gets them down daily:
"I get very frustrated with it, the problem is then I get irritated and take it out on the wife"

These RA patients report being unable to be spontaneous or to exercise and they struggle to explain their experience to their family. They feel their body has let them down and the idea that they are lucky is *"ridiculous"*.
In the previous qualitative interviews, which were used to inform the statements for this study, men discuss the need to adopt new coping strategies due to their RA: *"you can't go and thump a wall because you end up with a flare and you can't go and kick a football around or anything like that, so you need to find an outlet and talking is the outlet I suppose".* They also find support groups unhelpful: *"The self help groups don't confront it enough, it might be all lovey dovey but sometimes you have got to be quite hard about it".*

Conclusions: Whilst some patients cope well with their RA, others struggle to accept and adapt to their condition; the majority of these being male. This study indicates a need for an increased awareness of the support needs of male RA patients.

Appendix T5: Flurey, C.A., Morris, M., Pollock, J., Hughes, R., Richards, P., Hewlett, S. (2012a) Will I waste your time? Delays in help seeking for RA flares [abstract] *Annals of the Rheumatic Diseases*, 71 (Suppl. 3), p737

and

Flurey, C.A., Morris, M., Pollock, J., Hughes, R., Richards, P., Hewlett, S. (2012b) Will I waste your time? Delays in help seeking for RA flares [abstract] *Rheumatology*, 51 (Suppl. 3): iii19-iii26

Background: Anecdotal evidence suggests that patients vary in how long they wait before seeking medical help for an RA flare. The aim of this research is to explore why, and their tipping points for seeking help.

Methods: Q-Methodology: 29 RA patients sorted 23 statements (generated in previous qualitative interviews) about their help seeking behaviours when in a flare, across a forced distribution in ranked order of agreement. Data were analysed using centroid factor analysis with varimax rotation (i.e. the participants and not the items are the variables). Demographic and clinical data were collected and patients completed comments booklets about their rationale for sorting the statements.

Results: Consensus was reached on 9 statements and two factors were produced, which explained 51% of the study variance and accounted for 22 of the 29 participants. None of the Q-sorts were confounded (loading on more than one factor). A participant loading of 0.54 reached significance at p<.01.

Consensus: “When I just don’t know what to do anymore”: The top 3 of the 9 consensus statements are ‘when the pain becomes too intense’, ‘when the Flare has gone on longer than expected’ and ‘when the symptoms become uncontrollable’, suggesting these are the tipping points for seeking help.

Factor A: Definite Decision: “It won’t go away, so I won’t wait”: Sixteen participants: mean disease duration 15.2yrs (SD 10.3), age 54.8yrs (SD 9.6), HAQ score 1.360 (SD 0.8), 69% female, 69% on biologic therapies.
These patients will seek help quickly when they are in a flare, they know that their medical team can help and that their flare won’t go away on its own. They don’t worry about wasting their own or the Rheumatologist’s time and will not wait until their next scheduled appointment for help. Tipping points for seeking help for these patients are worries about long term damage to their joints, knowing their flare needs to be controlled by new medication and their quality of life being affected.

Factor B: Cautious Indecision: “Lying down and not moving until it goes”: Six participants: mean disease duration 18.7yrs (SD 13.9), age 50.5yrs (SD 15.4), HAQ score 1.23 (SD 0.9) 67% female, 0% on biologic therapies.
These patients wait to contact the medical team when they are in a flare. They are reluctant to seek help as they hope the flare will go away on its own and do not believe it will last until they seek medical help. They don’t like asking for help and worry about wasting the Rheumatologist’s time. They may wait until their next scheduled appointment before seeking help and will try to manage their symptoms themselves. These patients need to be prompted by a friend or family member to seek help.

Conclusions: Whilst consensus indicates pain is a tipping point, for some patients a complex interaction of beliefs hinders their help-seeking behaviour. Health care professionals should be aware that some patients delay help-seeking due to fears of time wasting, thus potentially risking further damage.

Appendix T6: Flurey, C.A., Morris, M., Pollock, J., Hughes, R., Richards, P., Hewlett, S. (2012c) "You make your own luck" Three different perceptions of living with RA: A Q-methodological study [abstract]. Rheumatology, 51 (Suppl. 3): iii52-iii92

Background: Most research about daily life with RA was conducted before current more aggressive medication. The aim of this research is to explore daily life on modern therapies.

Methods: Q-Methodology: 30 RA patients sorted 39 statements (generated in previous qualitative interviews) about daily life with RA across a forced distribution, in ranked order of agreement. Data were analysed using centroid factor analysis with varimax rotation (i.e. the participants and not the items are the variables). Demographic and clinical data were collected and patients completed comments booklets about their rationale for sorting the statements.

Results: Three factors were generated, which explained 33% of the study variance and accounted for 23 of the 30 participants. None of the Q-sorts were confounded (loading on more than one factor). A participant loading of 0.41 reached significance at p<.01

Factor A: Taking Control: "Just a fact of life": Seven participants: mean disease duration 22.7yrs (SD 10.8), age 61.7yrs (SD 10.3), HAQ score 2.0 (SD 0.6), patient global 3.1 (SD 1.7), 86% female, 71% on biologic therapies.
These patients constantly micromanage their RA, find different ways of doing the things they want to and will not let RA interfere with their responsibilities. They take their medication exactly as prescribed and will not 'over-do it'. Theyalso use tools as aids and plan rest time into their week. They do not believe in alternative medicines or special diets.

Factor B: Struggling Through: "It gets me down every single day": Eight participants: mean disease duration 15.3yrs (SD 14.3), age 55.5yrs (SD 7.1), HAQ score 1.3 (SD 0.9), patient global 4.8 (SD 2.5), 63% Male, 50% on biologic therapies.
These patients are never symptom free, experiencing pain and fatigue daily. They worry and get angry and frustrated about their RA. It gets them down daily. They report being unable to be spontaneous or to exercise and they struggle to explain their experience to their family. They feel their body has let them down and consider themselves unlucky.

Factor C: Keeping RA in its place: "It's a very small part of you": Seven participants: mean disease duration 9.9yrs (SD 10.1), age 42.4yrs (SD 11.2), HAQ score 0.5 (SD 0.5), patient global 1.7 (SD 1.0), 100% female, 71% employed, 86% mothers, 43% on biologic therapies.
These patients do not allow RA to interfere with their responsibilities, nor hold others back. Fatigue is their highest ranked symptom, but they do not plan rest time into their week as they are too busy. They are often able to forget about their RA as they do not need to use tools or ask for help and they will not consider their RA when choosing their clothes. They do not allow RA to get them down and consider themselves lucky in comparison to others.

Conclusions: Whilst some patients cope well with their RA, others struggle to accept and adapt to their condition. This study indicates a need for an increased awareness of the support needs of male RA patients.

Appendix T7: Flurey, C.A., Morris, M., Pollock, J., Hughes, R., Richards, P., Hewlett, S. (*In Press*) "A Computer Virus...An Endless Loop That Won't Stop": Making sense of the inexplicable [abstract] *British Pychological Society Division of Health Psychology Annual Conference*. Liverpool 2012

Background: Metaphors allow for expression of concepts that cannot easily be described, including various health conditions. The aim of this research was to explore whether patients use metaphors to make sense of life with Rheumatoid Arthritis (RA).

Methods: Semi-structured one to one interviews with RA patients sampled to reflect a range of age, gender, disease duration and drug treatments, explored daily life with RA. Interviews underwent secondary content analysis searching for metaphors. The broad use of the term metaphor has been used, to include all forms of abstract thought.

Findings: Patients used a range of metaphors to explain their experiences of living with RA. Metaphors are used to describe the physical symptoms of RA, which appears to be an attempt to improve the explanation of their symptoms. Wild animals are used to conceptualise the unpredictable, uncertain and aggressive nature of RA (*"[A tiger] stealthy, creeps up on you"*), whilst domestic animals or rodents typify RA being a disease that whilst unwelcome, patients have learnt to live with (*"My companion, but it [cat] can be quite vicious sometimes"*). Patients were careful to choose metaphors that were acceptable to them, for example rejecting ugly animals for cuter ones, indicating that RA has been incorporated into their identity.

Discussion: Patients use metaphors to communicate intangible thoughts, experiences of living with RA and to indicate distress. It is therefore vital that health psychologists listen for and respond to these subtle ways patients express their concerns to facilitate and effect change in managing their long term condition