

Challenging current perceptions:
An exploration of the nature and extent of foot complaints in
rheumatoid arthritis

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Abstract

The extent and nature of the impact of rheumatoid arthritis (RA) in the feet from the point of view of those with the disease is unknown. Most epidemiological studies of foot involvement in RA have been based upon radiological scoring or the findings of clinicians' examination of feet in clinically based populations. This thesis aimed to explore foot involvement in RA from the perspective of people with the disease integrated with the perceptions of rheumatologists and podiatrists.

Three questionnaires were developed *de novo* through an iterative process of integrating information gained from focus groups, illness narratives and literature reviews. Following piloting, questionnaires sent to participants enquired about symptoms in the feet, the anatomical distribution of those symptoms, and their impact on quality of life from the perspectives of 1040 people with RA, 78 podiatrists and 414 rheumatologists throughout the UK. Additionally, the availability of podiatric services and the usefulness of interventions for foot symptoms and foot function were triangulated from participants. Quantitative data were analysed using SPSS and a process of thematic analysis was used to interpret qualitative data.

Results from participants indicated that symptoms due to RA were prevalent in all parts of the foot and ankle but the metatarsophalangeal and ankle joints were most commonly and severely affected. Most people with RA (79%) reported suffering recurrent, moderate or severe foot pain every day. Other symptoms (stiffness, numbness and swelling) were also common. Overall, these findings were greater than those that have been reported previously.

Foot complaints were noted to have a profound effect on quality of life, with loss of mobility due to symptoms in the feet, and difficulties finding comfortable footwear, leading to loss of independence, anger, frustration and depression; findings that have not been previously reported in detail. A gap between the need for specialist foot care and receiving such care was highlighted, with a total 82% of respondents having discussed their foot symptoms with their rheumatologist. Amongst these patients 64% had been referred to a podiatrist. Clinicians' assessment practices varied widely both within and between professions. Patients reported that on average rheumatologists examined their hands every 6.2 months, whereas their feet were only examined every 16.5 months; this led some patients to feel that rheumatologists were disinterested in their foot complaints. Additionally, the type of assessment undertaken by clinicians did not fully take account of the issues people with RA were reporting. Issues that were key to patients were quality of life and the ability to participate in valued life activities. Difficulties with obtaining adequate foot health care were noted by those with the disease and clinicians alike.

Symptoms in the feet in RA are common, severe and tend to be under-reported by clinicians. Involvement of the metatarsophalangeal joints and ankles is especially troublesome. Motion in these joints is vital for normal propulsive gait. Severe involvement causes reduced mobility and impedes independence with considerable consequences for social integration. Outcome measures that exclude the feet discourage foot examination and thus do not fully account for domains of importance to those with RA. Rheumatologists and podiatrists need to work more closely in order for a more patient-centred service to be developed, where a biopsychosocial approach to foot care would more fully address the needs of people with RA.

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Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed

A handwritten signature in black ink, appearing to read "Spottler", is written over a light grey rectangular background.

Dated

1.0 Chapter 1

Introduction and background to the study

1.1 Foot complaints and rheumatoid arthritis

Foot complaints are frequently seen in people with rheumatoid arthritis (RA) (Dixon 1981, Woodburn & Helliwell 1995, Trieb 2005). In common with peripheral joints in the hands, clinical and radiographic studies have repeatedly demonstrated that signs and symptoms of RA in the feet are widespread both in the early and later stages of the disease (Brook & Corbett 1977, Dixon 1987, Van der Heijde et al. 1995, Sobel et al. 1998, Hulsmans et al. 2000). The extent of foot pathology seen throughout the course of RA also contributes to the overall disability experienced by patients (Helliwell et al. 2007). However, the extent and significance of foot involvement from the point of view of those with RA remains poorly understood and under-represented in the literature. Part of the reason for this under-representation is that most of the previous research that has considered foot complaints in RA has been undertaken from the perspective of the clinician rather than of those with the disease. Additionally, a number of reports have highlighted that foot complaints are seen as being of secondary importance when musculoskeletal pathology of other lower limb joints such as the hip or knee co-exists (Munro & Steele 1998, Gorter et al. 2000, Chen et al. 2003). Yet, some authors have suggested foot involvement in RA causes patients more distress than previously recognised (Gripton 2001). Indeed Wickman and colleagues (2004) report that involvement of the foot in RA, even to a mild degree, is an important marker for impaired mobility and reduced functional capacity as well as contributing to psychological disability. The subsequent loss of mobility seen in RA due to foot pathology can have a profoundly negative impact on social interaction and activity levels (Ailinger & Schweitzer 1993). For example, early loss of paid employment often results from the functional incapacity associated with the disease (Young et al. 2002), contributing to a marked economic burden for both those with RA and society as a whole (Cooper 2000).

There is general agreement throughout the literature to support the view that RA is a chronic, systemic, usually symmetrical, inflammatory poly-arthritis typically affecting peripheral joints (Thompson 1983, Griffith & Dacre 1994, Klippel et al. 1999, Albers 2001, Combe et al. 2007). The hallmark features of RA are a gradual onset of pain, swelling and stiffness over a number of weeks, typically affecting the small joints of the feet and hands (Dixon 1987, Moots & Jones 2004), as illustrated in figure 1.1.

Figure 1.1 - Inflammatory synovitis affecting the proximal interphalangeal joints of the hand



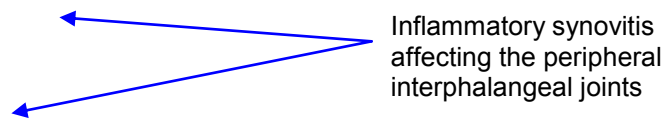


Image courtesy of the American College of Rheumatology

Untreated, these symptoms lead those with RA to report progressive disability (Boers 1998). In particular, involvement of the foot is a key determinant of disability in RA (Sobel et al. 1998). Yet, in spite of the early and extensive involvement of the feet in RA and the importance of foot function as part of overall mobility; foot examination currently only has limited representation in commonly used diagnostic, disease assessment and improvement criteria (Arnett et al. 1988, Fries et al. 1982, Felson et al. 1993). These instruments tending to favour examination of the upper limbs and hands. This approach may be seen as inconsistent with the reported extensive involvement of the foot both in the early and later stages of the disease (Young et al. 2000). This has led Korda and Balient (2004) to highlight the need for further research into the effectiveness of the treatment of foot complaints in RA; work that must involve the perspective of those with the disease. In the UK, the need for such evidence is seen as particularly important given the inadequate availability of foot health services for those with rheumatological disorders (Williams & Bowden 2004, Redmond et al. 2006), and the limited evidence that underpins the management of foot pathologies seen in RA where foot care services do exist (Bowen et al. 2005, Farrow et al. 2005).

The limited assessment of foot complaints commonly reported in RA together with a paucity of high quality foot care services in the face of an apparently clear requirement from those with the disease underlines the need to undertake an extensive and in-depth examination of the nature and extent of foot complaints from the perspective of those with the condition. Additionally, the evaluation of current assessment and management strategies for foot complaints in RA also requires exploration from the perspective of service users, referring clinicians and service providers to gain a greater insight into those factors that form the basis of views held about foot complaints in this disorder. Integration of the findings will enable differences and similarities between patients and clinicians views of foot complaints in RA to be determined. These requirements formed the basis of the aims and objectives for the current study, outlined below.

1.2 Aims and objectives

Aim 1

To interpret and critically analyse the existing literature that describes the nature and extent of foot complaints in RA.

Objectives

- Identify and appraise the literature that depicts the nature and extent of foot pathologies in RA from the clinicians' perspective.
- Identify and appraise the literature that portrays the lived experience of RA and the impact of foot complaints from the perspective of those with the disease.

Aim 2

To identify and explore the impact and effects of RA on the foot from the perspective of the person with RA.

Objectives

- Undertake a prevalence survey of foot complaints in RA.
- Identify and explore in depth the nature, extent and impact of RA on the foot.

Aim 3

To identify and explore the impact and effects of RA on the foot from the clinicians' perspective.

Objectives

- Identify and explore in depth the nature, extent and impact of RA on the foot.
- Identify and explore the approaches and methods clinicians use to assess, evaluate and monitor foot complaints in RA.

Aim 4

To interpret and synthesise data from emergent domains pertinent to the assessment, evaluation and monitoring of foot complaints in RA from the perspective of people with RA and that of clinicians.

Previously Tishelman and colleagues (1999) have criticised traditional enquiries for allowing the perspective of the researcher to predominate over that of the patient. Since people with RA have to live with the disease on a daily basis, their views are essential; particularly as previous authors have suggested that comparison of the patients' experiences of the disease may be of equal importance to the levels of disease activity typically measured by clinicians using objective outcome measures (Fries 1993, Long 1996, Wolfe & Pincus 1999). Yet, the incorporation of patients' views into clinical practice is not widespread (Clancy & Eisenberg 1998). Differences in perception between patients and clinicians with regard to expectations of treatment and unmet needs have been demonstrated (Ward 2004), but rarely has this been specifically associated with foot complaints, in spite of the frequent occurrence of foot pathologies in RA. These points highlight the need for new research to encompass the views and opinions of those with RA in conjunction with the perceptions of clinicians.

1.3 Methodological considerations

To achieve the stated aims of exploring both the nature and extent of foot complaints in RA from the perspective of both those with the disease and clinicians, both quantitative and qualitative methodological approaches need to be considered. It has been suggested that quantitative and qualitative methods belong to different paradigms based on philosophically distinct epistemological frameworks (Foss and Ellefsen 2002), as described in table 1.1 overleaf.

Table 1.1 – Distinctions between methodological paradigms

(Adapted from Coxon 2005, Moron-Ellis et al. 2006)

	Quantitative	Qualitative
Paradigm	Focused on the measurement of variables	Meaning-centred approach
Epistemology	Positivistic (empirical) observation of facts	Reasons-based interpretation of phenomena
Data conceptualisation	Formal measurement approaches	Natural language and speech based data
Data collection	Systematic rules-based formats	Discursive data elicitation
Data analysis	Statistical explanation based on linear models	Thematic, content-driven analysis

Coyle and Williams (2000) however, contend these distinctions are artificial, being predominantly based on the premise that quantitative methods are grounded in the epistemology of positivism, whereas qualitative methods are anti-positivistic. Previously, Clarke (1998) noted that many of the contemporary sciences are now post-positivistic and as such acknowledge the influences of the research process within the contextual basis of the work. Different kinds of knowledge can be generated using different methods, therefore Foss and Ellefsen (2002) argue that quantitative and qualitative approaches are not irreconcilable, but occupy different positions on a continuum. For this reason, it was important that contributions from both paradigms were considered throughout the literature search to inform the study design.

1.4 Searches of the literature

1.4.1 Factors guiding the literature search

A literature search was undertaken to inform the study design and determine whether suitable instruments with which to generate data were already in existence. To include views of people with RA as well as clinicians, the literature search encompassed a wide variety of sources. To guide the literature search, the strategies outlined by Brettell (1996) and Greenhalgh (2001) were adapted for the purpose of this work. These two guidelines were utilised for three specific reasons:

- Guidance was provided on how to search the rheumatology literature, while recognising the potential contribution of literature outside this speciality.
- A variety of electronic databases were explored in addition to other sources such as grey literature, in accordance with these guidelines.
- The advantages and disadvantages associated with searches of electronic databases were highlighted.

1.4.2 Search of electronic databases

To retrieve the maximum number of articles initially only two MeSh subject headings were used – *Rheumatoid Arthritis AND Foot OR Feet*. An extensive literature search was undertaken using a range of databases – Pubmed (1965 - 2007), Cinhal (1985 - 2007) and AMED (1985 - 2007). Searches were limited to English language and human subjects. The electronic search strategy gave rise to approximately 1000 possible references from the databases considered. To narrow down the search a number of exclusions were then applied utilising Boolean logic. Rheumatological disorders other than RA (e.g. osteoarthritis, gout, systemic sclerosis, systemic lupus erythematosus and so on) were excluded, as were distinct complications of RA (e.g. Sjogrens Syndrome). Further exclusions were based around sources referring to the management of RA that specifically ruled out the feet (e.g. hand surgery), as well as those references detailing imaging techniques that excluded the feet. The contents of the remaining 167 results are detailed in table 1.2 overleaf.

Literature obtained from searching electronic databases was then appraised according to the guidelines proposed by Greenhalgh (2001), as these relate to a variety of research-based evidence rather than to a single specific methodology. The findings of the literature search are discussed in chapters two, three and four.

Table 1.2 Results of the search of electronic databases

Category	Database		
	Pubmed	Cinhal	AMED
Plantar pressure	6	0	1
Radiology and imaging of the foot	28	3	1
Footwear and orthoses	6	3	2
Epidemiology	5	0	0
Single case reviews	13	2	3
Podiatric care	0	3	0
Foot and gait mechanics	20	2	2
Management of the foot in RA	6	0	0
Clinical features of the foot in RA	14	0	0
Outcome measures	5	1	1
Foot surgery in RA	0	6	6
Exercise in RA	4	0	1
Clinical features of RA	10	0	4
Diagnostic issues	3	5	0
Psychosocial issues	1	0	0
TOTAL	121	25	21

1.4.3 Contributions to the literature review from other sources

Autobiographical texts

Autobiographical accounts are seen to provide an increasingly important contribution to knowledge regarding the subjective experience of illness (Sakalys 2003). Hand searching the grey literature revealed two autobiographical texts where authors provide a reflective description of the lived experience of RA (Edgell 1992, Peterson 2001). Interestingly, both texts take an almost auto-ethnographic perspective, the subsequent discourse allowing further insights into the nature of the disease and how it affects daily living. Ellis and Bockner (2000) define auto-ethnography as “an autobiographical genre of writing that displays multiple layers of consciousness focussing outward on their social and cultural experience and inward exposing a vulnerable self.”

The items of particular importance from Edgell (1992) and Peterson (2001) included:

- The signs and symptoms of RA and its effects on quality of life.
- The restriction in function caused by RA.
- Effects of having RA on family life.
- The impact of RA on the body image of a young person.
- The effect RA had on an individual's self-esteem.

- The fear and uncertainty associated with RA.

The powerful discourse found in these autobiographical texts highlighted the importance of comparing views from patients with views from health professionals in order to gain a balance with regard to what is significant to each group, particularly as some issues such as fear and uncertainty are rarely discussed in the medically dominated literature.

Expert patients

The importance of contributions from expert patients and the need for their collaboration in the planning and delivery of care has been identified by a number of official policy publications (Dept of Health 1999, 2000, 2001). This highlights a shift in emphasis, whereby people with chronic diseases are no longer seen as mere recipients of treatment. Expert patients are well placed to discuss aspects of the disease important to sufferers, thereby breaking down barriers between professionals and patients, as well as providing health professionals with the opportunity to reflect on their own practice in relation to patients' needs and preferences (von Korff et al. 2002). The use of expert patients has been further enhanced by their role within the wider rheumatology community. Examples of people with RA discussing their experience of the condition can be found at the Database of Individual Patient Experiences (www.dipex.org) and through involvement with self-help groups, such as Arthritis Care (www.arthritiscare.org).

Narratives from expert patients often reported similar complaints in particular the physical features of RA that give rise to difficulties with aspects of daily function were highlighted (Peterson 2001a, Donovan 2004, Bosworth 2004). For example, Peterson (2001a) recounted how she was unable to play tennis (a sport at which she excelled to National level) due to the extreme fatigue and joint pain she experienced, and how this made her feel "ashamed" to have RA. Donovan (2004) expressed frustration that pain in the feet and lower limbs made it impossible for her to stand for long periods to prepare a meal, thereby preventing her fulfilling some of the household roles she would wish to undertake. Bosworth (2004) indicated in a moving presentation how her disease made her almost totally dependent on her husband in order to maintain mobility. She explained that without her husband she would be unable to go out and would be unable to live alone. This would force her to move into sheltered accommodation – a thought she dared not contemplate. These contributions highlight some of the issues of central importance to people with RA, in particular:

- The psychological impact of RA.
- The effects of physical disability.
- The restrictions on social interaction.

Illness narratives

Most of the previous research that has considered foot complaints in RA has been undertaken from the perspective of the clinician rather than of those with the disease. Frank (2000) suggests that medically based research can suppress the subjective element of a person's account through the use of objective methodologies. Bleakley (2005) explains that this suppression occurs because the analytical methods used tend to lose the emotional and personal element of the story within abstract categories. This is at odds with a clinical approach whereby the interpretation of a patient's narrative (sometimes combined with test results) forms the basis for diagnostic judgement (Greenhalgh 1999). Thinking about patients' stories also confers a series of advantages; for example, participants may be empowered by the interest a researcher shows in their story and accounts may allow empathy with the experience of illness, thereby complementing understanding of the narrative (Bleakley 2005).

Illness narratives are stories told by patients about their experience of an illness as opposed to the disease process (Sakalys 2003). As such, these narratives provide absorbing accounts of the subjective nature of being ill, allowing others to glance into their lives and share in their experiences (Frank 2000). The researcher has had opportunities over a number of years to engage in conversations with people who have RA about their subjective experience of foot complaints during consultations for foot care. This more holistic consideration of individuals' problems provided opportunities to develop a broader understanding of foot complaints that could not be achieved by other means (Greenhalgh & Hurwitz 1999). Additionally, consideration of what people with RA were saying was used as a comparison with the more formal elements of the literature to reach an integrated judgement regarding the importance of elements of foot complaints that had not previously been the subject of formal investigation.

1.5 Reviews of the literature - patients' and clinicians' perspectives

A key part of reviewing the literature described in section 1.4 was to determine if people with RA and clinicians views and perspectives were fundamentally different. There is some evidence that what people with RA consider to be important about their disease may differ from that which clinicians believe to be important (Kwoh et al. 1992, Berkanovic et al. 1995, Tallon et al. 2000, Hewlett 2003). This evidence can be readily extrapolated to apply to foot complaints seen in RA. It has also been suggested that these discrepancies occur because, understandably, there has been an over-emphasis by clinicians on correlating patients' day-to-day functioning with clinico-pathological information (Carr 1996, Sullivan 2003). Equally, areas of overlap and agreement co-exist, or there may be a mixture of perspectives, whereby there is consensus on some points but disparity about others.

The following three chapters will synthesise findings of the literature review further exploring the aims and objectives outlined in section 1.2. Three chapters are used so that there can be a logical

progression from a review of the nature and characteristics of RA as a whole, to a more detailed discussion on the features of foot complaints, before the broader implications of the impact foot complaints in RA on the individual are considered. Chapter five identifies the methodological approaches to the current study and justifies the use of techniques from both quantitative and qualitative paradigms that serve to complement each other. The results are presented separately in three chapters, closely mirroring the approach taken in the literature review. Further analysis, interpretation and synthesis of the findings from the results chapters are presented in the discussion.

2.0 Chapter 2

The definition, epidemiology, clinical presentation, treatment and evaluation of rheumatoid arthritis

2.1 Definition of rheumatoid arthritis (RA)

The primary clinical characteristic of RA is persistent joint inflammation predominantly affecting peripheral joints, resulting in joint damage and loss of function (Visser 2005). Currently there is no single, universally accepted definition of what constitutes RA, leading some to question whether RA is a single disease entity or a heterogeneous group of disorders (Weyland & Goronzy 1995, Emery & Symmons 1997). There appear to be two main reasons for the lack of an agreed definition. Firstly, the precise aetiology remains unknown and until the cause of RA is known, it remains difficult to define (Gordon & Hastings 2003). Secondly, RA has variable presentations, the effects of which are difficult to predict (Morel & Combe 2005, Soubrier & Dougados 2005). For example, in some patients a mild, non-erosive form of RA with little associated disability develops, whereas others experience a persistent aggressive disease with severe articular damage (Soubrier & Dougados 2005). Although RA is a well-recognised condition, the nature of symptoms people with RA experience can be wide ranging (Dixon & Symmons 2005) and are discussed in section 2.3.

2.2 Epidemiology of RA

The reported epidemiology of RA constantly changes (Symmons 2002); largely due to the lack of a single pathognomonic clinical or laboratory test, making the process of diagnosis difficult, especially in the early stage of the disease (Anderson 2001, Visser 2005). This is of vital methodological importance when undertaking or reviewing epidemiological studies (Isaacs & Moreland 2002), because early estimates of the prevalence of RA did not use diagnostic criteria and therefore may have over-estimated the actual prevalence (Lawrence 1977, Silman 1988). Equally, there are a number of reasons why both the incidence and prevalence may be underestimated. This may occur due to misdiagnosis when the presentation of RA is similar to other rheumatological conditions, those who do not seek medical care, or a failure to diagnose RA at all.

The worldwide prevalence of RA has been reported to vary from 0.2 – 5.3% (Hakim & Clunie 2002), but is approximately 1% of the population in the UK (Harris 1993), with rigorous evidence coming from the Norfolk Arthritis Register (NAOR). In most populations RA has a female: male predominance of approximately 3:1 and in the UK the ratio is suggested to be 3.6 women: 1.4 men (Symmons et al. 1994). Female predominance is thought to be important from an aetiological and pathological perspective (Hope et al. 1989, Harris 1993), aspects which are discussed further in appendix one.

2.3 Initial clinical presentation and diagnosis of RA

While RA can occur at any age, the peak age of onset was generally considered to be in the fourth or fifth decade (Duthie & Bentley 1983, Huskisson 1987). In men, the incidence increases with age from 45 years; whereas in women the incidence increases until age 45, plateaus and falls after age 75. However, more recent studies report the age range associated with the peak onset of RA appears to be rising (Symmons 2002). The pattern of onset of RA is usually one of insidious pain, stiffness and symmetrical swelling of small joints and is more commonly seen in women aged 40 - 50 (Wollheim 1993). While this insidious onset is seen in 50% - 70% of people with RA (Hollingworth 1988), several other presentations have been described (table 2.1).

Table 2.1 - Atypical presentations of RA

(Macfarlane 1990, Akil & Amos 1995, Scott & Steer 2007)

Presentation	Features
Acute (explosive)	15% of patients, particularly the elderly, sudden incapacitation.
Palindromic	Affects 10% of patients, recurrent oligoarticular arthritis of varying duration with no residual clinical or radiographic changes.
Monoarthritis	Single joint (often the knee) is solely affected.
Polymyalgic	Shoulder pain and stiffness mimics Polymyalgia Rheumatica, but inflammatory joint swelling develops over time.
Fibromyalgic	Similar pattern to RA but with greater pain, more severe disability and poorer quality of life.
Systemic	More common in men, minimal initial joint involvement with systemic illness.

Typically, RA affects the smaller joints such as those in the hands and feet (Gibson 1986). Characteristic symptoms of early RA include pain and swelling of metacarpal joints and proximal interphalangeal joints of both hands with similar pattern in the feet (Issa & Ruderman 2004). Although RA typically presents as a symmetrical inflammatory polyarthritis, other arthritic conditions may mimic this presentation; e.g. infection related arthropathies, and polyarthritis associated with connective tissue disease (Maini 2003, Williams & Fye 2003, O'Dell 2004). The differential diagnosis of inflammatory arthritis is complex owing to the variability in presentation (Walker 2007). Diagnosis of RA currently remains dependent on clinicians recognising the pattern of the disease and supporting this with evidence from X-rays and blood tests (Moots & Jones 2004), including a newer test for anti-cyclic citrullinated peptide antibody that appears to have greater sensitivity without a loss of specificity than previously available methods (Gao et al. 2005). To aid the differentiation of RA from other forms of arthritis the American Rheumatology Association (ARA) developed diagnostic criteria for RA (table 2.2).

Table 2.2 - The 1987 ARA criteria for the diagnosis of RA

(adapted from Arnett et al. 1988)

Criterion	Comment
Morning stiffness	Duration > 1 hr lasting > 6 weeks
Arthritis of a least 3 areas	Soft tissue swelling or exudation lasting > 6 weeks
Arthritis of hand joints	Wrist, metacarpal or Proximal IPJ lasting > 6 weeks
Symmetrical arthritis	At least one area lasting > 6 weeks
Rheumatoid nodules	As observed by a physician
Serum rheumatoid factor	As assessed by a method positive in < 5% of controls
Positive radiographic changes	e.g. periarticular erosions, joint space narrowing

Unfortunately, the ARA criteria are generally considered too restrictive and insufficiently sensitive to reliably diagnose RA early in its presentation (Maini 2003). To aid the early referral of people suspected of having early RA and institute early disease modifying treatment, Emery and colleagues (2002) have devised a trinity of signs for suspected RA, as summarised in figure 2.1 overleaf.

Figure 2.1 - Early referral recommendations for suspected RA

(Emery et al. 2002)



- | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ol style="list-style-type: none"> 1. MPTJ/MCPJ involvement
(squeeze test) 2. ≥ 3 swollen joints 3. Morning stiffness of ≥30 minutes |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Barbour and colleagues (2003) have since recommended a screening tool for inflammatory arthritis. The recommendations from Emery and colleagues (2002) are probably more straightforward for Allied Health Professionals such as podiatrists working in the primary care setting. However, some of the items (detailed in table 2.3) suggested by Barbour and colleagues (2003) may provide additional information specialist clinicians would wish to know.

Table 2.3 - Screening tool for inflammatory joint disease (IJD)

(Barbour et al. 2003)

Presence or absence of:

Early morning stiffness > 1 hour.

Characteristic joint distribution for IJD.

First-degree relative with IJD.

Clinical evidence of synovitis.

ESR \geq 20 mm/hr (men), \geq 30 mm/hr (women).

Positive rheumatoid factor.

Erosions on hands or feet.

Benefit from NSAID's or Steroids.

2.4 Clinical signs and symptoms of RA

Early joint involvement in RA is characterised by pain together with the other cardinal signs of inflammation, but not initially by damage or deformity of joints (Akil & Amos 1995a). As the disease progresses almost all joints can be affected and this distribution of joint involvement is shown in table 2.4.

Table 2.4 – Proportion of joint involvement reported in long-standing RA

(Woolheim 1993)

Cervical Spine 25-33%
Shoulder 50–70%
Elbow 40-60%
Wrist 70-80%
Metacarpophalangeal 90%
Hip 30-50%
Knee 70-85%
Ankle 30-50%
Metatarsophalangeal 80-90%

As highlighted in table 2.4 and 2.5, hands and wrists are affected in almost all people with RA and symptoms in these joints can reflect the overall disease status and progression (Anderson 2001, Gordon & Hastings 2003). The pain and progressive deformity affecting lower limb joints in particular can have serious deleterious effects on both posture and mobility, as highlighted in table 2.5 overleaf, and these aspects will be discussed further in the next chapter. If the disease remains active, uncontrolled inflammation will gradually cause irreversible tissue damage, causing deformity and instability of an increasing number of joints (Akil & Amos 1995a). It should be remembered that RA is a systemic disease and while articular signs and symptoms are common manifestations, extra-articular features are also prevalent. In terms of constitutional symptoms,

fatigue, malaise and prolonged morning stiffness are often reported, although fever is uncommon (Anderson 2001, Akil & Veerapen 2004). Fatigue is further exacerbated by a normochromic, normocytic anaemia of chronic disease, which is common in people with RA (Turnbull 1995). In particular, extra-articular manifestations tend to further impair function and lead to reduced quality of life with some (notably cardiovascular disease) leading to increased morbidity and mortality (Boers 1998, Scott & Steer 2007).

Table 2.5 Clinical features of RA in the upper and lower limbs

(Adapted from, Dixon 1982, Souter 1983, Windsor & Insall 1989, Hasting 1985, Inglis 1989, Gordon & Hastings 1993, Woolheim 1993, Paice 1995, Akil & Veergen 2004).

Joint	Effects
Cervical Spine	Atlantoaxial subluxation causing spinal cord compression leading to neurological deficit (e.g. paraesthesiae, sensory loss, sudden loss function)
Shoulder	Upward subluxation of the humerus due to glenohumeral joint destruction, leading to difficulty raising arms
Elbow	Flexion deformity consequent loss of pronation and supination, further exacerbating hand/wrist involvement
Wrist	Synovitis, Radiocarpal dislocation, Carpal supination subluxation, Carpal tunnel syndrome
Hand/ Fingers	Synovitis, Boutonniere deformity, Swan-neck deformity, „Flail“ interphalangeal joint, Loss of active flexion/extension triggering tendonitis, tendon rupture, median nerve involvement
Hip	Inhibits gait and overall function
Knee	External rotation, valgus deformity and flexion leading to contraction and/or instability
Ankle	Limited sagittal plane motion impairs gait, valgus deformity leads to further soft tissue complaints
Rearfoot	Valgus deformity accentuates walking difficulty and can lead to soft tissue complaints e.g. peroneal muscle spasm
Forefoot	Synovitis causes tenderness on palpation and severe pain on walking, nodules and bursae can ulcerate, particularly in the presence of vasculitis
Toes	Hammer toes and hallux valgus lead to painful skin lesions and difficulties with shoe fitting.

2.5 The medical management of rheumatoid arthritis

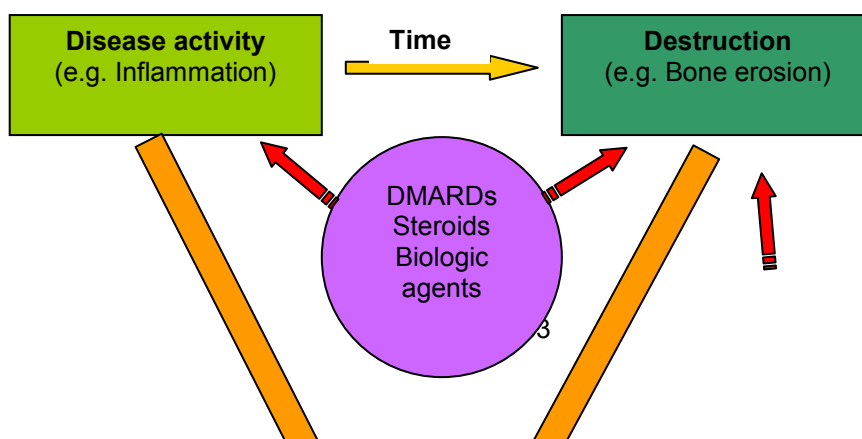
The goals of medical management in RA are to control pain, limit disease progression, preserve function, allow the patient to maintain a normal lifestyle and more recently achieve remission

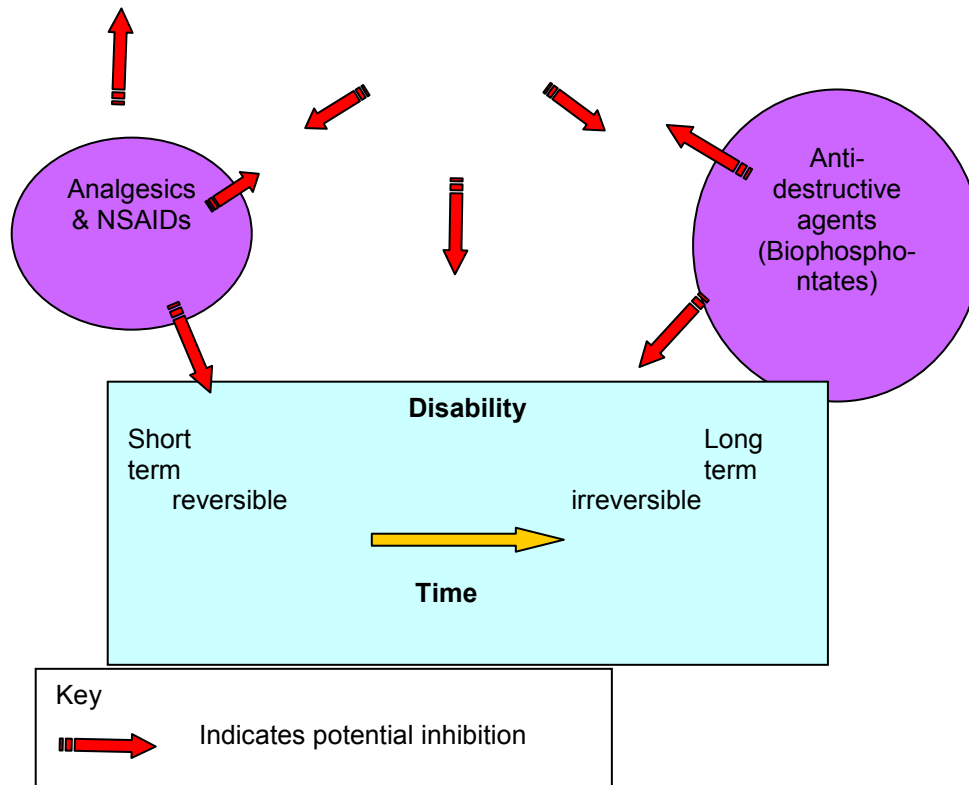
(Griffith & Dacre 1994, Akil & Amos 1995, Scheinecker & Smolen 2005). The approach of controlling inflammation and minimising joint damage has to be balanced against avoiding drug toxicity (Hughes 1997). There has been a paradigm shift in the approach to managing RA away from the traditional therapeutic pyramid and toward an earlier more aggressive approach. Contemporary practice now advocates starting disease modifying anti-rheumatic drug (DMARD) therapy early in the disease process to control inflammatory synovitis and reduce joint damage (van der Heijde 1996). Evidence that early use of combination therapy with DMARD's (+/- corticosteroids) improves physical function and decreases the rate of progression of joint damage has been reported from a range of randomised controlled trials (Boers et al. 1997, van Gestel et al. 1997, Landewe et al. 2002, Grigour et al. 2004, Korpela et al. 2004). A more detailed discussion can be found in appendix two, while figure 2.2 overleaf illustrates the current approach to the medical management of RA and demonstrates the inter-relationship between therapeutic options and pathophysiology.

RA remains a major cause of morbidity and disability and is associated with high health economic costs (McInnes 2005). There is now mounting evidence that early and sustained suppression of disease activity in RA is required to prevent joint damage with associated functional loss and disability (Piptone & Choy 2005, Keen & Emery 2005). Furthermore, an improved understanding of the pathophysiology of RA (as described elsewhere: van den Berg & Bresnihan 1999; Williams et al. 2000; Arend 2001) has resulted in the development of new more effective biologic therapeutic agents. In particular, the recognition that the pro-inflammatory cytokine, tumour necrosis factor alpha ($TNF\alpha$) mediates many of the pathogenic features of RA has enabled researchers to develop agents to specifically target this molecule, thus blocking a key part of the inflammatory disease process (Maini 2001). Placebo controlled trials demonstrate that in adults treated with $TNF\alpha$ blockers, responses are substantial, rapid and sustained (Maini et al. 1999, Weinblatt et al. 1999). Several clinical trials have demonstrated the efficacy of $TNF\alpha$ blockers in dramatically reducing the severity of both clinical, radiological and laboratory markers of RA (Lipsky et al. 2000, Bathon et al. 2002, Breedveld et al. 2004, Klareskog et al. 2004). However, the expense of these new drugs has led the National Institute for Clinical Excellence (NICE) to recommend these agents should be considered as options for the treatment of adults who have progressive, clinically active RA that has not responded to at least two DMARD's, including methotrexate (NICE 2000).

Figure 2.2 - The contemporary approach to the management of RA

(Smolen et al. 2007)





2.6 Outcome measurement in rheumatology

The topic of outcome measurement has achieved an increasingly high profile among clinicians, researchers and policy makers (Long 1996, Bowling 1997). In particular, the introduction of the internal market and commissioning process within the National Health Service (NHS) by the Conservative government in 1992 (Dept of Health 1992), together with the emphasis on health gain as part of the overall health strategy has forced clinicians, service commissioners and managers to evaluate outcomes following health care interventions more than ever before (Long & Silman 1995, Long 1996, Greenhalgh et al. 1998, Adams 2002). Similar requirements to evaluate the effectiveness of health interventions have also occurred in other countries in the developed World, notably the USA (Saltzman et al. 1997, Wrobel 2000) and Australia (Nancarrow 2001), even though these nations have very different models of healthcare provision.

In parallel with these health policy changes there has been a paradigm shift in the nature of outcome measures employed in healthcare in recent years (Liang & Katz 1992). Dixon (1996) reports, "at policy level, there is now a strong commitment for outcomes measurement to reflect patient concerns, to give patients an opportunity to report their experiences in their own terms, and to accumulate accessible and intelligible information on possibilities for patient involvement in decisions on treatment options." Within healthcare in the UK, there is a continuing move to a more patient-centred approach (Dept of Health 2001, 2004, 2005a, 2005b.). This policy was most recently illustrated by the importance accorded to the priorities of patients as part of the terms of

reference for the Darzi review (Dept of Health 2007b). In rheumatology there is now an increased emphasis on ensuring that quality of life is maximised for people with RA. In particular, the interactions of personal, social and environmental factors for people with the disease are now being given greater consideration (Wolfe & Pincus 1999, Barnes & Ward 2000, Goodacre et al. 2007). This has led to a greater focus on the wider aspects of health: it is now recognised that a persons' experience of the disease may be of equal importance to disease activity traditionally measured by objective outcome measures (Long 1996, Hammond 2004).

This commitment to a broader view of outcomes is not a new concept. The World Health Organisation (WHO) in its constitution defined health as "a state of complete physical, mental and social well-being... not merely the absence of disease or infirmity" (WHO 1947). This view represented a considerable shift away from the notion of health being considered as the non-existence of an identifiable disease, yet maintained the use of language more familiar to medical practitioners (Lucas & Lloyd 2005). The WHO definition has also been criticised for lacking conceptual or operational definitions, creating concern about the somewhat utopian nature of the WHO concept (Bowling 2005). Some authors have considered a broader view, highlighting the importance of social health as distinct from physical and mental health (Parsons 1972, Donald et al. 1978). However, these definitions have also been criticised for a lack of specificity in their criteria (Mechanic 1999). In recent decades lay and professional definitions of health have been profoundly influenced by the dominant socio-cultural paradigm. Bowling (2005) and Nettleton (2006) highlight that in Western industrialised societies the social requirement to be functionally able is a powerful determinant of how people perceive whether they are healthy. Definitions of health are further complicated by the ontological position of their architect. Lucas and Lloyd (2005) point out that most definitions of health are proposed by the academic community, and as such may not fully take account of the concerns and priorities of the wider population. Blaxter (1990) considered these issues and in a review of a series of studies considering laypersons' definitions of health (Herzlich 1973, Pill & Stott 1982, Blaxter & Paterson 1982, Williams 1983, Blaxter 1985), concluding „health" consisted of:

- An absence of disease.
- A reserve of health determined by an individuals „constitution".
- A positive state of well-being.

However, many of the studies included in Blaxter's review were carried out within a particular social class and clear differences occur between different social classes (Blaxter 1990, 1997, Bowling 2005). Nettleton (2006) argues that these differences may occur because the dominant paradigm of the biomedical model fails to fully account for social inequalities in health, owing to the changing size of social classes, difficulties analysing stratified data and the use of social class as an indicator of material resources. In the biomedical model disease is the dominant focus and the experience

of being ill is rarely considered. In contrast the biopsychosocial model challenges this view, by attempting to integrate psychological, environmental and biomedical contributing factors (Ogden 2004). To some extent this integration is seen in the work of Blaxter (1990) who in an exploration of lay people's beliefs about health and lifestyle identified eight categories to describe what it means to be healthy:

- | | |
|-----------------------------------------|------------------------------------|
| Health as not being ill. | Health as a reserve. |
| Health as behaviour – the healthy life. | Health as physical fitness. |
| Health as energy, vitality. | Health as social relationships. |
| Health as function. | Health as psychosocial well-being. |

Using the categories above suggested by Blaxter as determinants of health, highlights the need for a wide range of concepts to be considered when attempting to measure outcome.

Historically, outcomes in medicine have been based on specific events e.g. death, myocardial infarction, stroke and so on (Ebrahim 1990). However such end points, whilst relatively easy to measure, are not useful for either the patient or the clinician, as often they occur too late in the disease process to be of use in terms of helping to target therapy. Traditionally used measures of inflammation in RA (for example C-reactive protein) are predominantly associated with the disease process and consequently do not consider other aspects that are thought to be important to people with RA such as disability or the impact of the disease on quality of life (Clancey & Eisenberg 1998, Soon & Chen 2004). The cost of new developments in the pharmacological management of rheumatic diseases has led to an increased imperative for changes in measures of outcomes of therapeutic intervention. For example, the recent introduction of new, more effective anti-rheumatic agents (e.g. anti-cytokine agents (Maini et al. 2004)) has forced both researchers and clinicians to ensure their outcome measures are sufficiently sensitive and appropriate (van Reil & van Gestel 2000, Pipitone & Choy 2003).

Currently, it is not generally thought possible to measure the outcomes of disease activity in RA or its management with a single variable, nor is there a single „gold standard“ measure (van Gestel & van Riel 1997, Aletaha et al. 2006). RA can have a variable course and changes in patients' symptoms or functional capacity are along a continuum rather than absolute positions, requiring clinicians to consider a broad range of measures or indicators (Mirin and Namerow 1991, Albers et al. 2001, Smolen et al. 2007). However, the use of a range of outcome measures is not only time-consuming for both clinicians and patients, but also adds to administrative costs. These can form considerable barriers to their use in routine clinical practice (Prevoo et al. 1993, Ward 2005). Such issues have led researchers to develop indices that utilise parts of a number of different outcome measures as outlined in table 2.6 overleaf. The indices noted in table 2.6 are useful in that they are well validated and appear to have good discriminatory properties (at least for the items being measured), and are widely used in clinical practice. Indeed Leeb and colleagues (2005) have

suggested that monitoring disease activity in RA using these composite indices is now regarded as obligatory when following current recommendations for therapy. Nevertheless these indices are complex and the various professionals involved in the care of people with RA, not least the patient themselves, may not always understand the results.

Table 2.6 Composite indices used to measure outcome in RA

(Felson et al. 1993, Smolen et al. 2003, Aletaha et al. 2005, Smolen et al. 2007)

Measure	Variables Assessed	Formula	Interpretation of results
ACR response criteria	Tender & swollen joint count, ESR or CRP, PGA, EGA, PtP, PtF	Percentage improvement from baseline of SJC and TJC and the best three of the remaining five measures	ACR 20, 50, 70 or 90 indicates 20%, 50%, 70% or 90% improvement from baseline
Disease activity score 28	Tender & swollen joint count, ESR, PGA	$0.55\sqrt{(28 \text{ TJC})} + 0.28\sqrt{(28 \text{ SJC})} + 0.70\ln(\text{ESR}) + 0.014(\text{PGA [in mm]})$	Good response ≥ 1.2 improvement from baseline, moderate response $0.6 \leq$ improvement from baseline
Simplified Disease Activity Index	Tender & swollen joint count, CRP, PGA, EGA	$28 \text{ TJC} + 28 \text{ SJC} + \text{PGA} + \text{EGA} + \text{CRP}$	Major response ≥ 17 improvement, moderate response $7 < 17$ improvement
Clinical Activity Score	Tender & swollen joint count, PGA, EGA	$\text{SJC} + \text{TJC} + \text{PGA (in cm)} + \text{EGA (in cm)}$	Major response ≥ 14 improvement, moderate response $6.5 < 14$ improvement

CRP – C reactive protein
 ESR – Erythrocyte Sedimentation Rate
 PtP – Patients’ pain assessment
 SJC – Swollen joint count
 EGA – Examiners’ global assessment
 PGA – Patients’ global assessment
 PtF – Patients’ functional assessment
 TJC – Tender joint count

Perhaps more importantly, the composite indices developed for use in RA and to a lesser extent radiological measures, may have little direct relevance to patients as important aspects associated with chronic disease (e.g. the burden of suffering, the extent of disability and so on). These latter aspects are not major components in the most commonly used outcome measures for example, the Disease Activity Score 28 (DAS 28) or American College of Rheumatology (ACR) criteria (Soon and Chen 2004, Boers 2005). Furthermore, Wolfe and colleagues (2005) have reported that there is too much inherent variability in RA for these scores to be used as the sole indicator of disease activity. More recently, Greenwood and colleagues (2007) reported the response to biological

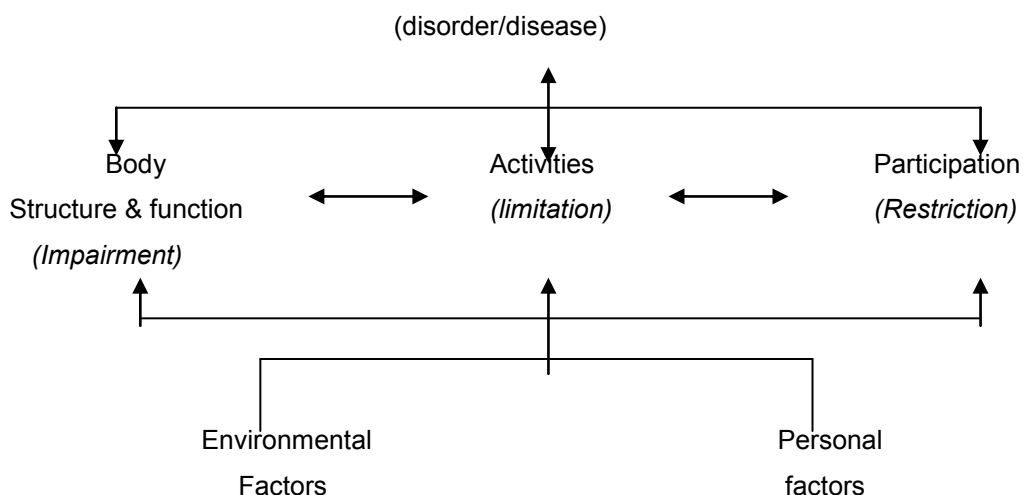
agents seen in DAS scores might represent a regression to an arithmetic mean, highlighting the need for more patient-centred measures. No general agreement remains about which instrument should be used in routine clinical practice to assess health status (Ahlmén et al. 2005). The development and utilisation of outcome measures such as the DAS 28 that are predominantly predicated on the findings of clinicians and laboratory tests moves further away from the more patient-centred view of health promoted as the future of health care at the beginning of this section.

In addition to composite indices, some of the most widely used outcome measures in rheumatology are plain film radiographs of the joints most frequently affected by RA, particularly the hands and feet. Various methods for assessing and scoring joints with X-rays have been developed over the past 50 years and the merits of these different approaches have been widely discussed in the literature (Sharp 2000, Boini & Guillemin 2001, van der Heijde 2004). The use of radiological assessment as a method of measuring disease progression in RA has sometimes been referred to as a „gold standard“ (van der Heijde et al. 1995, van der Heijde 2000). In addition to the difficulties associated with repeated exposure to ionising radiation, there remain continuing difficulties when using radiological measures with respect to reliability, sensitivity and validity, particularly when trying to compare trials using different protocols to measure radiological progression (van der Heijde et al. 1995, Emery et al. 2002).

In 2001 the WHO published a revised model of functioning, disability and health (the International Classification of Functioning (ICF)); where the various concepts of environmental, personal and disease activity issues associated with chronic disease are seen to be inter-related (figure 2.3 overleaf). The overall aim of the ICF was to provide a standard language for the description of health and health-related conditions in a common framework (World Health Organisation (WHO) 2001, Stamm et al. 2005). This model, while applicable to all chronic diseases, is especially pertinent in this context because RA highlights the interaction of the various components of the model particularly well. In relation to RA, Stucki and Cieza (2004) note that, “functioning is now seen in relation to health condition, as well as to personal and environmental factors”. Nevertheless, widely used outcome measures (e.g. the DAS 28) are seen to consider only a small proportion of the model's components (namely structure and function). Other measures such as the Health Assessment Questionnaire (HAQ) developed by Fries and colleagues (1982) include a broader range of concepts widely used in order to measure the course of RA, including function, activities of daily living and to a lesser extent participation in social activities. Some of these measures, particularly the HAQ, have been seen as a gold standard (Symmons 1995).

Figure 2.3 - Interaction of concepts of health (WHO 2001)

Health condition



Each of the components identified in the WHO model above consists of several chapters and within each chapter are categories, which are the units of classification.

However, a growing number of studies have reported differences of opinion between patients and clinicians when measuring signs, symptoms and treatment outcomes (Kosinski et al. 2000, Kwoh & Ibrahim 2001, Hewlett 2003). Indeed, in 1996 Carr reported that most of the measures of health status used in rheumatology are based on professional assumptions about what is an „acceptable level of function“ or what constitutes „quality of life“. More recently, Stamm and colleagues (2005) reported that factors particularly important to those with RA (such as fatigue) are not fully included in the ICF core set for RA. Such findings have led to an increased focus on what people with chronic disease feel are the important aspects to consider when measuring health outcomes and these issues are discussed further in chapter four.

2.7 The prognosis for people with rheumatoid arthritis

Klippel and colleagues (1993) reported that the prognosis for those with RA could follow one of three patterns:

- Polycyclic pattern – seen in 70% of patients with intermittent or cyclical patterns.
- Monocyclic pattern – a single cycle with remission for at least one year, seen in 20% of patients.
- Progressive pattern – aggressive erosive disease with increasing joint involvement, seen in 10% of patients.

Scott and Steer (2007) report an overall remission rate of between 10% - 36%, depending on the criteria used and the time frame over which remission is recorded. Some clinical features such as nodules, early erosions and positive rheumatoid factor are indicators of an unfavourable prognosis (Klippel et al. 1993, Young 1995). Other authors have suggested that early foot involvement may

also be a marker of more severe disease with a poorer prognosis (Fleming et al. 1976, Priolo et al. 1997). These issues are important as the identification of the patients who are likely to have poor outcome could help target therapy more effectively. For example, enabling closer communication between rheumatologists, employers and occupational health advisors would be in the patients' best interest as identifying those people with RA who are finding their role at work difficult to manage could be provided with support aimed at preventing work disability (Young et al. 2002).

2.8 Summary

RA is a highly variable disorder (or possibly group of disorders) that remains difficult to classify and characterise. In part this is because while the pathogenesis of the condition has been more clearly elucidated recently, the underlying aetiology remains something of an enigma. Furthermore, the management of RA has undergone radical change in recent years, yet the response of patients to therapy can be variable and remains difficult to measure holistically. The increasing expenditure on therapeutic agents has heightened the need for comprehensible measures of outcome. However, current measures are often predicated on the clinical importance of the status of the disease and are not always patient-centred. This chapter has highlighted the propensity for RA to affect peripheral (as opposed to axial) joints and the impact this disease has on the foot and lower limb are explored further in the next chapter.

3.0 Chapter 3

The Foot in Rheumatoid Arthritis

3.1 Introduction

Articular, periarticular and extra-articular manifestations of RA are frequently encountered in the feet (Dixon 1981, Woodburn & Helliwell 1995, Trieb 2005). Foot pathologies have been shown to markedly contribute to the morbidity associated with RA (Dixon 1981, Robinson et al. 2004, Matricali et al. 2006), owing to the wide range of articular and extra-articular complaints (discussed further in section 3.3). In addition, foot complaints commonly seen in RA can have a profound negative psychological impact (Gripton 2001, Wickman et al. 2004), which will be discussed further in section 3.6. Yet, in spite of the extent of foot complaints in RA, access to foot care services for people with RA remains highly variable and in some cases absent (Williams & Bowden 2004, Redmond et al. 2006).

3.2 Epidemiology of foot pathologies in RA

According to some studies the foot is affected first before other commonly involved joints such as those in the hand or wrist (table 3.1). However, other reports (Farrow 2004), together with recent imaging studies (Calisir et al. 2007), suggest these may be under-estimates and the occurrence of foot involvement at diagnosis remains an area for investigation.

Table 3.1 - Presentation of foot pain as the first reported symptom of RA

Author	Methods	Number of subjects	Source of subject recruitment	Incidence of foot pain as first reported symptom of RA
Vainio 1956	Clinical examination	955	In-patients	16%
Flemming et al. 1976	Clinical examination	102	Research clinic	13%
Kerry et al. 1994	Clinical examination	100	Not stated	32%

Where longitudinal studies have included the feet, it is estimated that some 21% of people with RA exhibit symptoms in the foot in the first year, rising to over 50% by three years, (Jacoby et al. 1973, Woodsworth 1983). In the latter stages of the disease (some 10-15 years post diagnosis) the majority of patients are reported to have some form of observable foot pathology – whether articular or extra-articular, (Vainio 1956, Jacoby et al. 1973, Vidigal 1978, Wollheim 1993).

The signs and symptoms that result from foot involvement are pain, joint stiffness and deformity (Speigal & Speigal 1982, Keenan et al. 1991, Costa et al. 2004). However, there remain relatively few large-scale epidemiological studies addressing the prevalence of foot pathologies in RA

(Farrow et al. 2004, Helliwell et al. 2007). In the largest study undertaken (n = 955), foot involvement was reported in up to 90% of people with RA (Vainio 1956 - described in table 3.2 overleaf). Vainio's study has become one of the seminal works on the epidemiology of foot problems in RA. However, Vainio's work was undertaken in the era before disease management with modern immunosuppressive agents. A number of later studies have also reported epidemiological aspects of foot complaints in RA (table 3.2), but these data are based predominantly on observations by clinicians, often in single centres. These studies have provided little information detailing sample size, or demographic and disease characteristics of the populations studied, thus making direct comparisons difficult. As the findings reported in table 3.2 are largely predicated on the opinion of the examining clinician, it also remains unclear whether the perceptions of those with RA are accurately reflected. In contrast to the prevalence of foot deformities presented in table 3.2, patients in the early stages of RA do not usually have severe foot deformities, rather they tend to complain of pain and swelling due to synovitis with little deformity (Kitaoka 1989). This may explain why some authors believe that more people with RA may present with initial symptoms in their feet than is currently reported in the literature.

Table 3.2 - Summary of epidemiological studies into the prevalence of foot involvement in RA

Author & year	Methods	Number subjects	Recruitment centre	Main findings	
Viano 1956	Clinical examination	955	In patients	Overall foot problems 89% Sub-talar joint affected 66.9% Hallux Valgus 58.8% Flat feet 46.5%	Hallux rigidus 10.4% Heel pain 9% Ankle joint affected 8.8% Tenosynovitis 6.5%
Flemming et al. 1976b	Clinical examination	102	Research clinic	MTPJ involvement 48% Sub-talar joint involvement 25% Mid-tarsal joint involvement 13%	13% reported the foot to be the first site of symptoms
Jacobi et al. 1976	Clinical examination	200	Out patient clinic	Hallux Rigidus 78% Hallux valgus 58%	Hallux tortus 29%
Videgal 1978	Clinical examination	104	In patients	MTPJ subluxation 76% Hallux valgus 70%	Hammer toes 30% "Pressure lesions" 30%
Kerry et al. 1994	Clinical examination	100	Not stated	Hallux valgus 65% Hindfoot pain 61% MTPJ subluxation 60%	Forefoot pain 59 % Claw toes 55% Midfoot pain 10%
Michelson et al. 1994	Clinical Examination Patient self report	99	Out patient clinic	Forefoot symptoms 71% Ankle symptoms 56% Hallux valgus 33% Heel symptoms 29%	Midfoot symptoms 27% Rigid hammer toe 26% Flexible hammer toe 17%
Farrow et al. 2004	Clinical Examination HAQ & DAS	244	Out patient clinic	Tender foot joints in 51% Those with tender foot joints; HAQ 1.59 & DAS 5.21 (73% had swollen hand joints)	Swollen foot joints in 45% Those with swollen foot joints; HAQ 1.63 & DAS 5.38 (66% had tender hand joints)

Table 3.2 cont. - Summary of epidemiological studies into the prevalence of foot involvement in RA

Author & year	Methods	Number subjects	Recruitment centre	Main findings	
Bal et al. 2006	Clinical exam X-ray HAQ & FFI	78	Not stated	X-ray findings; Pes Planus 80.7% Splaying foot 67.9% Hallux Valgus 64.1% Metatarsus primus varus 56.4% HAQ score – not stated FFI score – not stated	Clinical examination findings; Mallet finger [toe] 50% Claw toe 34.6% Calcaneal valgus 34.6% Hallux rigidus 29.4% Cock-up toe 21.7%
Matricali et al. 2006	Clinical exam, AOFAS Questionnaire & HAQ	285	Out patient clinic	Forefoot pain 81% History of foot ulceration 13% Current foot ulcer 5%	Previous forefoot surgery 48% Previous hindfoot surgery 12% Mean HAQ 1.17 (SD ± 0.79) Mean AOFAS 70.1 (SD ± 18.4)
Lohkamp et al. 2006	MFPDQ Questionnaire	185	Out patient clinic	74.1% foot pain in the last month MTPJ pain 51.6% Ankle pain 32% Toe pain 28% Midfoot pain 12%	MFPDQ results; 53.1% moderate disability 29.4% severe disability - <u>due to foot pain</u>
Firth et al. 2008	Questionnaire & clinical examination	883	Community sample	Foot ulceration; 3% point prevalence 10% overall prevalence	

KEY:

AOFAS – American Orthopaedic Foot & Ankle Society

MFPDQ – Manchester Foot Pain Disability Questionnaire

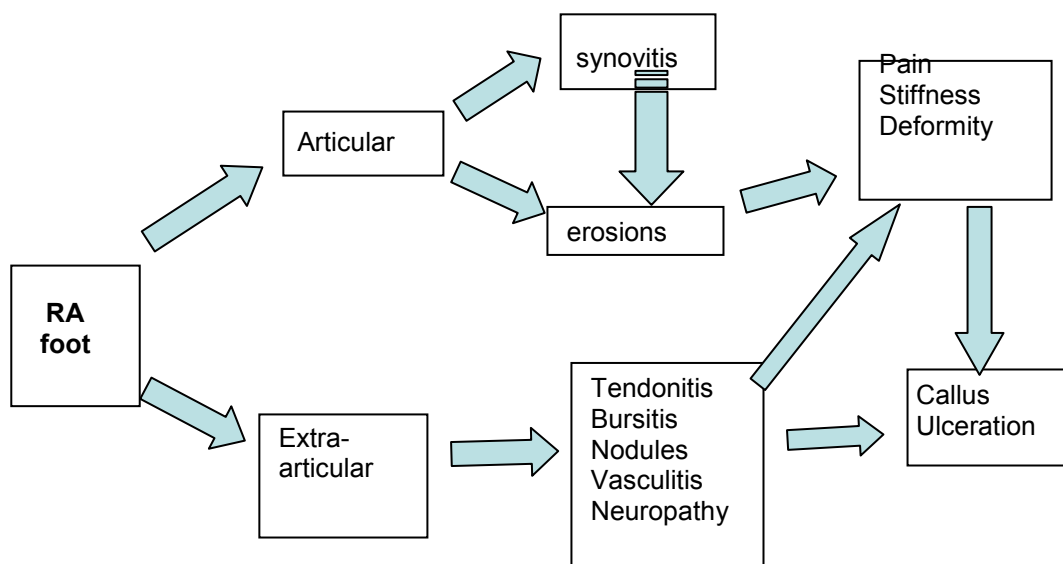
FFI – Foot Function Index

Table 3.23.3 Clinical features of the foot in RA

The typical signs, symptoms and clinical features commonly observed in the foot affected by RA are wide ranging and are outlined in figure 3.1 below.

Figure 3.1 – Impairment in the rheumatoid foot

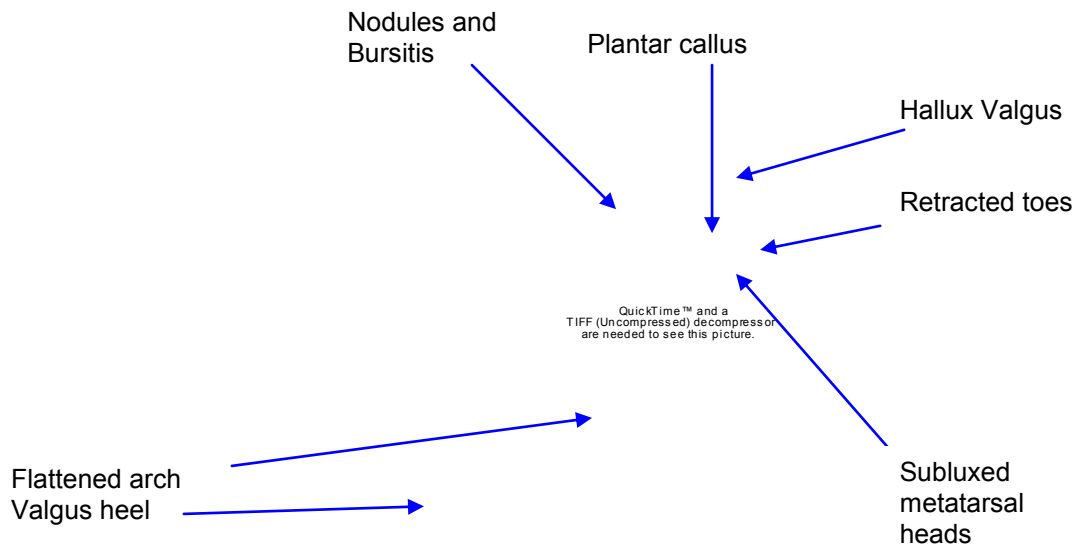
(Woodburn 2005)



When people with RA are seen in the clinical setting, commonly observed foot problems include: valgus deformity of the hindfoot; flattened medial longitudinal arch; subluxed and prominent metatarsal heads; hallux valgus and lesser toe deformities such as clawed or retracted toes (Dixon 1982, Cosh & Yoman 1982, Cracchiolo 1993), as illustrated in figure 3.2 overleaf. To some degree, the extent of foot complaints will depend on the nature of the presentation of RA discussed in section 2.3. For example, people with monoarticular RA predominantly in the knee may have fewer foot complaints than those with a more typical presentation. Worsening foot deformities are thought to result from the interaction of active synovitis and mechanical stress (Miller & Nash 1994, Cimino & O'Malley 1998). Consequently, the progression of foot deformities has been reported to be closely related to disease severity (Shi et al. 2000). Additionally, Mann and Horton (1996) have suggested that the frequency and degree of foot and ankle problems are proportional to the disease duration. Therefore as RA progresses over time, authors have noted more marked hindfoot involvement, with excessive pronation occurring at the sub-talar joint causing valgus deformity of the calcaneum and flattening of the medial longitudinal arch. For example, in a series of 55 subjects with RA, Spiegel and Spiegel (1982) noted only 5% of subjects with RA of less than five years duration had marked hindfoot deformity, but this increased to 25% after five years. Mitchelson and colleagues (1994) in a series of 50 people with RA found that 55% of people who had the disease for less than 10 years reported significant foot and ankle problems, but this increased to 76% for patients with disease duration beyond 20 years. In the forefoot, the hallux

continues to deform into a valgus position with hammertoe deformity of some lesser toes becoming increasingly evident, causing dorsal digital hyperkeratotic lesions. In addition, subluxation of some of the metatarsophalangeal joints leads to prominent metatarsal heads, which together with fat pad atrophy leading to the formation of adventitious bursae and plantar hyperkeratotic lesions (Saltzman & Vogelgesang 1997) as depicted in figure 3.2. It is these deformities that lead to emotive descriptions from those with RA such as, “like walking barefoot across a beach, shells & sharp pebbles digging in every step” (Peterson 2001). To provide the reader with a clearer understanding of the underlying pathomechanics, the forefoot and hindfoot are considered separately in appendix three.

Figure 3.2 - Typical clinical features associated with the foot in RA



As noted previously in chapter two, RA is a multi-system disease, which is frequently complicated by extra-articular features. Those extra-articular features that may occur in the feet are reviewed further in appendix three. The extra-articular pathologies commonly observed in the foot in RA may have a profound effect on function and therefore may adversely affect patient's quality of life (Young & Koduri 2007).

3.4 Radiological features of the foot in RA

In addition to the commonly occurring clinical features identified in the feet, radiographic changes are often seen in the feet of people with RA in a similar pattern to the hands as detailed in table 3.3 below and illustrated in figure 3.3 overleaf.

Table 3.3 - Typical patterns of X-ray findings in the foot

(Vainio 1956, van der Heijde et al. 1992)

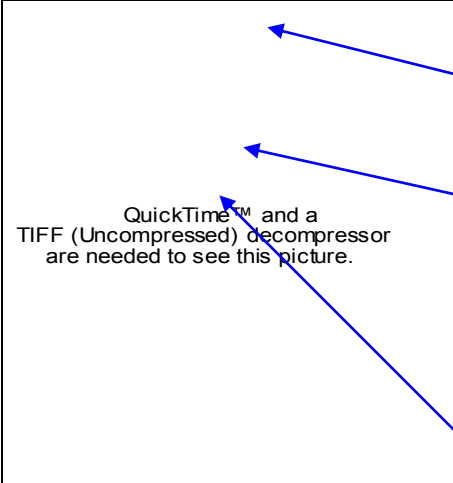
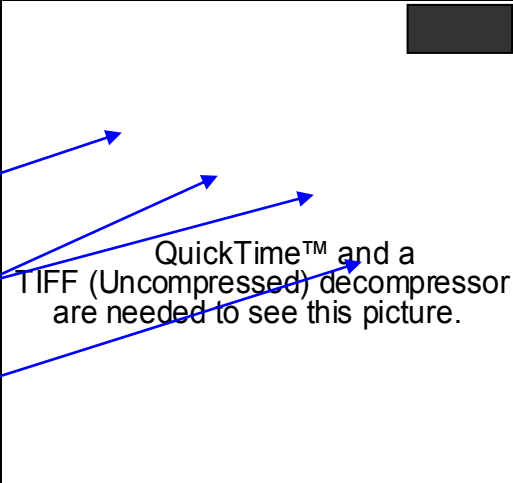
Forefoot	MTPJ erosions occur within 1-3 yrs of diagnosis & are commonest site of involvement in the foot: Almost all patients will have MTPJ erosions
Midfoot	Talonavicular joint space narrowing most common 3-6 yrs, erosions relatively uncommon: after 10 yrs complete joint space loss is common Calcaneocuboid joint demonstrates similar involvement, but with less severity Cuneonavicular joint commonly subluxes within 3-6 yrs of disease duration
Rearfoot	Sub-talar joint commonly involved, less frequently than talonavicular joint, joint space narrowing more common than erosions
Ankle	Least commonly affected joint in the foot, erosions uncommon, loss of joint space only occurs late in disease

Key: MTPJ = metatarsophalangeal joint

Radiographic evidence has demonstrated involvement of the foot early in the course of RA and studies have repeatedly reported erosions in the feet are more numerous, and appear in an earlier phase of the disease, than in the hands (Brook & Corbett 1977, Mottonen 1988, Eberhardt et al. 1990, van der Heijde et al. 1992, Hulsmans et al. 2000). In particular, the fourth and fifth metatarsophalangeal joints are often the earliest joints to be affected (Crim et al. 1996, Bancroft & McCleod 2000). Similarly, Magnetic Resonance Image (MRI) scans of the forefoot have detected changes associated with RA such as synovitis and bone oedema in people with early RA with normal MRI of the finger joints (Ostendorf et al. 2004). Nevertheless, as with the diagnostic criteria reported in section 2.3, most radiographic studies have been undertaken using the hand and wrist. Radiographic evidence has also shown an association between valgus deformity of the feet and valgus deformity of the knee in patients with RA, further highlighting the impact of foot complaints on mobility (Keenan et al. 1991, Mann & Horton 1996).

Figure 3.3 – Typical radiological features of the foot seen in RA

(Images courtesy of the Arthritis Research Campaign available at: www.arc.org)

Hand	Features	Foot
 <p>QuickTime™ and a TIFF (Uncompressed) decompressor are needed to see this picture.</p>	Joint space narrowing	 <p>QuickTime™ and a TIFF (Uncompressed) decompressor are needed to see this picture.</p>
	Osteoporosis	
	Joint subluxation	
	Periarticular erosions	

3.5 The gait cycle in Rheumatoid Arthritis

The gait pattern of people with RA is characterised by decreased cadence, shorter single limb support, a prolonged double limb support and a delayed heel rise (Diamonte & Light 1982). Additionally, factors such as pain, muscle weakness and abnormal joint mechanics may adversely affect gait (Saltzman & Johnson 1993), compared to the normal gait cycle as described by Rose and Gamble (2002) and Whittle (2002). Given the deformities commonly seen in the rheumatoid foot a number of plantar pressure studies have noted the spatial changes in foot pressure, for example an increase in the magnitude of plantar pressures and changes in the anatomical location of such pressures (Collis & Jayson 1972, Minns & Craxford 1984, Woodburn & Helliwell 1996). More recently, van der Leeden and colleagues (2007) reported that joint damage in the forefoot is related to increased forefoot plantar pressures. In addition to the spatial aspects of plantar pressure, changes in the temporal characteristics of forefoot plantar pressures (i.e. increases in the duration of pressure) have also been shown to be characteristic of established RA (Otter et al. 2004, Semple et al. 2007). Therefore, while it is possible plantar pressures are higher over the forefoot in RA, it is equally possible that forefoot plantar pressures (even if normal) may be present for longer and therefore have the potential to cause tissue damage. Overall, foot complaints have been shown to contribute to difficulty with walking in approximately 75% of people with RA and are the main or only cause of walking difficulty in 25% (Keenan et al. 1991).

Changes to the gait cycle could be due to intrinsic pathology of the foot or the impact of pathology more proximally. In terms of intrinsic pathology, as noted in appendix three, a number of authors have reported sub-talar joint pronation to be common in patients with RA (Vainio 1956, Gerber &

Hunt 1985, Smidt 1987). Mann (1991) postulated that if the foot is pronated during weight bearing, this might result in the talonavicular and calcaneo-cuboid joints adopting a more parallel position to the supporting surface than normal. This mechanism is thought to unlock the midtarsal joint, preventing resupination. This process, together with reported weakness in the triceps surae, is said to prevent heel rise and reduce the pressure over sensitive metatarsal heads owing to a delay in transition of foot loading from rearfoot through to forefoot and toe-off (Gerber & Hunt 1985, Keenan et al. 1991). Foot posture may also become altered secondary to hip, knee and ankle disease and may lead to the out-toed gait commonly observed in patients with RA (Marshall et al. 1980). This external rotation has been shown to reduce pressure on the forefoot as the lever effect on the foot is shortened (Keenan et al. 1991). Equally, the eversion and abduction associated with a pronated foot position described in appendix three may also lead to an out-toed gait (Turner et al. 2003). The process of developing an out-toed gait is further augmented by a lack of dorsiflexion of the foot during the swing phase due to weak triceps surae, which is thought to result in the patient placing the entire foot to the ground so that smooth forward progression is lost (Marshall et al. 1980).

Diamonte and Light (1982) demonstrated that the timing of the gait cycle is altered in RA, either by the pathological features associated with the disease or the compensatory mechanisms employed. Isacson and Brostrom (1988) reported that the duration of single-limb support is shortened, possibly due to the inability of the foot/ankle to act as a stable lever for propulsion. These features are said to result in the apopulsive gait pattern commonly seen in RA (Gerber & Hunt 1985). Diamonte and Light (1982) and Gerber and Hunt (1985) have suggested that pain in the feet and lower limbs, together with the need for stability may result in a prolonged double limb support phase to minimise discomfort. The reduced ability to achieve propulsion and therefore maintain forward progression (due to the limited range of motion, pain due to active synovitis and reduced muscle power) requires people with RA to have a greater double limb support (and thus slower cadence) in order to prevent loss of balance and reduce the potential risk of falls. While elderly people in general exhibit a slower gait (Menz et al. 2003) this is accentuated in RA and the changes reported here also require increased energy expenditure as reported by Kavlak and colleagues (2003), which may be a factor in the overwhelming fatigue often reported by those with RA (Hewlett et al. 2005).

3.6 The management of foot pathologies in RA

In recent years both Professional and Charitable bodies have commended the role podiatric care has to offer for patients with both early and established RA (SIGN 2000, Longrigg & Mainwaring 2001, Cushnaghan & McDowell 2003, ARMA 2004, Kennedy et al. 2005). Recent Government publications also highlight the need and importance of this aspect of care for those with chronic health complaints (Dept of Health 2004, 2005). Balint and colleagues (2003) cites Haas et al.

(1999) concluding that in addition to successful pharmacological management of RA, there is a need for effective local treatment for the foot and ankle. A number of authors (Shrader et al. 1999, Bowen et al. 2005, Farrow et al. 2005, Clark et al. 2006) have reviewed a range of therapeutic modalities that are useful for people with RA and these are summarised in table 3.4 overleaf. However as table 3.4 illustrates, the quality and quantity of the evidence base for these interventions remains limited. Furthermore, differences and limitations in methodology and mechanisms of measuring outcome make direct comparisons between reports difficult. To improve reporting of non-pharmacological interventions Boutron and colleagues (2005) have suggested a checklist to aid study evaluation and Vliet Vlieland (2007) highlights the need for continued investigation into the most clinically and cost-effective strategies of delivering non-pharmacological treatments.

Table 3.4 - An overview of non-surgical therapeutic interventions for foot complaints in RA.

Type of intervention	Description of evidence base	Level of Evidence
Callus/Corn reduction	<p>Mechanical sharp debridement recommended for painful superficial lesions (O'Donnell et al. 2002) and reported to reduce pain & plantar pressure in diabetes (Edmonds et al. 2002)</p> <p>Pain reduction recently reported to be short term at best (Davys et al. 2004, Timpson & Spooner 2005)</p> <p>Plantar pressure not altered by callus reduction in RA (Davys et al. 2004), therefore additional padding recommended</p>	Ib
Physical Therapy	<p>Suggested modalities include electrotherapy (ultrasound), heat (e.g. wax bath), cold (e.g. ice), contrast baths and laser therapy (Miller & Nash 1994, Hammond 1996).</p> <p>Evidence level is poor, sometimes limited to case studies; but recent systematic review of low level laser therapy suggests more effective than placebo (Brosseau et al. 2002)</p>	IIb
Insoles and Orthoses	<p>Largest number of studies available (n>20) with 3 randomised controlled trials (RCTs) generally reporting reduced pain, improved gait parameters (Bowen et al. 2005, Farrow et al. 2005, Clark et al. 2006)</p> <p>RCTs of variable quality; e.g. Conrad et al. (1996) high quality but recruited all male subjects therefore results not transferable; Woodburn et al. (2002a) was underpowered therefore lower quality, but of longer duration. Overall outcome measures in RCTs were appropriate & good completion rates.</p>	1b

Table 3.4 cont. - An overview of non-surgical therapeutic interventions for foot complaints in RA.

Type of intervention	Description of evidence base	Level of Evidence
Footwear	<p>Few RCTs related to footwear trials alone are readily available (n<5) as some also utilise insoles/orthoses. Significant reductions in pain and improvements in gait parameters are reported (Fransen & Edmonds 1996, Chalmers et al. 2000) supporting a recent Cochrane review (Egan et al. 2004) concluded <i>“preliminary evidence supports use of extra-depth shoes with or without insoles.”</i></p> <p>However trials are often relatively small and conducted over a short duration with dissatisfaction with shoe style being a reported adverse effect (Bowen et al. 2005), which may affect completion rates.</p>	Ib
Wound Care	Recent reviews (Bowen et al. 2005, Farrow et al. 2005) did not discuss wound care as an intervention in depth, as few studies highlight this as an outcome and some are related to surgical intervention	III

Key to evidence level (Shekelle et al. 1999)

- | | | | |
|-----|-------------------------------------------------------|-----|----------------------------------------------------------------|
| Ia | Meta-analysis randomised controlled trial | Ib | Evidence ≥ 1 randomised controlled trial |
| IIa | Evidence ≥ 1 controlled study (no randomisation) | IIb | Evidence ≥ 1 quasi-experimental study |
| IV | Expert committee, clinical experience | III | Non-experimental, descriptive study (e.g. case control series) |

3.7 Implications for the measurement of outcome in the foot and lower limb in RA

The extensive involvement of the foot early in the course of RA has prompted some authors to recommend that foot joints should be monitored in clinical practice (Smolen et al. 1995). In clinical practice, while there are a number of outcome measures available to assess foot and lower limb involvement in RA (reviewed in appendix four), there remain a number of fundamental methodological issues to resolve. The outcome measures reviewed in appendix 4 can be divided into two categories. Firstly, a number of instruments (Speigal et al. 1987, Platto et al. 1991 and Kitoka et al. 1994) determine the effects of RA on the feet by assessing deformity and measuring joint range of motion usually using clinical or goniometric measurement. Increasingly goniometric measurement is losing favour in clinical practice owing to repeated studies demonstrating the poor intra and inter-rater reliability of the clinical measurement methods utilised in these outcomes (McPoil & Cornwell 1996, Robinson et al. 2001, Gheluwe et al. 2002). The reported complications with these methods have included difficulties in maintaining the position of the patient, variability with regard to location of anatomical landmarks with which to position the relevant instrumentation, use of different measurement protocols and inability to apply a consistent and reproducible force with which to move the joint through its range of motion (Elveru 1988, Woodburn 1991, Rome & Cowieson 1996). From a psychometric perspective, it should also be noted that these measures are somewhat mechanistic and uni-dimensional, because no attempt is made to consider the impact any reduction in range of motion has on the patient in terms of symptomology, functional participatory limitations or quality of life. The second group of instruments are predominantly questionnaire-based (Budiman-Mak et al. 1991, Bennett et al. 1998, Garrow et al. 2000, Barnett et al. 2005, Helliwell et al. 2005). These instruments can be used to assess the effect of RA in the feet and lower limbs and in turn the impact foot and lower limb pathologies have on people with RA. This group of instruments tend to measure a broader range of constructs than those assessing deformity or range of motion and the constructs that are measured are identified in table 3.5 overleaf.

Table 3.5 Constructs measured by questionnaire-based outcomes measures specific to the foot/lower limbs

Construct	Instrument assessing that construct
Pain	Foot Health Status Questionnaire, Foot Pain Disability Questionnaire, Leeds Foot Impact Scale, Bristol Foot Score, Rowan foot pain assessment questionnaire
Function	Foot Function Index, Foot Health Status Questionnaire, Foot Pain Disability Questionnaire, Leeds Foot Impact Scale, Bristol Foot Score, Foot and Ankle Activity Measure
Footwear	Foot Function Index, Foot Pain Disability Questionnaire, Leeds Foot Impact Scale, Bristol Foot Score
Disability	Foot function index, Foot Pain Disability Questionnaire, Leeds Foot Impact Scale, Bristol Foot Score
General foot health	Foot Health Status Questionnaire, Foot Pain Disability Questionnaire, Leeds Foot Impact Scale, Bristol Foot Score
Activity limitation	Foot Function Index, Foot Pain Disability Questionnaire, Leeds Foot Impact Scale, Bristol Foot Score, Foot and Ankle Activity Measure, Foot and Ankle Outcome Score
Personal appearance	Foot Pain Disability Questionnaire, Leeds Foot Impact Scale, Bristol Foot Score,
Perception of self as a result of foot problems	Bristol Foot Score, Leeds Foot Impact Scale,
Sleep difficulties due to foot pain	Bristol Foot Score,
Impact on Sports activity	Foot and Ankle Activity Measure, Foot and Ankle Outcome Score
Impact on Social activities	Bristol Foot Score, Leeds Foot Impact Scale, Foot and Ankle Outcome Score

What is less clearly understood, and not well represented in the literature, is the relative contribution that questions about the impact of RA in the feet and lower limbs experienced by people with RA make to the overall scores of disease activity measures. Smolen and colleagues (1995) have suggested that inclusion of clinical examination of foot joints would not enhance the validity and reliability of composite outcome measures, such as the DAS 28. These issues are further complicated by reports from some authors (Hussain et al. 2003, Farrow et al. 2005) that instruments used to assess outcomes in the feet do not generally perform well when compared with the results from outcome measures more commonly used by rheumatologists. This could make cross-discipline communication difficult. However, other authors have reported strong correlations between generic and foot specific measures (Bal et al. 2005). It is possible that this

inconsistency occurs because foot-specific outcome measures (e.g. the foot function index) are designed to measure function of a specified anatomical region, rather than overall disease activity. In addition, instruments used assess the effects of RA on the foot/lower limb tend to utilise relatively simple scoring techniques (e.g. Likert-type scales, visual analogue scales, visual rating scales and dichotomous (true/false) scores); in contrast to the more complex scoring methods utilised by composite measures of disease activity such as the DAS 28.

In table 3.5, the constructs repeatedly measured by instruments used to assess foot involvement in RA include pain, disability and function. Constructs such as pain are often considered difficult to measure objectively as they rely heavily on such issues as attitudes, beliefs and cultures of individuals as well as the accuracy of self-reported behaviour (Meause et al. 2005). This contention lends support to Wrobel (2000) and Parker and colleagues (2003) who argue that a many of the outcome measures commonly used for foot assessment in RA require more rigorous validation. For example, previous qualitative studies have suggested RA in the feet has a severe negative impact on the patients' overall quality of life (Gripton 2001, Wickman 2004). This is a key finding as many of the outcome measures commonly used in clinical practice to assess and monitor foot complaints in RA do not allow those with the disease to contribute their personal views about what is important to them. An enhanced understanding of the relationship between foot complaints and their effect on more holistic outcomes such as quality of life may help explain why foot problems often go unreported in rheumatology. This is particularly important as it may not be the foot complaint(s) *per se* that go unnoticed, but more the patients perception of how important these complaints are to them in terms of the impact on their everyday lives, an area not routinely included in traditional outcome measures. It is this gap in understanding that the current study aims to explore, which supports the proposed methodology of exploring the views of both people with RA and clinicians.

3.8 Summary

This chapter (together with appendix three) has considered the prevalence of articular and extra-articular foot complaints seen as a result of RA and explored how these complaints develop in the context of the pathogenesis of RA. Important gaps in understanding with regard to issues such as the impact of foot complaints on quality of life are highlighted. In addition, the effect of foot complaints on the gait cycle is noted. The importance of this to people with RA in terms of the impact on their lives and therefore consideration of new ways to assess this element remain largely unexplored. Evidence for the efficacy of various treatment modalities used in the management of foot complaints in RA has been shown to be somewhat limited; with a need for much larger, better designed trials. As part of trial design careful consideration needs to be given to how outcomes are assessed, as the review of currently available outcome measures suggests many studies may not report what is of most importance to those with RA in a rigorous, validated manner.

Thus far the review of the available literature has largely concentrated on those aspects of RA that are the purview of clinicians, for example epidemiology, disease pathogenesis, management strategies and the mechanisms for reporting outcome. The importance of the patient's perspective is explored more fully in the next chapter.

4.0 Chapter 4

Rheumatoid arthritis: the patient's perspective

4.1 Introduction

Rheumatoid Arthritis (RA) has a considerable, sometimes crippling, biopsychosocial and economic impact on both sufferers and their families and therefore cannot be viewed from a physical standpoint alone (Bury 1988, Ailinger & Schweiter 1993, Lapsley et al. 2002). For example, laquinta and Larabee (2004) reported that nearly all their respondents with RA reported depression as a result of feeling physically ill and experiencing intense pain for prolonged periods. Some authors have expressed concern that clinicians generally focus on the measurable aspects of disease activity, whereas the dominant concerns for patients are associated with pain, reduced mobility, fatigue and psychosocial effects (Simpson et al. 2005). Particularly as some psychosocial factors have been considered to be better predictors of psychological morbidity (e.g. depression) than clinical variables (Hawley and Wolfe 1988). However, a review by Newman and Mulligan (2000) concluded that most of the psychological research into RA has focused on the psychosocial factors related to symptoms (e.g. pain or disability) or patients' well-being (e.g. depression and anxiety). In contrast, there has been comparatively little work on the lived experience associated with RA, yet these issues are particularly important in chronic musculo-skeletal complaints, because it has long been recognised that RA is associated with a significant social impact (Anderson et al. 1985, Revenson et al. 1991, Lapsley et al. 2002).

To gain a more in-depth perspective of the perceptions of those with RA a review of the literature grounded in phenomenology was undertaken. The qualitative research paradigm of phenomenology was considered most appropriate in this context because this methodological approach is deemed to provide a unique perspective or „window“ on the lives of people with chronic diseases (such as RA) capturing an individual's immediate, concrete experience as it is lived in, and lived through (Dilthey 1976). This is valuable because as Sullivan (2003) points out "facts known only by physicians need to be supplemented by values known only by patients". Toombs (1995) in her account goes further arguing that phenomenological accounts "disclose the emotional dimension of physical disorder" and "provide insights in to the profound disruptions of space and time that are an integral element of changed physical capacities". Phenomenology is seen to be a complex, multi-faceted methodology, which defies simple definition or characterisation primarily because there is no single philosophical standpoint (Schwandt 1997). However, phenomenology has been defined as a description of the meaning of lived experience (Maslen 2003). The insight into the lives of people with chronic musculo-skeletal complaints permitted by phenomenology affords an opportunity to conceive of the effects of the disease (and its treatment) on the person. These perspectives may allow improvements in medical care not previously determined by traditional quantitative methods through tailored treatment plans or alternatively may demonstrate

new management opportunities. Because the lived experience of RA is rarely included within the more traditional biomedical paradigm associated with the assessment and management of RA, a separate literature search was performed to identify the body of written work that would inform a review of the lived experience of RA.

4.2 Literature search specifically relating to the lived experience of RA

Relevant phenomenological studies were identified in the literature through a search of several databases including; Medline (1966 - Jan 2007), Cinhal (1982 – Jan 2007), Amed (1985 – Jan 2007), Social Science Citation Index (1981 – Jan 2007) and International Biography of Social Science (1960 – Jan 2007). The paired medical subject (MeSH) headings for keyword and text word searching used were; *rheumatoid arthritis*, *lived experience*, *phenomenology* and *insider perspective*. A total of 12 articles were retrieved and further searching of library catalogues revealed additional relevant sources, including two book chapters, two autobiographical works, a PhD thesis and conference proceedings. Each of the published research articles was reviewed for methodological rigour using a format recommended by Greenhalgh (2001), in order to determine that these works were the result of qualitative methods as opposed to being opinion pieces. A number of authors have produced criteria and checklists for reviewing qualitative work (Mayes & Pope 1995, Chapple & Rodgers 1998, Locke et al. 1998, Greenhalgh 2001). The format recommended by Greenhalgh (2001) was selected, owing to an almost equal use of criteria for academic rigour and relevance to clinical practice. Once identified and their key characteristics noted, these works were then read repeatedly and key concepts (interpretive metaphors) determined (Campbell et al. 2003) with the aim of understanding participants' descriptions of life with RA (Silverman 1989). To present the categories identified from these works, a multiple exemplar strategy (Dezin 1989) was used. This approach has been described as being more closely aligned to interpretive synthesis than analysis (Campbell et al. 2003). This approach was particularly appropriate in this instance, as this textual data has already been analysed by the original authors. A rich textual description from the literature, which is presented in subsequent sections, offered an insight into the issues of importance to people with RA.

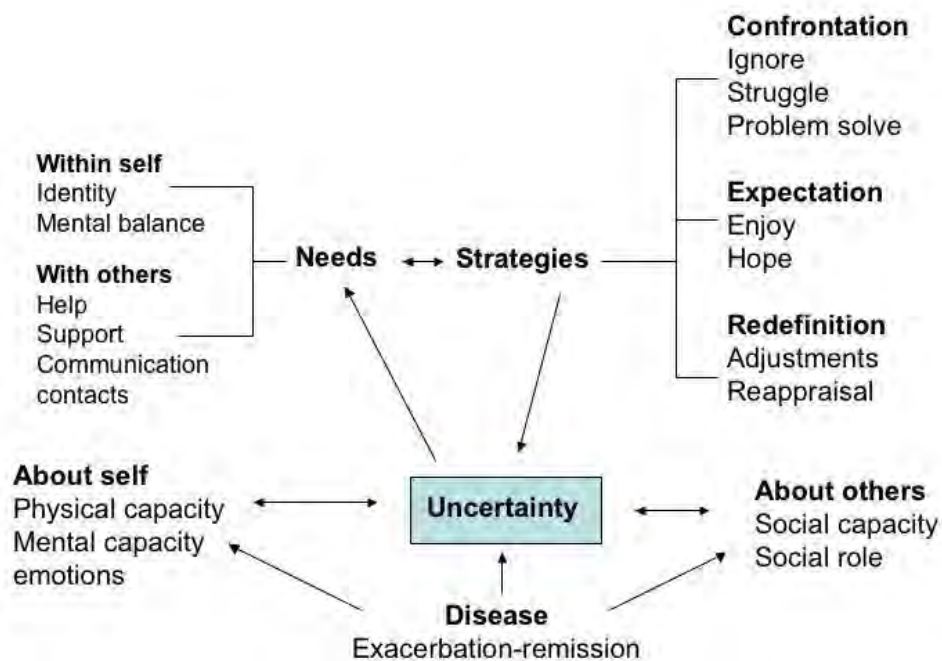
4.3 The reported lived experience of RA

The review of the published work revealed a number of common themes or domains relevant to the lived experience of RA, each with complex interrelationships. The most commonly reported, re-occurring theme throughout the literature was one of „uncertainty“ (Weiner 1975, Bury 1988, Williams & Wood 1988, Stenstrom et al. 1993, Melanson & Downe-Wambolt 1995, Edwards et al. 2002, Maslen 2003, Campbell & Abernethy 2003). Uncertainty appeared to be a complex concept and did not simply refer to not knowing what the future might hold, but was also associated with explanations about what caused RA, the inherent variability in symptoms, whether symptoms would deteriorate, how this would affect daily living and the impact of all of these factors on

significant others. Some medical sources also identified the significance of psychosocial factors such as uncertainty in the overall management of the rheumatoid patient (Harris 1993), but most emphasised the importance of managing physical manifestations, for example the value of pain control and prevention of deformity (Akil & Amos 1995b, Hawley 1995, van Riel et al. 1998, van der Heijde et al. 1999). Yet a number of authors have reported that the theme of uncertainty was the most consistent finding throughout their research (Weiner 1975, Stenstrom et al. 1993, Edwards et al. 2002). This points to a possible discrepancy in understanding between clinicians and patients of what is most important to people with RA. Weiner (1975) accepts that life in general requires toleration of a certain amount of uncertainty, but life with RA appears to require toleration of an exaggerated level of uncertainty applicable to all facets of the disease and thus takes over the patient's lifestyle (Locker 1983, Bury 1988). The feelings of uncertainty can be further exacerbated by periods of delay between visits to different specialists, receiving a preliminary diagnosis and waiting for test results (Williams & Wood 1988). Maslen (2003) succinctly sums up respondent's feelings with respect to uncertainty, "their bodies were plunged into a bleak personal and medical world full of unfamiliar feelings, strange languages and practices. Fear permeated". Iaquinata and Larrabee (2004) suggest that the fear associated with uncertainty often elicits anger owing to the pain or limitations imposed by the disease, "I feel like an angry old woman trapped inside a young person's body". What appears to be clear from the literature is that many of the factors responsible for the negative feelings of fear, anger and uncertainty are closely interrelated with other factors including symptomology, disease chronicity, impairment, deformity and dependence on others (Weiner 1975, Stenstrom et al. 1993, Edwards et al. 2002). Stenstrom and colleagues (1993) developed a theoretical framework for these factors (figure 4.1), with the identification of uncertainty as a central theme.

Figure 4.1 – Theoretical framework of everyday life with RA

(Stenstrom et al. 1993)



The maintenance of identity, personal integrity and personal and social relationships with others are key issues for people with RA and are closely linked to the issues of uncertainty, body image and appearance. Williams and Wood (1988) comment that people with RA in their study indicated that their bodies appeared to have become “detached creating a hiatus between their wishes and actions”. Iaquinta and Larabee (2004) noted that respondents conveyed self-consciousness due to the physical changes brought about by RA. Overboe (1999) in his essay grounded in the lived experience of disability cites Caddick (1995) who argued that the difference between ugliness and beauty is heightened by Western Societies’ preoccupation with „the body beautiful“. Edwards and colleagues (2002) report that the negative effect of RA on body image can be intensified by admission to hospital. This consideration is supported by Peterson (2001), which through an autobiographical account allows glimpses into the culture of some medical/health professions, “Dr X, like a god, stands with his team of young student doctors and nurses... I wish they’d stop gawping. I am not an exhibit”. These findings would seem to tie in with the concept of personal integrity, with respondents in Stenstrom’s work (1993) reporting “it’s as if you have to tell people about your disease”. Similarly, Iaquinta and Larabee (2004) describe the concept of „disease validation,“ with participants reporting they felt they had to authenticate the disease by describing the pain that existed in the absence of visible signs or lack of deformity, particularly early in the course of RA. In earlier work Williams and Wood (1988) coined the term „ontological security“ to

identify how chronic illness undermined patients' day-to-day lives giving rise to intense feelings of uncertainty.

The nature of the relationship RA sufferers have with others whether fellow patients, relatives, friends or the public is another consistent theme throughout the literature, although there is not always agreement between reports. One possibility for this is that the thoughts and perceptions of a person with a chronic disease may be predicated not so much on their own direct experience, but on how they view others. Peterson (2001) writes, "A small lady with white curly hair sits hunched in her wheelchair opposite me. She lifts her head, stares at me blankly and then looks down again. For the first time I feel uneasy". Edwards and colleagues (2002) recognise that other (often younger) respondents found meeting other people with RA a negative experience, possibly because witnessing the progression of the disease in terms of deformed joints and other pathologies was distressing, or perhaps because of a fear or uncertainty that their disease may progress in a similar manner. Equally, Edwards and colleagues (2002) argue it is possible that a more positive perception can exist, with respondents acknowledging that meeting peers with RA was helpful as they could act as role models. Stenstrom and colleagues (1993) in their series found that respondents reported other patients "spoke the same language". This highlights some of the communication difficulties that may exist between health professionals and patients, as well as acknowledging the need to take into account the patients' perception. This area can be further complicated by patients' expectation of medical treatment. Long and Scott (1994) suggested that there can be a discrepancy between what physicians can provide and what patients expect. They admit that, "patients expectations may be ill-informed". Carr et al. (2003) reported that often younger, more confident female patients with a positive mood have very high expectations of treatment. The lack of a shared understanding could be a potential barrier to achieving successful coping strategies. This is a complex area that Edwards and colleagues (2002) acknowledge when discussing the patients evolution from „novice" to „expert". Evidence for this „journey" was also provided by Shaul (1995) and also by Iaquina and Larabee (2004), they detailed how people with RA masterminded new ways of managing their disease highlighting the importance of partnership with health professionals with one participant remarking, "I am the real manager of this disease". This supports Sullivan's view (2003) that "it is the patient, not the physician who has the authority to judge his quality of life". While much of the work relating to the lack of a shared understanding does not extend to specifically include foot complaints, similar issues may exist. An important part of the current study is to explore potential discrepancies in understanding.

A further feature of the lived experience of RA is the resilient spirit, optimism and positivity expressed by many respondents (Stenstrom et al. 1993, Melanson & Downe-Wamboldt 1995, Maslen 2003). Iaquina and Larabee (2004) report some respondents develop a spirit of courage when confronted with daily pain and apparent loss, participants recognised their physical limits, did

not exaggerate them and instead demonstrated perseverance in using their remaining ability. Coping with the physical and emotional challenges rheumatoid arthritis brings inevitably affects social and personal relationships. Both Stenstrom and colleagues (1993) and Ryan (1996) develop themes related to issues surrounding role change and self-esteem, further highlighting the economic dependence that may occur through people with RA not being able to work and therefore having to rely on families or social welfare. Support from significant others was found to be particularly important to patients (Stenstrom et al. 1993, Melanson & Downe-Wamboldt 1995). Yet, although social contacts were seen as being of great importance; this was made difficult for some because the disease necessitated increased effort to engage in social activities, even everyday activities took a great deal more time and energy (Locker 1983, Dildy 1996). Therefore some respondents became more discerning with regard to the social interaction being sought "it must be something worth doing" (Stenstrom et al. 1993). A similar theme is discussed by Toombes (1995) in a discourse based on multiple sclerosis, arguing that everyday actions are seen as effortful owing to the disability, when previously they were effortless, thus there is a temptation to limit interaction with the outside world. Furthermore, Williams and Wood (1988) noted that the unpredictability with which people with RA are greeted during routine social encounters is another threat to daily interactions, thus risking further social isolation.

4.4 The lived experience related to foot complaints in RA

Much of the orthodox medical literature focuses on the physical complaints associated with RA in the feet with phrases such as „walking on pebbles or marbles” often being used (Helliwell et al. 2007). The impact of symptoms such as pain has also been widely reported in the literature surrounding the lived experience of RA. Gripton (2001) noted that many respondents with RA reported concentrating on the more physical dimensions, for example; "I try hard not to think about my feet ... It's not so much that I actually think about my feet but they are forcing themselves on me". Previously Weiner (1975) highlighted the sacrifice one respondent reported in trying to maintain independence and to continue working: "It was harrowing. When I got up in the morning my feet were so painful I couldn't stand on them". In particular, the visible changes to hands and feet cause distress to people with RA. Peterson (2001) in her autobiography writes, "I look at my feet in disgust... I'm becoming flat-footed and all the toes are dislocated". These feelings have been echoed by respondents in other studies whose respondents commented on the impact of foot problems, "whatever I put on, my feet never look smart" (Stenstrom et al. 1993). Increasingly studies are reporting that foot complaints have a profoundly negative impact on psychological well-being. Ailinger and Schweitzer (1993) noted 25% of respondents reported other psychological symptoms including irritability and depression due to deformity of hands and/or feet. The importance attached to psychological complaints emphasises the need for suitable methods of collecting and collating information from people with RA and calls into question the sensitivity and specificity of some of the currently available outcome measures for the feet and lower limbs. As

noted in section 3.8 and appendix four, many of these instruments rely heavily on describing and measuring physical deformities in the feet.

4.5 Current outcome measures and the lived experience of RA

While the outcome measures commonly used in rheumatology, (discussed in section 2.7) have all been extensively validated, their primary function is to provide objective measures of physiological endpoints of the disease, generally expressed numerically. In particular information about the disease itself, collected by clinicians using measures such as number of swollen or tender joints and levels of inflammation may not necessarily reflect outcomes that are important to people with chronic disease (Soon and Chen 2004). Mirin and Namerrow (1991) suggest that the ability to participate successfully in interpersonal relationships and to function within the context of a family or social group is equally important. The growing importance of actively considering the patient's perspective to complement traditional biomedical outcomes was outlined in section 2.7. The perceived value of this approach is reinforced further by the various patient involvement initiatives and policies that have been implemented within the National Health Service in recent years. These include the expert patient (Dept. of Health 2001), patient empowerment (Dept. of Health 2004, 2005a), changes to the commissioning system (Dept. of Health 2000, 2004) and the implementation of local involvement networks (Dept of Health 2007c). However, the need to take into account the impact of a chronic disease such as RA on the social functioning of the individual has long been recognised (Long & Scott 1994). Yet, Ashcroft (1996) reports that in her experience "few, if any, carry this forward, due in the main to their tradition of working entirely within the medical model of disability". Even though Long (1996) suggests that comparing the patient's experience of the disease may be of equal importance to the levels of disease activity measured by objective outcome measures.

4.6 Social models of disability, patient-centred approaches and subjectivity

Perceptions of health status and the need for healthcare have been shown to differ between health professionals and patients (Kwoh et al. 1992, Molzahn & Northcott 1989, Berkanovic et al. 1995). In particular, aspects of illness that are adversely affected in RA, (such as pain and quality of life), often demonstrate different results when assessed by people with RA and professionals who manage the disease (Molzahn & Northcott 1989, Leeb et al. 2005). Berkanovic and colleagues (1995) go further suggesting these differences in opinion are particularly important in the area of physical functioning. Physical function is often adversely affected in RA and this area is often the focus of patient-centred self-management models designed to help people with the condition to develop and improve coping strategies and enhance self-efficacy (Lorig et al. 1993, Barlow et al. 2000). The lack of a patient-centred approach during clinical assessment may lead to ignorance about symptoms that are of key importance to the patient (Tallon et al. 2000). Sullivan (2003) argues, "facts known only by physicians need to be supplemented by values known only by

patients...because patient outcomes are valid because they are subjective.” Therefore it is considered essential to include the views of people with chronic disease as it encourages others including health professionals to consider each other’s expectations and objectives (Kogan & Redfern 1995).

In rheumatology attempts have been made to quantify the treatment priorities of people with RA (Carr et al. 2003, Ahlmen et al. 2005, Hewlett et al. 2005). Repeatedly the most important themes to those with RA emerging from the literature are summarised in table 4.1.

Table 4.1 – The treatment priorities identified by people with RA
(Carr et al. 2003, Ahlmen et al. 2005, Hewlett et al. 2005).

Priority	Explanation of priority
Independence	Reduced reliance on the support of others for everyday tasks
Pain	Reduction in the levels of pain experienced
Mobility	Improved overall mobility
Well-being	Greater feeling of being „well“
Emotional impact	Reduction in the negative effect RA has on the emotions of those with the disease and their loved-ones
Fear of the future	Alleviation of patients concerns about how RA might progress in the future
Return to normality	Wish to be able to undertake the valued life activities participated in prior to the onset of RA

Interestingly the theme of uncertainty does not feature here, possibly because all of these listed contribute to the overall concept of uncertainty. Many of the outcome measures discussed in section 2.7 do not always reflect the patient-centred issues outlined above (Ashcroft 1996, Wright & Young 1997, Soon & Chen 2004). This is key as not only is biological functioning impaired in RA but so is patients’ psychological health and social functioning (Armstrong 2003). For instance, the prevalence of depression in people with RA is increased (Paliakas et al. 1990) with some estimates indicating people with RA are at least twice as likely to suffer from depression when compared to the rest of the population (Dickens & Creed 2001, Sheehy et al. 2006). Yet, often within rheumatology the emphasis (especially from a research perspective) is on clinical criteria, which tend to exclude key social and psychological factors, thus reinforcing the medical model (McHorney 2000). The acceptance of a purely medical model risks the exclusion of a role for social theory (Armstrong 2000). However, as Charmaz (2000) points out, understanding the patient’s perspective (which by definition includes their social interactions) brings a new insight into an individual’s attitudes and actions. For example, the manner in which patients’ cope with their disease may well influence the extent to which they participate in a variety of mandatory and

discretionary activities (Blackman 2006). Therefore, people with chronic disease are ideally placed to make judgements about their concerns and priorities regarding the risks and benefits of interventions (Coulter & Fitzpatrick 2000). In theory, the dominant methods used to assess disease and identify the impact of treatments are often grounded in the philosophy of objectivity and empirical measurement following the principles of hypo-deductive methods (Bowling 2002). However, in practice psychosocial factors profoundly influence the way in which symptoms are perceived and the presence of these symptoms affects both psychological well-being and social participation (Blackman 2006). This highlights the value of mixing qualitative and quantitative methodologies when generating data from those with RA.

4.7 Summary

Evidence from the literature grounded in lived experience identifies a discrepancy between what is important to those with RA compared with what is assessed by clinicians. Therefore Ashcroft (1996) reports that existing instruments do not always capture the essence of what clinicians need to know and what patients wish to report. This has led some clinicians and researchers in rheumatology to ask if there should be a reduced emphasis on clinical outcome and greater attention paid to individual patients perceptions of outcomes (Scott et al. 1995, Long 1996). Consequently difficulties may arise with regard to expectation of both patients and clinicians. The purpose of a methodological approach that mixes quantitative and qualitative paradigms proposed by the current study is supported by the need to provide explanations regarding the similarities/differences between patients and clinicians opinions about the nature and extent of foot complaints in RA. It is anticipated this approach will afford a greater insight and understanding as to what aspect each group of participants consider important to the other, providing a new contribution to knowledge about the impact of foot complaints in RA.

5.0 Chapter 5

Methodology

5.1 Introduction

People with rheumatological disorders such as RA can suffer a wide variety of signs and symptoms of the disease in the feet and lower limbs as described in chapter three and four. The change in foot health status that may occur as RA progresses over time requires treatments to be monitored to meet clinical governance requirements as well as satisfying both the patient and practitioner (Adams 2002). As highlighted previously, existing measures used to monitor outcome tend to focus primarily on patients' clinical status rather than how individuals integrate into their occupational and social environment or the impact of RA on constructs such as quality of life and the ability to participate in valued life activities. Difficulties in determining the issues of importance for people with rheumatological conditions may be further compounded because values (i.e. the importance attached to issues such as mobility) may change over time, not only because of personal circumstances but also due to the changing experience of the nature of the illness itself (Sangha et al. 1998). Therefore the multi-factorial effects of RA together with the variable course of this disease require a broader consideration of factors important to those with the disease. The approaches used to gather both what is important to those with RA (e.g. pain, immobility and so on) and also how important these issues are to sufferers as individuals, was key to this area of study.

However, the current study did not aim to undertake a purely phenomenological exploration of the lived experience of RA and how foot complaints form a part of that experience. Particularly as the review in chapter four has identified a number of areas of key importance relating to the impact of foot pathology. Instead as outlined in the aims and objectives, the purpose of the current study was to examine professional and clinical practice in the light of an enhanced understanding of how foot complaints affect those with RA. To commence, identification and exploration of the nature and extent of foot complaints from the perspective of both those with RA and clinicians was required. Analysis of these data would permit consideration of what clinicians' report their patients tell them about what foot complaints they experience and how this affects their lives. Clinical and phenomenological reasoning (Toop 1998, Bauman et al. 2003) suggests these are extremely valuable data that enable the tailoring of interventions to the individual. However, the literature reviewed suggests, at least anecdotally, that clinicians often choose not to utilise such information. This is possibly because of its perceived inherent subjectivity, but equally because of familiarity with the more objective, numerically based scales, even though these instruments often do not include foot complaints. Determining the importance clinicians and people with RA attach to foot complaints, as well as ascertaining current practice with regard to assessment and management of foot complaints will help identify gaps in understanding and ultimately inform each group of how services can be developed and improved. To achieve the aims and objectives of exploring both

the nature and extent of foot complaints in RA from the perspective of those with RA and clinicians, both quantitative and qualitative methodological approaches were considered. It has been suggested that quantitative and qualitative methods belong to different paradigms based on philosophically distinct epistemological frameworks (Foss & Ellefsen 2002) as described in table 5.1.

Table 5.1 – Key distinctions between qualitative and quantitative methodological approaches
(Adapted from Coxon 2005, Moron-Ellis et al. 2006)

Research process	Quantitative	Qualitative
Paradigm	Focused on the measurement of variables	Meaning centred approach
Epistemology	Positivistic (empirical) observation of facts	Reasons based interpretation of phenomena
Data Conceptualisation	Formal measurement approaches	Natural language and speech-based data
Data collection	Systematic rules based formats	Discursive data elicitation
Data analysis	Statistical explanation based on linear models	Thematic content-driven analysis

Coyle and Williams (2000) however, contend this distinction is artificial, being predominantly based on the premise that quantitative methods are grounded in the epistemology of positivism, whereas qualitative methods are anti-positivistic. Previously, Clarke (1998) noted that much of contemporary science is now post-positivistic, adhering more closely to the framework of „critical realism“ (Guba & Lincoln 1994), which acknowledges the influences of the research process and contextual basis of the work. Different kinds of knowledge can be generated using different methods, therefore Foss and Ellefsen (2002) argue that quantitative and qualitative approaches are not irreconcilable, but occupy different positions on a continuum. This has led some to suggest that the mixing of quantitative and qualitative methods confers a series of benefits including increasing the accuracy of, and confidence in, findings while reflecting the complexity of a phenomenon (Greene et al. 1989, Moron-Ellis et al. 2006). A number of authors have suggested combining quantitative and qualitative methodologies can serve a number of different purposes and these are detailed in table 5.2.

Table 5.2 – Potential advantages of combining quantitative and qualitative methodologies
(Greene et al. 1989, Kelle 2001, Moron Ellis et al. 2006, Bryman 2006)

Advantage	Explanation of how benefits are gained
Triangulation and/or	Emphasis is on the convergence of research results to seek

Validation of findings	corroboration between quantitative and qualitative methods
Development of chosen method	The results from one methodological approach can help develop and inform a different approach
Complimentarity	Quantitative and qualitative results may relate to different phenomena, but can be used to explain one another
Explanation/expansion of chosen method	Different methods seek to increase the breadth and depth of a particular enquiry

The use of an approach that combines quantitative and qualitative methodologies more closely mirrors the complexity of research involving these different groups and the likelihood of a multi-faceted ontology of the subject matter (Coyle & Williams 2000). To fully explore a multi-faceted phenomenon requires the integration of methods throughout the research process rather than just at one distinct phase. To gain a deeper understanding of the nature and extent of foot complaints in RA, and inform the development of a suitable methodological approach, the literature review discussed in chapters two, three and four considered contributions from a range of sources. Reflections on the literature review from a methodological perspective are discussed in section 5.2.

5.1.1 Ontological position of the researcher

Key to the debate surrounding the methodological approach to the current study is the education and training of podiatrists, which similar to other Allied Health Professions is grounded in the biomedical model. This is not to say biopsychosocial components are ignored, but these do not form the mainstay of the curriculum. The researcher being qualified as a podiatrist and employed within an educational institution is inevitably influenced by the culture of the profession within the biomedical model. Equally, podiatry as a profession does not possess a long tradition of research, although this is changing, largely with the advent of a degree entry profession over the last 15-20 years. Research in podiatry is still in its infancy, particularly when compared to the medical profession or pharmacy.

Many branches of medicine (notably in this context, rheumatology), and therefore the research that underpins the medical profession, are dominated by the positivistic quantitative paradigm. Additionally, much of the author's previous work has been quantitative in nature as evidenced by the list of publications in appendix 12. Reflection on the strengths and weakness of the quantitative paradigm in this context, particularly in the light of the literature review, drew attention to the valuable contribution a qualitative approach could offer. It was also recognised that the true nature and extent of foot complaints in RA required further investigation due to the methodological flaws of previous epidemiological studies highlighted in section 3.2.

5.2 Findings from, and reflections on, reviews of the literature.

The generation of suitable data required the consideration of a range of methodologies that would capture the breadth of information from both those with RA and clinicians. A number of potential research methodologies were considered to be appropriate in this context including questionnaires, interviews and focus groups. Key to selecting an appropriate methodological approach was the recognition in chapter three and four that previous work has been largely limited to considering the clinicians perspective, whereas the purpose of the current study was in part to compare the views of RA sufferers with those of health professionals with regard to the nature, extent and impact of foot complaints. The wide range of foot complaints seen in RA identified in chapter three highlighted opportunities within the study design where consideration could be given to mixing methodologies.

To fully meet the stated aims and objectives of the current study the views of both health professionals and patients were considered, so that each group's expectations and objectives with regard to the delivery and outcome of healthcare interventions could be considered (Kogan & Redfern 1995). Using this approach with, for example, focus groups could be detrimental as one sector of a mixed-participant group could dominate discussions, thus preventing meaningful epistemological enquiry. Individual semi-structured interviews were also considered, but thought to be unduly time consuming given the number of interviews that would possibly be required to reach saturation for both people with RA and clinicians. Instead as elucidated by both Oppenheim (1996) and Denscombe (2003) a semi-structured questionnaire-based approach provided a series of advantages pertinent to the current study. Firstly, both quantitative and qualitative paradigms could be incorporated within a single data collection tool. Secondly, questionnaires can generate data from large samples relatively easily. Thirdly, the use of self-administered questionnaires provided an opportunity to generate data from a wide range and number of participants at relatively low cost while also minimising of researcher bias. Finally, a questionnaire could be used to identify subjects who would be willing to participate in future research as well as determining what themes are required as part of further investigations. From a methodological perspective within the context of a questionnaire, it would be feasible to develop data collection instruments for patients and clinicians in parallel, such that the development of questions for one group of potential respondents naturally informed the development of questions for other groups. Thus, as emphasized by Tobin and Begley (2004), the use of a mixed methods approach to the development of a questionnaire-based data collection instrument rather than a purely linear approach, could be dynamic and interactive in nature allowing the researcher to move between design and implementation more easily.

A major finding from the literature search was that no single, previously validated method was found that was specific or sufficiently sensitive for the purpose of determining how and to what extent foot complaints affect people with RA. The absence of a suitable existing instrument

necessitated the development of a new questionnaire. Streiner and Norman (2003) have expressed concern that often, existing instruments are dismissed and researchers try to develop new scales, a process that is not always wholly successful. While it might have been possible to use a series of parts of existing questionnaires for this purpose it was felt such an approach would be excessively time consuming and onerous for participants. In addition, Fitzpatrick and colleagues (1998) point out such a strategy means that the items removed from their context may not retain the measurement properties inherent within the original instrument.

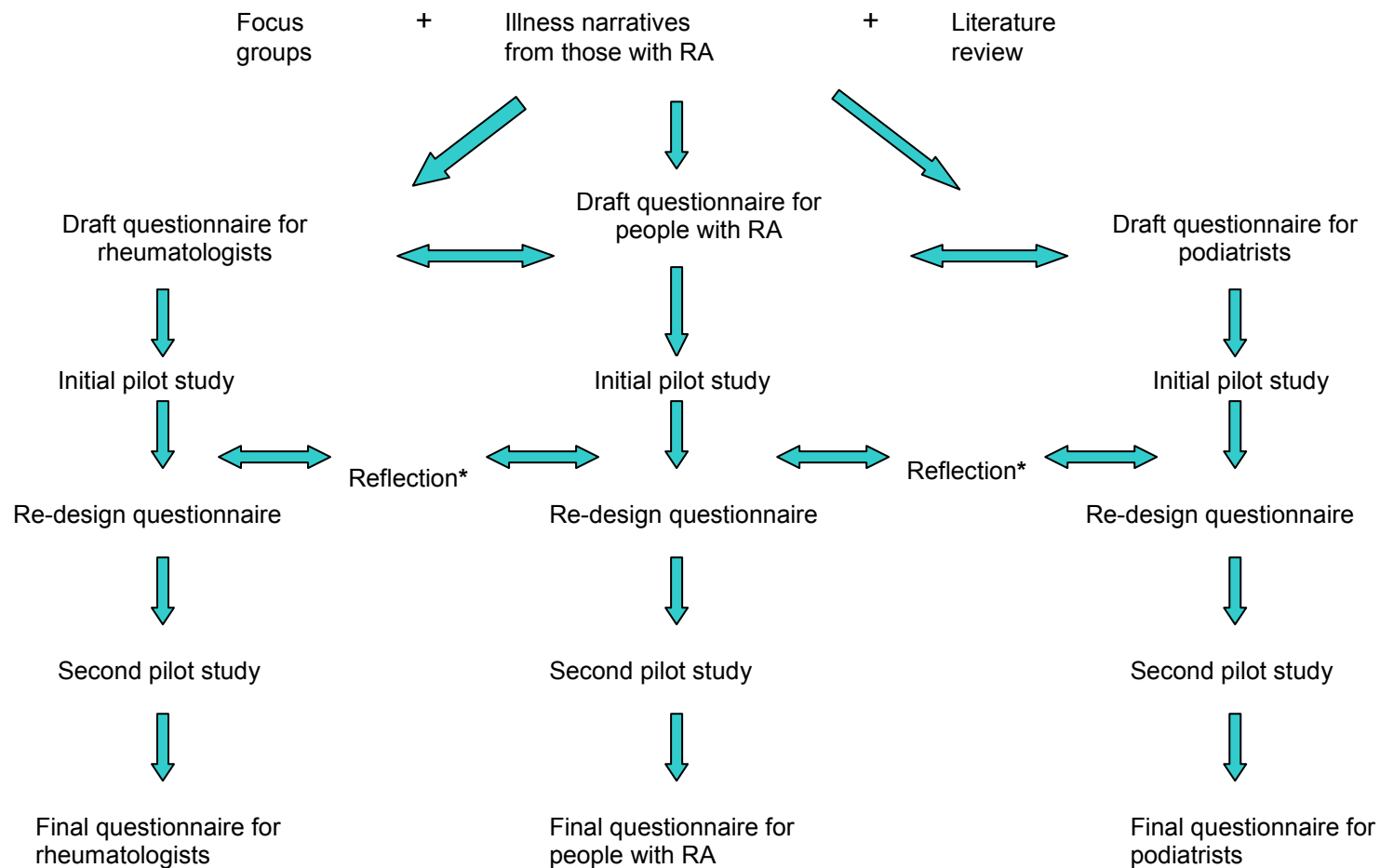
The mixing of research methods within a given approach added to the breadth and depth of the data generated and also helped to encompass several perspectives in a single project (Moran-Ellis et al. 2006). The complexity of present-day health services provision implies that mixed methods approaches are a more appropriate method of obtaining meaningful data from those who make use of health services. The importance of this is further underpinned by the current emphasis placed by the Department of Health on obtaining users views (Coyle & Williams 2000, Foss and Ellefsen 2002). Greene and colleagues (2001) have explored the ways in which methods from different paradigms can be used within the same project and have suggested a four-part theoretical framework detailed in table 5.3 overleaf.

Table 5.3 – Theoretical framework highlighting how methods from different paradigms can be used within the same project Greene and colleagues (2001)

Mixed method	Explanation of how mixed method is achieved
Triangulation	The use of multiple methods when investigating the same phenomenon to strengthen the validity of inquiry
Multiplism	Enhanced validity through a convergence of results from multiple methods
Mixing methods and paradigms	Mixing paradigms to initiate, elaborate or corroborate findings
Mixed method design strategies	A combination of these key ideas as a starting point for research

During the literature review, it was also recognised that a range of professionals including rheumatologists, nurses, orthotists, occupational therapists, physiotherapists as well as podiatrists can and do provide foot assessment and foot care for those with RA. The purpose of the current study was to consider both patients’ and clinicians’ perspectives. However, there was risk this aim could be compromised if some clinicians felt unable to make a meaningful contribution owing to a lack of familiarity with the assessment and management of foot complaints seen in RA, particularly as for some clinicians the percentage of time devoted to the management of foot problems is relatively small (Moore 1996). Therefore a pragmatic perspective was taken that involvement of clinicians in the current study would be restricted to those specialists who most commonly assess and manage foot complaints in RA, namely rheumatologists and podiatrists specialising in rheumatology. The views of people with RA, rheumatologists and podiatrists would be explored with an emphasis on determining the perceptions regarding the nature and extent of foot problems in RA, mechanisms of monitoring and evaluating new and on-going disease, in addition to therapeutic and referral practices. The wide range of foot complaints seen in RA and the potential impact of these complaints on broader constructs such as quality of life and valued life activities, together with the potential for differences of opinion between clinicians and people with RA, a mixed methods design strategy was considered to be the most appropriate approach. The flow chart in figure 5.1 overleaf illustrates how different methodological paradigms were used in the development of the questionnaires used in the current study.

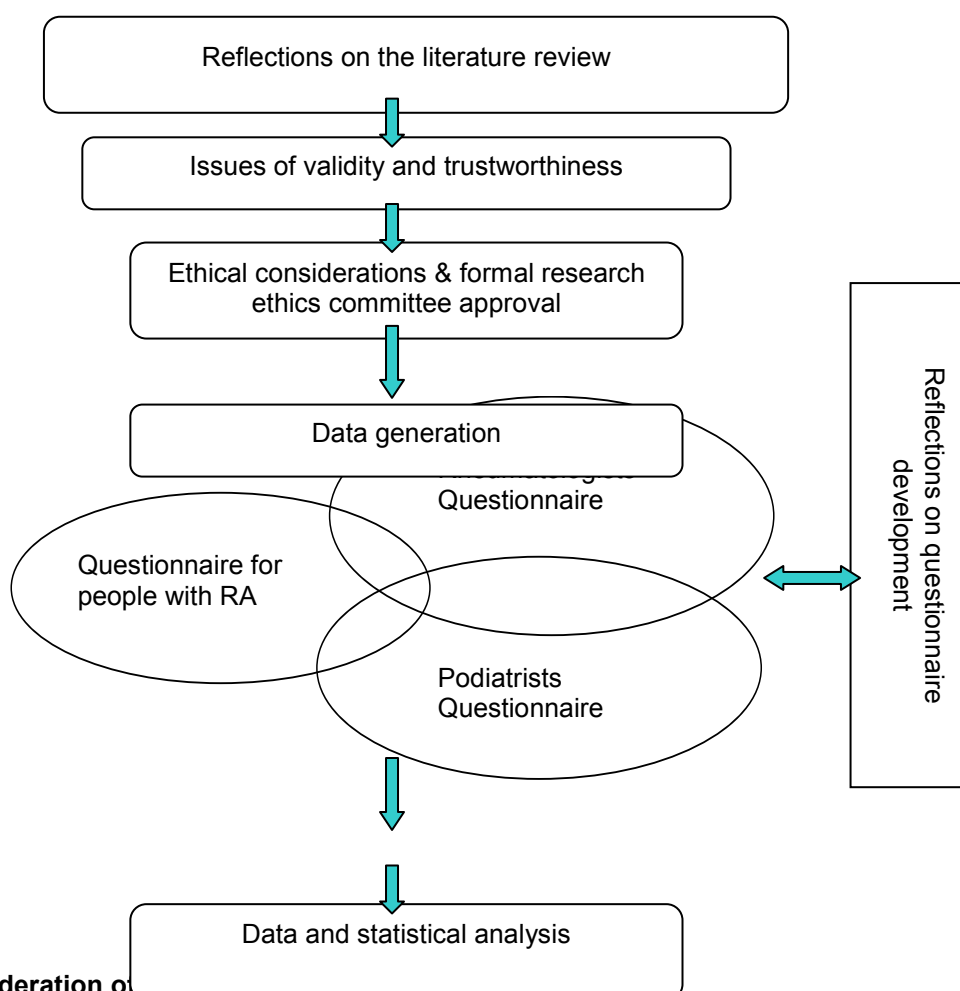
Figure 5.1 - Flow chart to illustrate phases of questionnaire development



* - The process of reflection permitted the development of one questionnaire to influence the development of others

The approach illustrated in figure 5.1 also helped to take account of the likely variations in participants' perceptions and values owing to differences in the experience of RA. For example, if a podiatrist commented a particularly novel or important aspect of assessment practice during the focus group, a similar question could be included during the development of questionnaires for other participants prior to the pilot process. Factors peculiar to clinicians such as professional culture and differences in training and education could be accounted for within a mixed methods design strategy by the use of different paradigms to explore and corroborate findings. The remainder of this chapter will detail the methodological approach taken to developing the questionnaires used to generate data, the data collection process and subsequent data analysis, as illustrated in figure 5.2.

Figure 5.2 – Diagrammatic structure of the development of tools for data collection as part of the method



5.3 Consideration of

The utilisation of a mixed methods design strategy required consideration of the principles of validity to ensure confidence in the findings of the questionnaires. Dijkers (1999) is of the opinion

that the concept of validity has been sub-divided by psychometricians into a number of different aspects, unfortunately the resultant terminology is often not universal and some confusion remains. Table 5.4 overleaf outlines the major factors associated with validity and reliability and indicate how these issues were addressed in the current study.

Table 5.4 - Issues of validity and reliability; definitions and solutions

(Adapted from; Streiner & Norman 2003, Dijkers 1999, Saltzman et al. 1998)

Concept	Sub-division	Definition	Approach used in the current study
Reliability	Internal consistency	The degree to which items within 1 dimension correlate with one another	Pilot study
	Test-retest OR stability	The extent to which measurements are repeatable over a defined period of time	Not required as repeated measurements were not taken
Validity	Content	The scale adequately covers the domain under investigation	Literature review
	Criterion	Measures success in predicting an important state or behaviour	Not applicable as questionnaires were not predictive
	Construct	Whether the instrument captures the relevant aspects of the underlying problem, in comparison with other measuring	Literature review and peer review with supervisors
	Face	Do the items appear, on the surface, to be measuring what they actually are measuring	Peer review
Responsiveness	Responsiveness	Whether changes in the attribute are reflected by changes in the scores on the instruments	Pilot study
	Sensitivity	The size of the smallest unit the instrument can distinguish	Use of scales anchored at 0 -10
Practicality	Interpretability	Ability of users to have a sense of what the numbers mean	Pilot study
	Acceptability	Is the content & length of the instrument reasonable to use in routine practice?	Follow-up questionnaire used as part of pilot study

Previously, authors have contended that the issues of validity and reliability belong to the positivist paradigm associated with quantitative research and as such have little relevance to qualitative enquiry (Lincoln & Guba 1985, Tobin & Begley 2004). The concept of trustworthiness with a series of underpinning criteria with which rigour may be demonstrated in naturalistic enquiry has been recommended (Lincoln & Guba 1985). The current study proposes to utilise a mixed-methods approach for the reasons outlined previously in section 5.2. As such the issues associated with demonstrating rigour in the qualitative element of the current project are of equal importance to the issues outlined in table 5.4. Table 5.5 outlines how the elements seen as an essential part of the concept of trustworthiness will be addressed in the present study.

Table 5.5 Issues of trustworthiness; definitions and solutions

(Adapted from Tobin & Begley 2004)

Concept	Definition	Approach used in the current study
Credibility	Addresses whether researchers explanation fits the respondents description	Peer review with supervisors
Transferability	Refers to generalisability of inquiry	Two stage sampling Large overall sample
Dependability	Ensuring process of research is logical and traceable	Use of thematic analysis Reflexive dialogue
Conformability	Establishing that interpretations are derived from data	Exemplars consisting of direct quotes to illustrate themes
Authenticity	Demonstration that researcher can express a range of different realities	Cross reference between data from different groups respondents Critical discussion of literature Discussion of research limitations

The authors who originally proposed the concept of trustworthiness (Lincoln & Guba 1985) in their seminal text highlight that in doctoral study the inquirer should avoid using members of the supervisory team for debriefing, but seek to use peers. However, in the present climate of research governance, advice from Research Ethics Committees indicated it was preferable to undertake debriefing with those familiar with the study and who represented differing professional areas (i.e. the supervisory and advisory team) rather than involving external colleagues.

5.4 Ethical considerations and formal Research Ethics Committee approval

This research sought to generate data from those with RA, rheumatologists and podiatrists. Considering data would be generated from three groups of participants, three separate applications

were made to relevant research ethics committees prior to the development of the questionnaires used to generate data. Ethical approval was sought prior to questionnaire design as it was proposed that people with RA, rheumatologists and podiatrists would be involved in the development of questionnaires that would be used to generate data.

Research Ethics Committee approval to develop and pilot questionnaires as well as to undertake final data collection from those with RA was granted from University of Brighton Research Ethics Committee (REC05-59) and Brighton and Hove Local Research Ethics Committee (06/Q1907/12). Details of ethical approval are provided in appendix 5.1 and 5.2 respectively. Ethical approval to develop and pilot questionnaires and to generate data from rheumatologists who were members of the British Society for Rheumatology was granted from University of Brighton Research Ethics Committee (REC05-53), details of approval are provided in appendix 5.3. Ethical approval to develop and pilot questionnaires and to generate data from podiatrists who were members of the Podiatric Rheumatic Care Association was granted from University of Brighton Research Ethics Committee (REC05-17), details of approval are provided in appendix 5.4.

All the prospective participants who completed a questionnaire were assured their personal details were confidential and responses to the questionnaire were anonymous. Participants were not requested to sign a consent form, consent being assumed if participants completed the questionnaire. Prospective participants who did not wish to complete the questionnaire were free to do so. A system of reminders was not used at the specific behest of research ethics committees in full agreement with the researcher. It was agreed that if someone with a chronic disease does not wish to complete a questionnaire (for whatever reason) this view should be respected and it is arguably coercive to continue to approach that person.

5.5 Development of a questionnaire with which to generate data from people with RA

5.5.1 Contributions to an item pool from which to design the questionnaire



The literature review identified several different sources from which contributions to the content of a questionnaire could be derived to enable exploration of the nature, extent and impact of foot complaints on those with RA. Reviewing the literature established a number of reoccurring themes. These were:

- Physical signs (e.g. foot deformity).
- Symptoms (e.g. pain in the feet).
- Limitation of normal function (e.g. difficulty standing or walking).
- Impact on quality of life (e.g. inability to leave the house easily).
- Restriction of social activities (e.g. unable to readily participate in hobbies).
- Effects on family (e.g. unable to fulfil household roles).
- Obtaining podiatric treatment (e.g. access to appropriate foot care).

- Psychosocial issues (e.g. uncertainty).

As a wide variety of themes were identified, it was important to ensure that the content of any questionnaire sufficiently inclusive. Therefore, the themes derived from the literature review were cross-referenced (table 5.6 overleaf) with the sources to determine which themes occurred most frequently. As table 5.6 illustrates, each of the themes identified arose from at least two different sources.

Table 5.6 - Illustration of the frequency of themes for inclusion in the questionnaire for people with RA

Source 	Questionnaire based outcome measures	Non-questionnaire based outcome measures	Expert patients	Auto-biographies	Illness narrative
Theme 					
Physical signs	●	●	●	●	
Symptoms	●	●	●	●	●
Functional limitation	●	●	●	●	●
Quality of life	●	●	●	●	●
Restriction of social activities	●		●	●	●
Effects on family	●		●	●	
Podiatric treatment	●			●	●
Psychosocial issues	●		●	●	

In a review of patient-based outcome measures used in clinical trials, Fitzpatrick and colleagues (1998) described nine dimensions (table 5.7 overleaf), which they considered to be currently assessed by patient-based outcome measures. The themes identified as part of the current study in table 5.6 appear to broadly match the dimensions considered in the review conducted by Fitzpatrick and colleagues in table 5.7, with considerable areas of overlap being evident. This suggests the areas of importance identified by people with RA have been captured by the literature review process and should provide appropriate content validity for the questionnaire.

Table 5.7 - Range of dimensions assessed by patient based outcome measures

(Fitzpatrick et al. 1998)

Physical function (e.g. activities of daily living).
Symptoms (e.g. pain).
Global judgements of health.
Psychological well-being (e.g. anxiety and depression).
Social well-being (e.g. social contact).
Cognitive functioning (e.g. memory).
Role activities (e.g. employment).
Personal constructs (e.g. satisfaction with bodily appearance).
Satisfaction with care.

Considering none of the themes identified in table 5.5 appeared to be redundant, all were included when exploring the nature, extent and impact of foot complaints in RA. The questionnaire was designed in accordance with principles outlined in texts related to questionnaire design (Oppenheim 1992, Burns 2000, Bowling 2002, Denscombe 2003, Boynton et al. 2004a-c). Recent studies using questionnaires to survey people with RA about their foot complaints (Westhovens 2005, Lohkamp et al. 2006) were also consulted for indications regarding layout and wording. In addition instruments developed for other chronic disease where foot involvement is common (notably diabetes (Bann et al. 2003)) were also consulted during the design process.

5.5.2 Pilot study for the draft questionnaire to generate data from people with RA

On completion of a draft questionnaire (detailed in appendix 6.1) members of the supervisory team with expertise in chronic disease management, psychosocial aspects of health and rheumatology assessed the inclusiveness of the questions and considered issues of face validity. The design of the questionnaire format was deliberate, being based on information integrated from the sources identified previously in figure 5.1 and following the principles outlined by Oppenheim (1996), Burns (2000), Bowling (2002), Denscombe (2003) and Boynton and colleagues (2004a-c). Therefore statistical testing of questionnaire items (e.g. Cronbach's Alpha) for internal consistency was not appropriate as many questions yielded either nominal data, or required qualitative description and therefore were unsuitable for statistical testing.

To be confident that the findings of the draft questionnaire met the aim of determining the nature and extent of foot complaints in RA, a pilot study was performed to determine validity and trustworthiness. Additionally, the continued involvement of people with RA in the development of this questionnaire would further enhance confidence in its comprehensiveness. Van Manen (1990) summarised that a person cannot reflect on lived experience without having lived through the experience therefore people with a confirmed diagnosis of RA were selected from an out-patient

University podiatry department in Southeast England. To avoid the need for additional clinic visits, twenty people with RA were asked to participate during their normal podiatry appointment. Sampling was therefore both purposeful and convenient; but achieved a male/female ratio of 3:1, which fits the existing reported epidemiological patterns for the disorder (section 2.2).

To ensure that the questionnaire was understandable and readable by respondents, people with RA involved in the pilot study were invited to complete a draft questionnaire. They were also invited to provide both verbal and written feedback on the following areas developed from Oppenheim (1992) and Denscombe (2003):

- Were the questions easy to understand?
- Was the questionnaire simple to complete?
- Did they find any of the questions ambiguous or vague?
- Did they feel there is anything missing from the questionnaire?

To ensure the draft questionnaire was meaningful to the population of interest, respondents were also invited to consider the relative importance of individual questions, as there was concern about the length of the questionnaire. Subjects were requested to rank the importance of each question by using the following descriptors:

not at all important a little important quite important very important.

This approach has been previously used and validated by others when undertaking research to determine the relative importance of outcomes to people with RA (Hewlett et al. 2001, Hewlett et al. 2002, Carr et al. 2003). The use of ranking the importance of questions further reduces the risk of introducing bias that might occur via a Hawthorne effect if the researcher asked subjects which questions were most important.

5.5.3 Researchers reflections on the pilot study findings from people with RA

Data from the pilot study together with the reflexive thoughts of the researcher suggested the first draft of the questionnaire appeared to be readily understood by respondents and easy to complete. However, there were some issues related to content. Firstly, the questionnaire did not contain any questions relating to socio-demographic issues such as age or gender. This information is required to determine if the final sample group match known epidemiological characteristics of RA. Secondly, additional socio-demographic information such as employment status might also influence the findings. For example people who work full-time, particularly in occupations where standing-up for long periods is required, may report a higher incidence of foot pain. Conversely, people with RA may have to retire early. Young and colleagues (2004) reported that approximately 30% of people with RA have to give up working within five years of being diagnosed with RA, therefore, capturing this information was considered to be important.

Some information relating to RA that would be of value had not been included. For example, how long people have been diagnosed with their arthritis and whether the duration of any symptoms (particularly in the feet) were noticeable prior to receiving the diagnosis itself. The medication(s) prescribed could also be important, for instance people taking the newer anti-TNF α inhibitors described in section 2.8 may report less pain due to the effectiveness of these newer agents than those subjects on more traditional treatments. This was determined to be a valuable *a priori* subgroup analysis that may provide additional new knowledge regarding the impact of biologic agents in the context of foot complaints.

Items related to symptoms in the feet, foot function and the effect of the foot pathology on mobility and so on, appeared to provide useful information. Some limitations were noted however, for example the anatomical location of foot pathology has been the subject of a number of reports as identified in chapter three, yet the patient's perception of this has received relatively little attention. The use of diagrams and the inclusion of more free text response formats would provide respondents with an opportunity to identify both the nature and location of foot pathologies that were most important to them. Nonetheless, care had to be taken not to invoke a Hawthorne effect. Because the draft questionnaire consisted only of questions about foot problems, this may focus respondents into thinking only about their feet, even though as noted in section 2.5, RA has a particularly adverse effect on the upper limbs and hands, therefore additional questions relating to symptoms in other anatomical locations (notably the hands) would be valuable.

Finally, the overall appearance of the questionnaire could be improved and made more attractive to prospective participants. This would have the added advantage of making the questions clearer and easier to read, elements which a number of authors (Bowling 1992, Oppenheim 1992, Burns 2000 Denscombe 2003) consider to be fundamental in good questionnaire design.

Overall, there were a number of major changes that were instituted, namely:

- Use of a tabulated format, giving a clearer, neater appearance and making the questionnaire easier to read as well as simpler to complete and score.
- Inclusion of a section on the demographic characteristics of respondents (e.g. age, gender, body mass index and so on) as well as questions relating to the features of their disease (e.g. duration of symptoms, when they were diagnosed, current medication and so on).
- Diagrams were used to provide respondents with a simpler mechanism of providing information about which parts of their feet were affected and the severity.
- Questions were included about other parts of the body (apart from the feet) to reduce the potential for a Hawthorne effect.

- Questions were included relating to the potential restrictions on quality of life due to foot problems for some respondents (see section 5.7 for details of subject selection).

5.5.4 Second pilot study of the draft questionnaire to generate data from people with RA

Considering a number of fundamental changes to the questionnaire had been instituted, a second pilot study was undertaken with the revised version of the questionnaire. Ten people with a positive diagnosis of RA were selected from the same out-patient podiatry department. Sampling was both convenient and purposive, with five of the subjects having participated in the previous pilot study and five of who had not seen the previous version of the questionnaire being selected. To match the reported epidemiological characteristics of RA the group consisted of three male and seven female subjects. The key issues of face validity, ease of understanding and completion, relevance and inclusiveness of questions were addressed as described previously in section 5.5.2. All ten respondents reported the revised version of the questionnaire was easy to understand and simple to complete, no questions were reported as being ambiguous or vague. The respondents felt the questionnaire was inclusive and no additional areas were suggested.

5.5.5 Content of the final version of the questionnaire for people with RA

The final questionnaire comprised 28 items divided into nine sections under four main headings. Both quantitative and qualitative response formats were utilised together with validated mannequins (appendix 7.1). The justification for the number and content of each group of questions is presented below in the same order as in the questionnaire.

Socio-demographic details

To effectively describe the population being studied a number of variables were enquired about. Age and gender were not only important in terms of descriptive data, but foot pain has been reported to be more prevalent in women (Munro & Steele 1998, Dunn et al. 2004) and the elderly (Menz et al. 2006), therefore similar patterns could be considered within this study. Other socio-demographic factors could also be associated with foot complaints, for example Helliwell and colleagues (2007) have questioned the potential for an association between Body Mass Index (BMI) and foot complaints, subjects were invited to include their height and weight so BMI could be calculated. Previous work has demonstrated cigarette smoking is strongly associated with both disease expression and disease severity in RA (Padadopoulos et al. 2005, Klareskog et al. 2006a, Klareskog et al. 2006b, Manfredsdottir et al. 2006) and this could apply to foot complaints leading to the inclusion of a question regarding smoking habits. Finally it was considered occupation may affect foot complaints, for example in those who stand all day therefore subjects were invited to describe their current occupation where applicable. Details of respondents' current occupation were selected instead of classification of roles into manual or non-manual categories owing to the changes in low-income work that now includes many non-manual jobs in shops and offices (Marsh & McKay 1994).

Characteristics of RA in the populations studied

To compare the work of the current study with previous findings and to determine if a representative sample of those with RA had been recruited, subjects were invited to describe how long they had been diagnosed and suffered symptoms associated with RA such as morning stiffness. Additionally these data would enable identification of the effect of the duration of RA on symptoms in the feet.

Chronological order of joint involvement during the course of RA

As described in chapter three, foot complaints are common in RA, yet there is disagreement regarding how frequently foot pain is the initial symptom of RA, particularly as diagnostic criteria often emphasize the upper limbs and hands (Arnett et al. 1998). Therefore subjects were invited to indicate where the symptoms of RA were first noted and the pattern of progression of subsequent symptoms in a range of joints.

The reported nature and prevalence of foot pathology

A series of questions enquired about the type of foot complaints people with RA reported (as opposed to the clinicians opinion reported in chapter three). Questions were included about foot pain, but also other symptoms reported in the pilot studies to be important such as stiffness and swelling. The frequency with which those with RA reported foot complaints was also considered, as were the different types of foot pathology.

The anatomical location and impact of pain in the feet

Symptoms in the feet can occur at a number of anatomical sites as described in chapter three. Therefore a series of validated mannequins were provided for subjects to highlight where foot symptoms were located. A sense of the magnitude of symptoms such as foot pain was obtained with the use to 10cm visual analogue scales (VAS). The anchors for the scale for magnitude of foot pain were „no pain“ and „worst pain ever“. A VAS was selected as it has been suggested this scale is more responsive than five point Likert scales or 11 point numerical rating scales (Bellamy 2005a). Subjects were provided with the opportunity to comment on the severity of symptoms in their feet and the impact of foot complaints on other aspects of their life.

Medical management of respondents RA - the patients' perspective

As part of the characteristics of RA in the populations studied, subjects were invited to detail which disease modifying medication(s) were currently being prescribed. It was considered that medication might have an impact on foot complaints, further strengthening the rationale to enquire about this aspect of patients' care.

Perceptions of foot assessment by clinicians from those with RA

Previous authors have highlighted the importance of a systematic approach to joint assessment in RA (Doherty et al. 1992, Coady et al. 2004). However, it has been suggested this may not always extend to the feet (Woodburn & Helliwell 1995, Korda & Balian 2004). Therefore the experience of those with RA of foot assessment was considered to be particularly important in this context

Management of foot complaints from the patients' perspective

Following on from the assessment of foot complaints and the work of others regarding the availability of foot care (Redmond et al. 2005), a series of questions enquired about whether respondents were in receipt of specialist foot care, what types of treatment were available and concordance with treatment.

The impact of foot complaints on quality of life

A previous international study highlighted the negative impact of foot complaints on quality of life (Katsambas et al. 2005). Given the range of foot complaints seen in RA five questions were included to determine the impact of foot complaints on quality of life in RA. It should be noted however, that these questions were only provided to respondents in the second cohort who were geographically closer to the researcher's place of work. Quality of life is a complex construct (Allinson et al. 1997, Carr & Higginson 2001), therefore additional data could be generated more readily using a follow-up interview with those subjects who lived locally as work separate from this thesis.

5.5.6 Selection of people with a diagnosis of RA for data collection

To generate sufficient data to develop meaningful conclusions, a large group of participants were required. To gather sufficient data from people with RA, as well as overcoming potential difficulties such as low response rates and consequent poor reliability would potentially require relatively large samples (Wolfe 2007). Collaboration was sought with Brighton and Sussex Medical School (BSMS) and the National Rheumatoid Arthritis Society (NRAS) to gain access to databases of those people with RA. Potential respondents were invited to participate via a postal questionnaire that included stamped addressed envelopes for return of the completed questionnaire. The sampling frame for this study was people diagnosed with RA by the consultant rheumatologist in charge of their care. Two groups of subjects were identified: the first group comprised all members (n=650) of the UK National Rheumatoid Arthritis Society (NRAS) (a group providing information, education and support for people with RA, their families and carers). However, it was considered that these respondents (motivated to join NRAS and receiving support from this group) might not be representative of the wider RA population. Therefore, a second cohort (n=390) were recruited, comprising all patients with RA attending outpatient appointments at three different hospitals over the course of one month (May 2005) in a Teaching Hospital NHS Trust (Brighton and Sussex University Hospitals (BSUH)) in the UK. The inclusion/exclusion criteria are detailed in table 5.8.

Table 5.8 - Inclusion and exclusion criteria of people with RA for the main data collection

Inclusion criteria	Exclusion criteria
Confirmed diagnosis of rheumatoid arthritis by a Consultant Rheumatologist	Age <18 years. Diagnosis of Juvenile Idiopathic Arthritis. Diagnosis of an Inflammatory arthropathy other than RA (e.g. Psoriatic arthritis).

Subjects below the age of 18 were excluded because comparing the expressed thoughts of children with inflammatory arthritis with those of adults given the differences in social, developmental and emotional maturity would be outside the remit of this thesis. Consideration was given to an upper age limit of 75 years due to the increased likelihood of osteoarthritis. However, while previously the peak age of onset of RA was generally considered to be in the fourth or fifth decade (Duthie & Bentley 1983, Huskisson 1987); more recent reviews of the epidemiological data suggested this is rising and peak onset is now in the sixth decade (Scott et al. 1998). Conceivably therefore people may develop RA in their seventies or even eighties and so an upper age limit was not imposed. Juvenile Idiopathic Arthritis apart from affecting children is considered to have a different pathogenesis and would require separate domains within the questionnaire owing to issues such as growth retardation (Caselli et al. 1998, Falcini & Cimaz 2000). Finally, different inflammatory arthropathies have distinctly diverse disease patterns and manifestations. To include other conditions would require separate domains within the questionnaire as suggested by the recent development of outcome measures for arthropathies other than RA (Garret et al. 1994, Isenberg et al. 2003) and so these were not included.

5.6 The development of a questionnaire with which to generate data from rheumatologists

5.6.1 Methodological approach to the development of a questionnaire for rheumatologists

The purpose of surveying rheumatologists was to ascertain current practice with regard to the examination and investigation of foot complaints, determine which outcome measures rheumatologists use to monitor foot pathology and explore referral practices for foot complaints. Little published literature exists on how rheumatologists assess the foot/lower limb therefore simply basing a questionnaire on the literature was not possible. Previous authors have used „paper patients“ (i.e. forms giving values for clinical variables before and after treatment), but reported that opinions expressed by rheumatologists might differ from their actual clinical practice (Kirwin et al. 1983, 1986), particularly with regard to key clinical variables that might be important in the feet, such as extra-articular features. The paucity of literature relating to how rheumatologists actually assess and monitor foot complaints suggested the researcher required to facilitate a discussion rather than conduct an interview guided by a pre-determined schedule. It has been proposed that focus groups are particularly useful to generate information for constructing questionnaires (Gibbs 1997, Krueger & Casey 2000). In particular, the attitudes, beliefs and feelings are thought to be more likely to be revealed via the social gathering of a focus group and the interaction this permits allowing a multiplicity of views to be elicited from the group (Gibbs 1997). Individual face-to-face interviews with a series of rheumatologists were considered, but not only were logistically difficult to achieve, but also may not provide the consensus required to develop a data collection instrument. Therefore a focus group was used as a starting point to develop a tool to gather this information from rheumatologists.

5.6.2 Participants in focus group discussions

Purposive sampling of local rheumatology departments identified three rheumatologists who held joint academic and clinical posts, thus being well placed to inform debate regarding clinical practice and training of rheumatologists. Together with members of the supervisory team, the focus group discussion centered on how rheumatologists undertake consultations with people with RA. The researcher facilitated the group and took field notes as part of the role of moderator. A further member of the supervisory team took notes as the assistant moderator. The guidelines for these roles outlined by Krueger and Casey (2000) were adhered to. The small size of the focus group was deliberately planned partly owing to the extensive experience of the rheumatologists participating as all were at senior consultant grade. Additionally, the relatively small size of the focus group permitted a more in detailed consideration of how foot complaints in RA are assessed and monitored are part of the wider consultation process. The focus group discussion was held at a medical school in the South East of England.

5.6.3 Structure and content of the focus group discussion with rheumatologists

Following a brief summary of the aims and objectives pertaining to this part of the thesis, discussions centred around three broad areas:

- History and examination

Rheumatologists undertake a systematic approach to the history and examination of people with musculoskeletal complaints (Gibson 1986, Dawes 1995, Coady 2005). The researcher, not being a rheumatologist, wished to enquire how this approach was applied specifically to foot complaints. The group considered what rheumatologists might ask about foot complaints and subsequently how a foot examination might progress in the context of what valuable information this might provide about the patients' overall disease in addition to the examination of complaints specific to the foot.

- Tests and investigations

Rheumatologists routinely use investigations such as a series of blood tests to help exclude specific diagnoses (Dawes 1995). It was considered important to determine whether rheumatologists would order specific tests/investigations for foot complaints and under what circumstances as the team felt there might potentially be a wide variation in practice.

- On-going monitoring of foot complaints

Consistently throughout the literature (discussed in section 2.6) it has been reported that some recommended outcome measures do not include the feet as part of the assessment process. The group discussed whether rheumatologists relied on such measures, undertook additional foot assessment or utilised any of the foot specific outcome measures reviewed in appendix four.

5.6.4 Analysis of focus group discussions with rheumatologists and validation of findings

Notes from the focus group discussion were analysed based on a thematic analysis method described by Van Manen (1997) and Marczak and Sewell (2006) involving the steps detailed in table 5.9. This type of thematic analysis is deemed by Fitzgerald (2005) to be the most effective approach to analysing information from focus groups.

Table 5.9 - Steps for thematic analysis

Van Manen (1997) and Marczak and Sewell (2006)

Both sets of field notes from the focus group discussion were read	
At a second reading sections from the field notes were marked according to factors that related to each section identified in section 5.6.3.	
When conducting analysis consideration was given to five factors;	
Words	The actual words and meanings of these words were determined and similar concepts clustered together

Context	Context of words was examined by finding the triggering stimulus and interpreted in light of that context.
Internal consistency	Changes were noted that occurred after interaction with others.
Specificity of responses	Responses that were specific and based on experiences were given more emphasis than responses that were vague and impersonal.
Themes	The trends or ideas that cut across the entire discussion were sought
Once analysis is complete a descriptive report is presented that interprets the meaning of the data	

To maintain trustworthiness a process of respondent validation was carried out. This process consisted of focus group participants being invited to read through the textual analysis to check this account truly reflected what they said. This process took place less than one month after the initial focus group. Participants agreed that the text was a true reflection of the discussion.

5.6.5 Development of the focus group discussion with rheumatologists and the emergence of themes

Information from the focus group discussions, integrated with information from the literature (Doherty et al. 1992, Dawes 1995, Coady et al. 2004, 2005, Woolf 2004) suggested that when consulting people with RA, rheumatologists may take different approaches to the assessment of foot complaints depending on several factors,

- If the consultation was the first encounter or a follow-up appointment
- If a definite diagnosis had been reached
- How the patient was progressing
- Whether any complications had been reported
- Findings of routine tests and investigations
- What the purpose of that appointment was (e.g. a review and/or change in medication)

Overall rheumatologists participating in the focus group agreed that consultations were usually divided into five phases as detailed in table 5.10.

Table 5.10 - Phases of a patient consultation

Open phase	Active listening to patients' complaint
History	Symptoms and their impact Symptom chronology - both temporal and anatomical

Examination	Musculoskeletal system GALS (gait, arms, legs, spine screening) REMS (regional examination of the musculoskeletal system) Systematic examination
Investigations	Diagnostic tests Monitoring tests and outcome measures
Conclusion	Analysis & Interpretation of findings to determine a management plan

In terms of actual foot assessment (parts of the GALS and REMS screen), there was general agreement that the following areas would normally be considered:

- Observe deformities.
- Assess skin temperature.
- Palpate foot pulses.
- Squeeze the metatarsophalangeal joints.
- Palpate and assess movement in the mid-tarsal, sub-talar and ankle joints.
- Review footwear.
- Assessment of the patient standing.
- Assessment of the gait cycle.

One area however, that could not be resolved was whether rheumatologists would undertake the assessment of foot complaints and subsequent referral/management differently in those people with newly diagnosed RA as opposed to those whose diagnosis was an undifferentiated inflammatory arthropathy. Determining any differences in approach was considered important owing to the increased recognition of the early stages of RA described by rheumatologists in recent years (Emery et al. 2003, Altheta et al. 2004) as previously outlined in section 2.3. It was considered that the only way to resolve this was during the piloting stage of questionnaire development, by using two separate questionnaires to determine whether foot complaints in people with early RA were assessed differently from those with an undiagnosed inflammatory arthropathy.

5.6.6 Design of draft questionnaires to generate data from rheumatologists

Based on the phases of the consultation identified in table 5.9, two questionnaires were initially devised. One to determine if and subsequently how rheumatologists assess, examine and monitor the feet in a case of early RA, the other questionnaire being for an undifferentiated inflammatory arthropathy. Each of the questionnaires used the same basic structure and was based on a brief case scenario followed by ten questions across five domains based on sections outlined in table 5.6 and 5.10. A mix of both structured and unstructured response formats were selected with the aim of maximising the data gathered while keeping each questionnaire to an acceptable length. The draft questionnaires (detailed in appendix 6.2) were reviewed by members of the focus group to ensure face validity.

5.6.7 Selection of subjects to participate in a pilot study of draft questionnaires to generate data from rheumatologists

A pilot study using both questionnaires with a group (n=10) of rheumatologists with a special interest in outcome measurement from a database held by the Early National Arthritis Network (www.nwtrac.com/eras/contacts.htm (accessed 10.3.2006)) was conducted during a national rheumatology conference. This group was specifically chosen owing to their interest and expertise in designing and using questionnaire based outcome measures in rheumatology practice. The purpose of this pilot was two-fold. Firstly, to determine whether rheumatologists' approach to early RA differed from their approach to an undifferentiated inflammatory arthropathy. Secondly, to consider how clearly questions had been interpreted as the responses to the draft questionnaires provided an indication of how well the questions had been understood. The issues of face validity, ease of understanding and completion, relevance and inclusiveness of questions were addressed as described in section 5.5.3.

5.6.8 Researchers reflections on the pilot study with rheumatologists

Data from the pilot study with rheumatologists revealed some possible weaknesses. Some questions appeared to cause misunderstanding, for example, in the first question asking about history taking the use of the word „systematically,, appeared to be confused with „consistently“. One respondent did write that although a history of foot problems was taken it could not be considered systematic.

In terms of description of foot examination there were some unacceptable inconsistencies in the results. For example, while nine out of the ten rheumatologists reported that they examined the feet, seven respondents did not report examining the skin. It seemed unreasonable to suggest that while examining the feet, a rheumatologist would not see skin lesions, particularly as assessment of the skin was specifically mentioned in the focus group discussions. This suggested the phrasing of this question and/or the response format was unclear.

In responses to questions about routine investigations, only one respondent noted they undertook an ESR, yet this blood test is routinely undertaken in rheumatological practice as a marker for inflammation (Moots & Jones 2004). This suggested rheumatologists did not link particular blood tests with inflammatory disease in the foot; again this needed to be made clearer in the question.

Responses to questions relating to outcome measurement were more helpful in that it was clear rheumatologists did routinely use outcome measures in their practice and were clear about which measures were being used.

Perhaps more importantly, no differences were noted with regard to the assessment of people with early RA compared with those with an undifferentiated inflammatory arthropathy, suggesting that a single questionnaire would be required as opposed to two questionnaires as had been piloted. However, the overall lack of clarity suggested the questionnaire required redesigning and the focus group was reconvened to undertake this task. A series of major changes to the structure and content of the questionnaire for rheumatologists were instituted, namely:

- The development of a single questionnaire, which incorporated sections of both draft questionnaires.
- Use of a tabulated format, giving a neater appearance and making the questionnaire easier to read as well as simpler to complete and score.
- The wording of all questions was revisited and altered to enhance clarity.
- Inclusion of a section on the demographic characteristics of respondents (e.g. where respondents worked, their experience and so on).
- Fewer questions requiring free text and more use of response formats such as 10cm visual analogue scales and tick-box formats that would provide respondents with a simpler mechanism of answering questions. Although this would yield more ordinal data, it was felt this approach might also encourage greater completion rates.
- Questions were added relating to referral practice to other professions.

The re-design of the questionnaire followed the principles outlined by Oppenheim (1996), Burns (2000), Bowling (2002), Denscombe (2003) and Boynton and colleagues (2004a-c).

5.6.9 Second pilot study with the draft questionnaire to generate data from rheumatologists

Considering a number of fundamental changes to the questionnaire had been instituted, a second pilot study was undertaken with the revised version of the draft questionnaire. The second draft of the questionnaire was returned to those involved in the original pilot study for comment by email. As described in section 5.5.2, those participating in the second pilot study were also invited to provide feedback on the following areas developed from Oppenheim (1992) and Denscombe (2003):

- Were the questions easy to understand?
- Was the questionnaire simple to complete?
- Did they find any of the questions ambiguous or vague?
- Did they feel there is anything missing from the questionnaire?

No further suggestions for improvements to the questionnaire were made from those participating in the second pilot study.

5.6.10 Content of the final version of the questionnaire for rheumatologists

The final questionnaire comprised 23 items divided into six sections. Both quantitative and qualitative response formats were utilised, (appendix 7.2). The justification for the number and content of each of the questions is presented below in the same order as in the questionnaire.

The epidemiology of foot complaints

A series of questions invited respondents to detail the nature and extent of foot complaints seen in RA from the perspective of the rheumatologist, in order that these findings could be compared with the views of those with RA. Additionally, rheumatologists were invited to indicate the frequency with which commonly occurring foot pathologies were reported by their patients.

Rheumatologists' assessment and examination of foot complaints

The assessment and examination practice of rheumatologists during consultations of people with RA was the subject of a series of questions to determine the triggers for foot assessment in different clinical situations. In addition, the approach taken to ordering common tests (such as X-rays of the feet) was enquired about and compared with the approach to examination of the hands.

Referral of people with foot problems

Rheumatologists were invited to indicate which health professional(s) they referred their patients with foot complaints to (if at all), and with what frequency. As explained in section 5.2, while the current study examined the nature and extent of foot complaints from the perspective of people with RA as well as rheumatologists and podiatrists, it was recognised that a number of other health professionals can be involved in providing specialist foot care. Therefore it was deemed necessary to identify the frequency with which these services were utilised.

Availability of local foot care services

Following the work of Redmond and colleagues (2005), this section of the questionnaire enquired about not only the availability of podiatric care (as different from specialist foot care delivered by other health professionals), but also the likely triggers for referral to podiatry services.

Use of outcome measures

In section 2.7 commonly used outcome measures were discussed, two questions were included to determine which outcome measures (if any) were routinely used, and if foot-specific outcome measures were used by rheumatologists.

Demographic details

A limited number of questions relating to respondents' demographic characteristics were included. It was thought to be helpful if respondents would indicate how long they had been in practice so any differences between those newly qualified and those with more experience could be determined. Additionally, where rheumatologists were based and their gender was included so that the cohort could be described and seen to be representative of the rheumatologists practising in the UK.

5.6.11 Selection of rheumatologists for the main data collection

The sampling frame for rheumatologists was taken from the register of „ordinary“ members (as opposed to those members who were listed as retired or non-clinical) of the British Society of Rheumatology (BSR). To comply with the principles of the Data Protection Act (1998), access to the register was in conjunction with BSR members from Brighton and Sussex Medical School. The questionnaire was forwarded to every other ordinary member of the British Society of Rheumatologists (BSR), based on the 2003 BSR members“ handbook (this was the most up to date version available at the time of the study). This approach provided a possible sample of n=414. This stratified sampling frame limited potential sampling errors by reducing the possibility that certain groups would be over-represented, (e.g. experienced rheumatologists compared with those more recently admitted to the speciality), while providing a meaningful sample that was not so large as to be unmanageable in the timeframe permitted by the PhD process (Coggon et al. 2003).

5.7 Development of an item pool from which to design a questionnaire to generate data from podiatrists

5.7.1 Methodological approach to the development of a questionnaire for podiatrists

The purpose of using a questionnaire to survey podiatrists was to identify and explore in detail the approaches and methods podiatrists use to assess, evaluate and manage the foot and lower limb in RA. As with rheumatologists, there was little published literature relating to how podiatrists specialising in rheumatology assess the foot/lower limb, therefore simply basing a questionnaire on the literature was not possible. For the same reasons outlined in section 5.5.1, focus group discussions with podiatrists were considered to be the most appropriate method of generating an item pool from which to develop a questionnaire. The researcher recognised that undertaking a focus group with fellow podiatrists required meticulous consideration. For example, as Koch (1996) points out, during discussions in focus groups the act of listening is important such that the researcher hears what is actually being said rather than placing their own interpretation on what is being said. Equally, in the traditional positivist quantitative paradigm the researcher remains distant from the object of the study, whereas the qualitative paradigm recognises that the researcher's background influences the study (Coyle & Williams 2000). However, both Koch (1996) and Bowling (2002) suggest divorcing oneself from one's own professional culture is not desirable as such values make research more meaningful. Therefore in the current study, the researcher by reflecting on one's own ontological position (section 5.1.1) could provide an enhanced depth of insight coming from within the podiatry profession, providing that the background of the researcher is acknowledged when reflecting on the focus group discussion.

5.7.2 Participants in focus group discussion

Purposeful sampling of the three local NHS podiatry services revealed only two podiatrists with extensive experience in managing patients with rheumatological disorders in both the acute and community setting. In addition, these professionals had expertise in other „at risk“ foot conditions, notably diabetes and wound management. This experience provided a greater breadth to the discussions, as the management strategies for people with different chronic conditions could be compared. Two members of the supervisory team were also present, specifically for their extensive expertise in podiatric care, wound management and health psychology. Therefore the focus group consisted of five people, which including the researcher totalled four podiatrists. The facilitation and moderation of the focus group discussion was undertaken in the same way as described previously in section 5.6.2. Similar to the focus group conducted with rheumatologists, the relatively small size of this group permitted a more detailed exploration of the subject areas than would have been possible with a larger group.

5.7.3 Structure and content of the focus group discussion with podiatrists

As an introduction to the focus group discussion, the aims and objectives of the current research study were outlined, as well as the purpose of the focus group discussion. Topics for the focus group session were specifically selected to closely match the objectives for this section of the current study outlined in section 1.2. These topics were and similar to the issues discussed with rheumatologists described in section 5.6.3 and considered key areas pertinent to clinical practice. Trigger questions (detailed in table 5.11) to facilitate the discussion were grouped under three broad headings:

- The assessment and monitoring of foot complaints.
- Referral patterns.
- Service development.

Table 5.11 - Trigger questions for the focus group discussion with podiatrists

Please can you describe the process you undertake when assessing a patient diagnosed with RA in your clinic
As part of this assessment process do you carry out any clinical measurements (such as joint range of motion), if so what do you measure?
Do you assess people standing and walking, if so what are you looking for?
Do you enquire about people's quality of life?
What do people with RA tell you about their feet & how this affects them day-to-day?
How are people with RA referred to your service?
Do you feel the referral process is effective?
How do you think the podiatry service could be improved for people with RA?

The assessment and monitoring of people with RA was the first topic to be discussed. Firstly, what aspects of foot assessment podiatrists undertook with people with RA would highlight aspects of assessment podiatrists considered to be important. Secondly, how these assessments are undertaken in practice. For example, how pain is recorded would outline the type of information podiatrists elicit from their patients. This was valuable information, not only to compare with the approach to assessment undertaken by rheumatologists, but also to consider how this information compared with what people with RA determined was important. Additionally, the literature search suggested the assessment (and measurement) of joint function predominated and it would be valuable to confirm or refute this report with a view to including this element of practice. Within this section the use of validated outcome measures was also considered.

Referral patterns both to podiatry services and from podiatrists were discussed in detail. This was considered to be important because how people with RA access the podiatry service may affect the assessment process. Additionally, whether podiatrists refer people to other health professionals may influence what information they record.

How podiatrists would wish to develop rheumatology services within podiatric practice was also explored to determine any barriers that podiatrists perceive exist which may hinder the provision of foot care services.

Finally, through the course of the focus group discussion it became clear that patients told podiatrists about their disease and how it impacts on their quality of life, information that may not be discussed with other healthcare providers. The iterative nature of the focus group discussion permitted this topic to be explored in greater depth. This was particularly illuminating because such issues are not widely discussed within the podiatric literature. Podiatrists tend to spend more time than most health care professionals in one-to-one consultations with patients owing to the time psychomotor-based practice (e.g. callus reduction) takes. It was therefore valuable to know if what patients say is incorporated as part of the assessment process; additionally this information could be contrasted with how podiatrists undertake their assessments.

Members of the focus group were invited to reflect upon and comment on the broad areas of practice identified above. In common with rheumatologists, the focus group discussions with podiatrists were not constructed around a formal interview schedule, thus allowing a fuller exploration of the topics that were deemed to be important by the group. Focus group discussions were predicated on the understanding that patients seen by podiatrists would have a confirmed diagnosis of rheumatoid arthritis by the time of their first consultation with a podiatrist. Members of the group were encouraged to ask for clarification or expansion of ideas during the discussion. Finally, at the end of the session group members were asked if they had any questions for the researcher or additional points to make.

5.7.4 Analysis of focus group discussions and respondent validation

The analysis of the field notes from the focus group discussions with podiatrists were analysed in the same manner as described in section 5.6.4 with the steps detailed in table 5.8 being followed. Once complete, findings based on the analysis of field notes were returned to members of the group for validation that the content of the focus group discussions had been accurately and fully captured.

5.7.5 Development of focus group discussions and emergence of themes

As suggested by the literature review and confirmed by the focus group discussion, a large part of the podiatrists' assessment process focused on non-weight bearing examination of joint function. This provides a baseline for future assessments and enables differential diagnosis of foot pathologies that may present as part of, or separate from an inflammatory arthropathy. Joint range of motion was not usually measured. Pain was typically assessed using a 10cm visual analogue

scale, suggesting these practitioners found such a scoring mechanism useful in a busy clinic. In addition to the musculoskeletal system, which is predominantly affected in rheumatic complaints, other physiological systems that may affect lower limb function (notably peripheral vasculature and neurological function) were also assessed. In terms of weight bearing assessments, gait and static stance were considered, however some of the common criteria for normality (e.g. Root et al. 1975) commonly used within podiatry were thought to be inappropriate when dealing with systemic diseases such as RA.

Podiatrists reported that because patients often spend up to 30-40 minutes with a practitioner on a one to one basis (an approach more akin to complementary medicine appointments (Rose 2006)), their patients had more opportunity to tell them about a wide range of issues, including how their arthritis affected them in social, domestic and work settings and how this made them feel. This is information that perhaps few other health professionals are privileged too, yet because of the somewhat isolated nature of podiatric practice (Mandy 2000, Mandy & Tinley 2004), such information may not be drawn on to enhance care. The podiatrists involved in this discussion were aware that their patients tended to unburden some of the emotional impact of the disease during their podiatry treatments and they felt this was potentially valuable for patients.

One of the more interesting aspects of the discussion from the researcher's perspective was how the disease not only affected the sufferer but also significant others. One example given by the podiatrists in the focus group was how these issues might manifest in the selection of footwear, with male partners in particular having a dominant role in the choice of socially acceptable footwear, irrespective of the medical needs of the wearer. It may be possible that the issues surrounding footwear may indicate how the disease may affect relationships. Some expert patients (Bosworth 2004) have indicated how their role within the home has changed since they were diagnosed with RA and they are increasingly dependent on family members, particularly their spouse. These issues of not being able to fulfil the household roles to which they aspire may lead to feelings of guilt and inadequacy. Alternatively, or possibly in addition, the issue of body image may well be of importance here. This was an area repeatedly referred too in the autobiographical work of Peterson (2001), possibly because people with RA may perceive themselves to be disfigured enough, without having to wear unfashionable shoes, leading to feelings of resentment.

Part of the focus group discussion considered how the process of receiving a referral from a rheumatologist or other health professional could be improved such that patient care is enhanced. This aspect of the discussion was important because the issues of referral to and from other healthcare professionals was closely linked to the theme that podiatrists are in a strong position to improve the overall care for people with RA, owing to the richness and detail of the information their patients reveal to them during the course of podiatry treatments. However, focus group

members were disappointed with both the timing and quality of the referrals they received. It was felt by members of the group that the care for rheumatology patients could be improved and streamlined, as podiatrists' skills were not being fully utilized and this aspect required further exploration in the main data collection.

5.7.6 Design of a draft questionnaire to generate data from podiatrists

Reflections on the focus group discussions with podiatrists indicated the structure of the questionnaire required three broad domains:

- How podiatrists currently undertook their assessments of people with RA such that information regarding the assessment of foot pain, foot function, gait, general foot health and use of existing outcome measures was included.
- How patients with RA describe their disease to podiatrists.
- How podiatrists would ideally like to assess and manage their patients with RA.

A draft questionnaire was developed along the principles outlined by Oppenheim (1996), Burns (2000), Bowling (2002), Denscombe (2003) and Boynton and colleagues (2004a-c) utilising the information generated from the focus group together with approaches to questions used in previously validated questionnaires in rheumatology (Lohkamp et al. 2006, Matricali et al. 2006) and other chronic diseases where foot involvement is common, for instance diabetes (Bann et al. 2003). A mixture of structured and unstructured questions was used throughout the draft questionnaire as part of the mixed methods approach adopted by the current study. The draft questionnaire developed from this process is detailed in appendix 6.3.

5.7.7 Pilot study of the draft questionnaire to generate data from podiatrists

Podiatry is a relatively small profession in terms of membership compared to some other Allied Health Professions, yet there is a wide-range of sub-specialities within the profession. To ensure the questionnaire was as inclusive as possible, podiatrists currently working in a wide range of sub-specialities from a variety of centres in the UK were contacted and invited to participate in the pilot study; therefore sampling was purposive (Bowling 2002). For the pilot study podiatrists (n=10) from the following clinical specialities were requested to complete the draft questionnaire:

Rheumatology	(n=2)	Diabetes	(n=1)
Wound care	(n=1)	Dermatology	(n=1)
Biomechanics	(n=2)	Private practice	(n=1)
Podiatric surgery	(n=1)	Psychosocial aspects of health	(n=1)

As described in section 5.5.2, those participating in the pilot study were also invited to provide verbal or written feedback, again using the areas developed from Oppenheim (1992) and Denscombe (2003) described in section 5.5.2 and 5.6.9.

5.7.8 Reflections on the pilot study of the draft questionnaire for podiatrists

In general the responses to the draft questionnaire were favourable, it was easy to understand, found to be simple to complete and the questions were felt to be inclusive. It was commented on that for two pairs of related questions, respondents found it difficult to differentiate between these questions as the wording was too similar. Therefore the stem of those particular questions was re-worded to improve clarity.

In terms of answering the questions, the yes/no format was thought to be restrictive and greater differentiation was required to gain a better understanding of podiatrists' current practice. A five-point Likert-type scale was considered, however this would still not enable direct numerical comparison, as ordinal data would be produced. As a compromise the „yes/no“ format was altered to „yes/sometimes/no“.

Although respondents found the questionnaire easy to complete, more space was required for three questions where a free text response was invited. Finally, the only item respondents thought to be missing was a question relating to the assessment of footwear and shoe wear patterns, therefore a question pertaining to this was added. Following these changes the revised questionnaire was returned to the pilot study group, where no further amendments were suggested.

5.7.9 Content of the final version of the questionnaire for podiatrists

The final questionnaire comprised 18 items divided into four sections. Both quantitative and qualitative response formats were utilised and an example of the final questionnaire is included in appendix 7.3. The justification for the number and content of each of the questions is presented below in the same order as in the questionnaire.

Assessment of foot complaints in RA

Podiatrists were invited to describe the type and frequency of foot assessment they undertook when seeing someone with RA via a series of questions relating to examination of the patient both seated and when standing/walking. Respondents were invited to describe in detail their assessment process such that the comprehensiveness of the assessment could be compared with the approach taken by rheumatologists and the opinions of those with RA.

Information provided by those with RA during consultations

An important aim of the current study was to understand the nature and extent of foot complaints in RA. In addition to asking those with the disease it was also possible to draw on the strength of the lived experience of RA in the context of what is reported to practitioners. Podiatrists were invited to describe what their patients had said to them when receiving treatment in terms of the symptoms

experienced in the feet, the impact of foot complaints on mobility, activities of daily living and quality of life.

Outcome measurement

As with rheumatologists, podiatrists were also invited to indicate which outcome measures they used in their practice, but also what outcome measures they would like to use and to identify any barriers that prevented them doing so.

Provision of specialist foot care

Previous authors have reported foot care is limited for some people with rheumatic diseases (Williams & Bowden 2004, Redmond et al. 2005). In the current study podiatrists were invited to identify factors that would enhance the podiatric care they could provide for those with RA.

5.7.10 Selection of podiatrists for the main data collection

The sampling frame for podiatrists consisted of all members (n=78) of the Podiatric Rheumatic Care Association (PRCA). This group was chosen for two reasons. Firstly, members have a special interest in rheumatology and as such would probably be more likely to be interested in this research and complete the questionnaire. Secondly, as rheumatology specialists these podiatrists regularly undertake consultations with people with RA and therefore are more likely to be familiar with the issues being addressed by the questionnaire. In contrast, podiatrists who specialise in other areas or undertake general podiatric practice may see people with rheumatic disorders relatively infrequently, making the questionnaire much more difficult for them to complete. To comply with the Data Protection Act (1998) and ensure anonymity the covering letter and questionnaire were forwarded to the secretary of the PRCA who posted these to members of the group. Each postal questionnaire contained a stamped addressed envelope to facilitate ease of return.

5.8 Data analysis and presentation

5.8.1 The analysis of quantitative data from respondents

Quantitative responses from completed questionnaires were initially entered into three Excel spreadsheets, one for each group of respondents. Details of response rates are presented in each of the results chapters. Quantitative data for statistical analysis were then exported into SPSS (v14). The analyses of quantitative data were undertaken according to a pre-defined protocol. Initially the data sets were examined for overall accuracy, with box plots and scatter graphs used to view the spread of responses (the raw data from the current study is available on the compact disk in appendix 8). Responses that fell outside the 95% confidence intervals were re-checked against the raw data for accuracy – details of this process are provided in the results chapter.

Socio-demographic characteristics of each group of respondents (people with RA, podiatrists and rheumatologists) were described using descriptive statistics, (mean, median, range \pm standard deviation). Additionally histograms, pie charts and where appropriate annotated illustrations were used to provide a visual interpretation. More complex data were tabulated then described in a similar manner.

Inferential statistics were used to test for significant patterns within each data set. Assuming data met the generally accepted conditions for parametric testing (Field 2005), for continuous variables, unpaired two-tailed Students t-tests were used for comparing the means of groups. One-way analyses of variance (ANOVA) were used to compare categorical independent variables and continuous variables. Where an ANOVA test suggested a significant difference between categorical and continuous variables, where appropriate Tukey's HSD *post-hoc* multiple comparison test was applied to compensate for the risk of a type I error¹ occurring (Vogt 1999, Field 2005). To test the relationship between continuous variables, a Pearson correlation coefficient was applied to measure the degree of linear association (Gore & Altman 1982). For independent categorical variables the Chi square tests were used to compare components (Field 2005). Throughout, significance was set at the 95% confidence level ($p < 0.05$). Statistical advice was sought from the University of Brighton, School of Mathematics and Computer Science.

It was expected that response rates would be less than 100%. In order to adjust for this estimates were calculated based on a series of assumptions regarding those who and did not respond to the questionnaire. A summary of these assumptions is provided here, following the methodological approach outlined by Ferry and colleagues (1998):

1. The first estimate is based on the total number who responded to the questionnaire.

¹ A type 1 error occurs when it is believed there is a genuine effect on the population, when, in fact, there is not.

2. A second estimate assumes a similar symptom distribution for the non-responders as for those who did respond.
3. A third estimate assumes the non-responders did not have any of the symptoms reported by those who returned the questionnaire.

This generates prevalence estimates based on the entire number of people with RA (n=1040) who received a questionnaire. One estimate assuming that all non-responders were asymptomatic provides the minimum estimated prevalence, and the second estimate assuming a similar prevalence of symptoms among non-responders to that among responders. It is likely that the true prevalence figure lies between these two assumptions.

Finally, two *a priori* sub-group analyses were planned based on the results from those with RA. Firstly, foot complaints in those people taking biologic therapy for their RA. Respondents in this group were recoded and data regarding foot complaints were compared to those people not currently taking biologic therapies. Secondly, people from the BSUH cohort were invited to respond to a series of five questions designed to explore how foot complaints affected their quality of life. It is intended to follow-up these findings with one to one interviews as work separate from this thesis.

5.8.2 The analysis of qualitative data from respondents

During the development of the questionnaires, it was considered that entirely structured response formats might conceivably miss important information respondents wished to provide. Therefore, as recommended by texts guiding questionnaire design (Bowling 1992, Oppenheim 1992, Burns 2000, Denscombe 2003), opportunities were provided for free text in addition to those questions that required a pre-defined response.

People with RA in particular, felt passionately about their foot complaints and many provided rich textual accounts in addition to the completed questionnaires. These accounts described aspects of the lived experience of foot complaints in RA and, as such, were suitable for qualitative analysis (Olier-Boyd 1993). A variety of methodological approaches to the analysis of qualitative data were considered. The method advocated by Parse (1990) was not suitable, as no discussion or „dialogical engagement“ had taken place between the researcher and the subject – a pre-requisite for this approach. The approaches of Van Kaam (1966) and Giorgi (1970) of classification and ranking were considered unsuitable, as there was a possibility of unintentional bias as not every respondent provided textual accounts. Colaizzi's (1978) method was suitable and has been used by a number of authors reporting on the phenomenological explorations of RA (Ryan 1996, Ryan et

al. 2002, Iaquinta & Larrabee 2004). However, NRAS subjects had responded anonymously², therefore validating findings by returning to each subject was not possible, thus violating an important element of the process recommended by Colaizzi. Instead the thematic analysis explained by Van Manen (1990) was selected. Thematic analysis was previously described in section 5.6.4 and focuses on identifying themes and patterns of behaviour (Aronson 1994). The uncovering and identification of themes facilitated by this approach permitted meanings to be explored. Van Manen (2002) also suggests thematic analysis enables the meanings of human experiences to be recovered from text. It was envisaged this technique would also help to explain some of the responses given to structured questions, further contextualising the quantitative data. The techniques used to ensure trustworthiness of the identification of themes were noted in table 5.4. The demographic characteristics of those respondents who provided qualitative comments are outlined in appendix 9 and the themes uncovered as part of this analysis are detailed in appendix 10 supported by extracts from the raw data. In keeping with the mixed methods design strategy used in the current study qualitative and quantitative findings are presented together as described in the next section.

5.8.3 Presentation of data

To aid clarity and guide the reader, the findings from this study will initially be presented in three separate chapters, one for each group of subjects (people with RA, podiatrists and rheumatologists). For each group, findings are presented in a format that closely mirrors the structure of the questionnaires from which these data were generated. Typically, the quantitative data is presented and then expanded and given a more contextual emphasis when combined with the qualitative findings (Foss & Ellefsen 2002, Bryman 2006). This combination is achieved by the use of examples from the transcripts of qualitative data. This approach allows the reader to „visualise“ the phenomenon being discussed thus aiding understanding of the results as a whole. Provision of such examples is also thought to enhance the „trustworthiness“ of the findings as a whole (Koch 1996).

5.8.4 Analysis and synthesis of results

In the current chapter the integration of quantitative and qualitative methods has been explained in a stepwise fashion. Firstly, both quantitative and qualitative approaches were utilised to develop three questionnaires with which to generate data. Secondly, quantitative and qualitative approaches are also used within each of the questionnaires themselves. The process of integrating approaches was continued into the analysis sections of the present study.

² Permission was sought from Brighton and Hove LREC for BSUH subjects returning questionnaires to identify if they would consider participation in future research. It is anticipated this will form post-doctoral study, subject to further ethical approval.

As explained previously, the current study generated data from people with RA, rheumatologists and podiatrists. Some researchers would argue that a theme from one group of respondents can be further explored from the perspective of another group to generate a more multi-faceted picture of the phenomenon (Fielding & Schrider 2001, Moran-Ellis et al. 2006). Considering the current study was concerned with the exploration of foot complaints from different perspectives, integrating the views of people with RA, rheumatologists and podiatrists was undertaken in the discussion of the findings of the present study. In the discussion chapter of this thesis a process of interpretative integration will be employed (Moran Ellis et al. 2006), where explanations are generated from empirical work where the knowledge produced by different methodological approaches is incorporated and amalgamated into a single coherent account.

Chapter 6

Results - Foot complaints in RA, views and perceptions from those with RA

6.1 Introduction

This chapter aims to present the findings of the epidemiological survey into the extent and nature of foot complaints reported from two groups people with RA:

Members (n=650) of the National Rheumatoid Arthritis Society (NRAS).

A sample (n=390) of people from Brighton and Sussex Hospitals NHS Trust (BSUH).

As described in section 5.5.6, to ensure findings were as representative of the wider RA population as possible, two cohorts of people with RA received a postal questionnaire. The questionnaire used to generate data in the current study was developed by the researcher in conjunction with people with RA to ensure face and content validity, Consisting of both structured and unstructured questions, questionnaire responses generated a range of quantitative and qualitative data. The results will be organised in a similar manner to the structure of the questionnaire with the following sub-headings (sections 6.4 – 6.13):

- Socio-demographic details.
- Characteristics of RA in the populations studied.
- Chronological order of joint involvement during the course of RA.
- The reported nature and prevalence of foot complaints.
- The anatomical location and impact of pain in the feet.
- Medical management of respondents RA - the patients" perspective.
- Perceptions of foot assessment by clinicians from those with RA.
- Management of foot complaints from the patients" perspective.

Additionally, findings from *a priori* subgroup analyses for the impact of foot complaints on quality of life (section 6.9) and the effects of anti-TNF α medication related to foot complaints (section 6.11) will also be presented.

Initially, data for socio-demographic details and disease characteristics from the two populations were analysed separately prior to being compared and contrasted. The reasons for this approach were two-fold. Firstly, to identify if there were appreciable differences between the two populations that might account for variations in the foot complaints reported. Secondly, to demonstrate whether both groups could be considered representative of the RA population as whole. Assuming any differences in the socio-demographic details and/or nature of the disease characteristics were within acceptable and expected limits, it was proposed that the remaining analyses would be carried out on combined data for both groups. In terms of presentation, throughout this chapter quantitative information will be combined with qualitative findings. In each the sections outlined above, relevant inferential statistics are also presented.

6.2 Response Rates

The survey of foot complaints reported by people with RA was carried out over an eight-month period. Of the two groups of people with RA that formed the overall sample, the entire membership of people with RA from NRAS (n=650), were posted a questionnaire. A total of 395 useable responses (61%) were received without the use of reminders. A further 390 questionnaires were posted to a sample of people with RA attending BSUH, 190 useable replies (49%) were received also without the use of reminders. In summary, table 6.1 illustrates that a total of 1041 potential respondents with a diagnosis of RA were invited to take part and responses were received from 585 subjects, an overall response rate of 56.2%.

Table 6.1 – Summary of response rates

	NRAS (%)	BSUH (%)	Both groups (%)
Number of questionnaires posted	650 (100)	390 (100)	1040 (100)
Post office returns	0	20 (5)	20 (1.9)
Received a questionnaire	650 (100)	370 (94.7)	1020 (97.9)
Unusable questionnaires	0	0	0
Unable to complete questionnaire	0	7 (1.8)	7 (0.7)
Non-responders	255 (49)	173 (44.2)	428 (41.2)
Completed questionnaires	395 (61)	190 (49)	585 (56.2)

In addition to answering the questions posed by the questionnaire, over half of the respondents felt strongly about their foot complaints. Of NRAS members, 211 (53.4%) provided qualitative comments and a similar proportion (104 (55.6%)) of BSUH subjects also provided additional qualitative information). A summary of the demographic and disease characteristics of those who provided qualitative comments is provided in tabular format in appendix 9.

6.3 Data Screening

Reviews of the distribution of data from both populations of those with RA were undertaken prior to descriptive or statistical analyses being carried out. Box plots and scatter graphs were used to screen for outliers. Any responses found to be outside 95% confidence intervals were re-checked against the raw data to ensure accuracy. During this process only two anomalies were found. Firstly with regard to body mass index (BMI), although seven responses fell outside 95% confidence intervals only one response (respondent 82) was found to be physiologically unlikely. A BMI of 9.2 was originally calculated because the respondent had identified their height as 2 meters 67cm, based on current World Records this was not thought to be possible. However, it was also impossible to know the respondents' true height, therefore this BMI calculation was discarded and the value was assigned as „missing“. The other six outlying values for BMI were found to be correctly calculated and plausible following reviews of the relevant raw data. The only other outlying value was isolated when reviewing the severity of foot pain. Respondent 561 had a pain

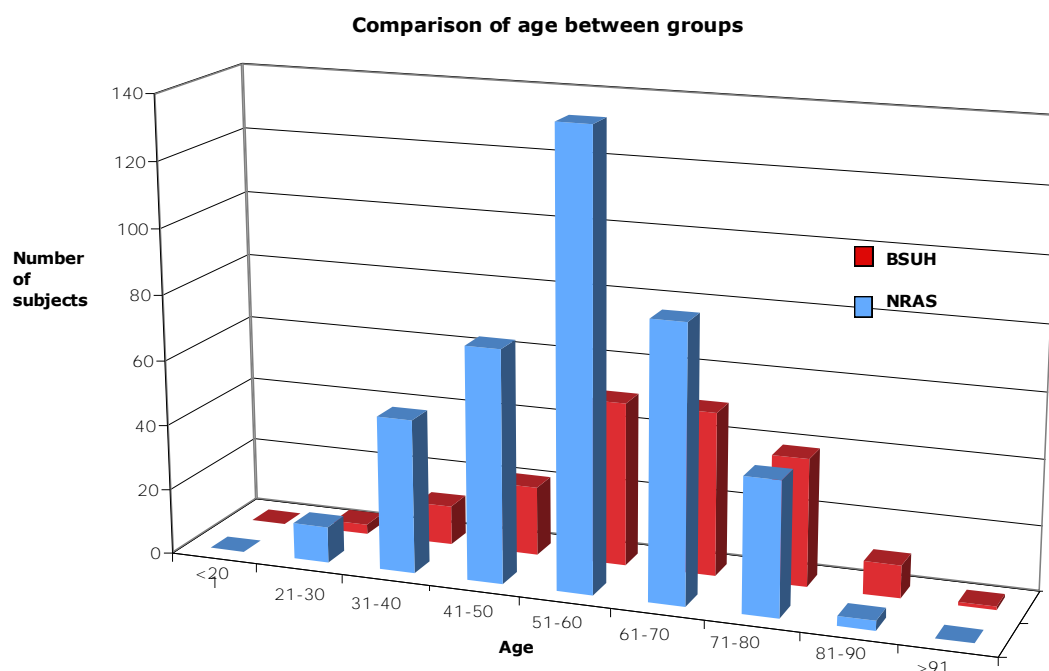
score of 75 on a 0-10cm visual analogue scale. On re-checking the raw data this was found to be an error and should have read 7.5, the data sheet was corrected accordingly prior to statistical analysis being carried out.

Prior to inferential statistical analysis being carried out on the categorical data, the distribution of these data requires consideration. Assessing normality of data requires a variety of methods and some data were considered unsuitable for this purpose. For example as described later it was inappropriate to use Body Mass Index as people with a chronic disease might reasonably be expected to have a higher Body Mass Index owing to reduced opportunities to engage in physical activity. To allow for such factors the most appropriate indicator was thought to be the age range of the population studied. This had the added advantage of being completed by all but eight respondents, with no other question being completed by more respondents. Table 6.2 overleaf (together with figure 6.1), describes the variety of indicators that can be used to assess normality and the findings for each of these indicators in the present study.

Table 6.2 - Exploring the distribution of the data SPSS (2005)

Indicator of normality	Findings in the present study
Does the histogram demonstrate a normal curve?	Figure 6.1 illustrates a slightly negatively skewed distribution, as there are greater numbers of subjects to the right of an ideal Gaussian curve.
Is the distribution in the histogram symmetrical?	
Are the mean, mode and median values equal?	Mean = 57.47 years Mode = 58 years Median = 58 years
Does skewness equal zero?	Skewness = -0.236
Does kurtosis equal zero?	Kurtosis = -0.186

Figure 6.1 - Histogram to compare age ranges between the two groups of respondents



The findings in table 6.2, suggest the data were not perfectly normally distributed, however to some extent this was to be expected for three reasons:

- Anyone under the age of 18 was excluded.
- RA is more prevalent in subjects aged over 50.
- The region where the BSUH subjects were recruited from (Southeast England) over-represents elderly adults.

Advice from the department of mathematics and statistics at the University of Brighton and the SPSS helpline indicated that when these three factors are considered, on balance there was sufficient evidence to suggest these data were suitable for testing with parametric statistics. The use of more advanced statistical techniques to test for normality (e.g. the Kolmogorov-Smirnov test), were not considered to be appropriate because of the confounding factors listed above.

6.4 Socio-Demographic details

Demographic details are reported for respondents from NRAS and BSUH groups of respondents in table 6.3a and 6.3b respectively. In terms of gender, in the NRAS cohort there were more female than male respondents - a ratio of 4:1, however, this was expected as the NRAS has a higher proportion of female members, with approximately 80% of the membership being female. The ratio of female to male respondents was 3:1 for the BSUH group in line with the reported epidemiology of RA discussed in section 2.2. The gender distribution of respondents also appeared to be characteristic of the wider RA population.

Table 6.3a - Demographic details for the respondents from NRAS (n=395)

Gender (%)	Male 63 (15.9%)	Female 332 (84.1%)	
Age (yrs)	Range 23 - 82 (mean 55.65 ± SD 11.84)		
BMI	Range 13.3 - 53.7 (mean 25 ± SD 4.99)		
Smoking status	Non smoker	Previous smoker	Current smoker
	189 (48.3%)	158(40.4%)	44 (11.3%)

Table 6.3b - Demographic details for the BSUH group (n=190)

Gender (%)	Male 47 (25.1%)	Female 140 (74.9%)	
Age (yrs)	Range 27 - 95 (mean 61.3 ± SD 13.4)		
BMI	Range 13 – 47.9 (mean 25.2 ± SD 4.7)		
Smoking status	Non smoker	Previous smoker	Current smoker
	75 (40.1%)	89 (47.6%)	23 (12.3%)

The age range for both cohorts was broad as described in table 6.3a and 6.3b, and confirmed the current study sampled a wide cross-section of the population of people with RA. A two-tailed Students t-test (appendix 11 – table 1) revealed that the BSUH cohort was significantly older than the NRAS group ($p < 0.001$ $t = 5.134$). The mean difference between the two groups was 5.646 years. The BSUH cohort was recruited from an NHS Trust in the Southeast of England, the hospitals within this Trust fall within a catchment population that is widely recognised to over represent elderly adults.

The World Health Organization adopted the weight classifications developed by the National Institutes of Health (NIH) through an expert panel convened in 1995 recommending the use of Body Mass Index (BMI), a measure of weight in relation to height. An individual's BMI was calculated as weight in kilograms divided by the square of height in meters (Thoenen & Wright 2002). Using this measure, definitions of each BMI category are outlined in table 6.4.

Table 6.4 - BMI categories

(Thoenen & Wright 2002)

Category	Definition	Frequency of respondents' n (%)
Underweight	<18.5	43 (6.6)
Normal	18.5 - 24.9	288 (49.2)
Overweight	25.0 - 29.9	191 (32.6)
Obesity Class I	30.0 - 34.9	52 (8.9)
Obesity Class II	35.0 - 39.9	10 (1.7)
Obesity Class III	40+	6 (1)

In respect of BMI, a Students' t-test (appendix 11, table 1) revealed no significant difference between the two groups ($t=0.384$ $p=0.701$). As table 6.3a and 6.3b illustrate, although the NRAS group did exhibit a slightly higher range of BMI, mean values were very similar. Overall almost one half of respondents fell into the „normal“ category with just over a third being classed as „overweight“, a total of 11.6% were obese as opposed to 6.6% who were underweight.

The figures for smoking are outlined in table 6.3a and 6.3b, the results for both groups are seen to be broadly similar. In the current study a total of 11.4% of subjects were currently smokers across all age groups and in general figures for the proportion of respondents who smoke were slightly lower than current national trends reported by the Office for National Statistics (2005).

A series of questions enquired about employment status, the results for both cohorts are summarised in table 6.5. In both groups more subjects were retired than were employed, which is not surprising given the age range of the respondents being studied. A considerable proportion of subjects had never worked, which may reflect the higher proportion of women in the sample, particularly when combined with the older age of subjects in the present study. Considering the BSUH group were significantly older, it is not surprising more respondents from this group were retired and fewer respondents were in full or part-time employment. Finally, it is noteworthy that in table 6.5 figures for each column sometimes total more than 100%, as more than one employment category could be applicable to a single respondent for example, retired and undertaking voluntary work.

Table 6.5 – Employment status of respondents with RA

Employment status	NRAS (n=395)	BSUH (n=190)	Total (n=585)
Full-time worker	58 (14.7%)	18 (9.5%)	76 (12.9%)
Part-time worker	65 (16.5%)	28 (14.7%)	93 (15.8%)
Sick leave	32 (8.1%)	2 (1.1%)	34 (5.8%)
Retired	147 (37.2%)	75 (39.5%)	222 (34.7%)
Never worked	99 (25.1%)	69 (36.5%)	168 (28.6%)
Voluntary work	21 (5.3%)	13 (6.9%)	34 (5.8%)

6.5 Characteristics of RA in the populations studied

The characteristics of RA in terms of the duration of the disease and whether respondents were seeing a specialist and receiving treatment are detailed in table 6.6 for both cohorts. There was a wide range of disease duration for both groups of respondents (1-54 years for the NRAS group; 1 month – 63 years for BSUH group). This provides further evidence in support of the postulate that the current survey sampled a broad cross-section of people with RA. A Students' t-test on these

categorical data (all statistical workings are detailed in appendix 11, table 2) revealed the BSUH cohort reported a significantly longer duration of RA ($t = 2.987$, $p=0.003$). The NRAS group reported a mean duration of RA of 11.13 years (\pm SD 10.3 years, standard error of the mean 0.521), whereas the BSUH group reported being diagnosed with RA on average 3.3 years longer (mean 14.26 years, \pm SD 12 years, standard error of the mean 0.907). However, considering the BSUH cohort was significantly older as described previously, this finding was not unexpected. In view of these findings, the duration of symptoms were also significantly longer in the BSUH group than the NRAS group ($t=2.948$, $p=0.002$). The time taken to diagnose RA from the onset of symptoms was not however significantly different between the two groups, ($t=0.131$, $p=0.896$). The mean difference between the onset of symptoms and receiving a diagnosis of RA were also similar for both groups - a mean of 1.6 years for the NRAS group and 1.7 years for the BSUH group.

As table 6.6 overleaf illustrates, the duration of morning stiffness for both groups was considerable, with 86.62% ($n=492$) of respondents reporting some degree of morning stiffness. A broad range of values was provided for the duration of morning stiffness with a reported mean of 2.8 hrs (range 10mins – 24hrs, \pm SD 6) for the NRAS group and a mean of 3hrs for the BSHU group (range 10mins – 24hrs, \pm SD 5.6). However, a two-tailed Students t-test revealed no significant difference in the duration of morning stiffness (i.e. how long morning stiffness is present for) between the groups ($t =0.333$ $p=0.719$ (appendix 11, table 2)). There was a small difference in the duration of morning stiffness between males and females with the mean duration of morning stiffness being 2.7 hours for women compared with 3.7 hours for men. However, this difference did not reach statistical significance ($t = 1.212$, $p = 0.228$) – appendix 11, table 3)).

Table 6.6 - The disease status for both cohorts

	Cohort					
Disease characteristic	NRAS cohort (n=395)			BSUH cohort (n=190)		
Mean duration symptoms	1 – 54 years (mean 12.73 ± SD 10.84)			1 month – 63 years (mean 15.96 ± SD 12.5)		
Mean duration disease	1 – 53 years (mean 11.13 ± SD 10.26)			1 month – 63 years (mean 14.26 ± SD 12)		
Currently seeing rheumatologist	Yes 377 (95.4%)	No 15 (3.8%)	No response 3 (0.8%)	Yes 173 (92.5%)	No 14 (7.5%)	No response 0
Currently prescribed medication for RA	Yes 374 (94.7%)	No 17 (3.4%)	No response 4 (1%)	Yes 171 (90%)	No 14 (7.4%)	No response 2 (1%)
Currently experiencing morning stiffness	Yes 329 (83.3%)	No 56 (14.2%)	No response 10 (2.5%)	Yes 163 (85.8%)	No 20 (10.5%)	No response 4 (2.1%)
Mean duration of morning stiffness	2.8 hrs (range 5 minutes – 24 hrs ± SD 5.5)			3 hrs (range 5 minutes – 24 hrs ± SD 6)		

To summarise data relating to socio-demographic and disease characteristics, the BSUH cohort were approximately 5 years older but otherwise did not differ significantly in any other respect from the NRAS cohort. A greater proportion of the NRAS cohort were employed, but given the age difference this was to be expected. The BSUH cohort also reported a significantly longer duration of disease (by approximately 3 years), but the overall mean duration of RA was similar across both cohorts. The numbers of subjects in both groups reporting they were under the care of a rheumatologist and receiving disease modifying treatments were also similar as was the proportion and duration of morning stiffness. Crucially there were no differences in the overall proportion of subjects who reported foot pain during the course of the disease – although expected daily variations were noted in both quantitative and qualitative data. Therefore all subsequent statistical analyses are presented amalgamated for both cohorts.

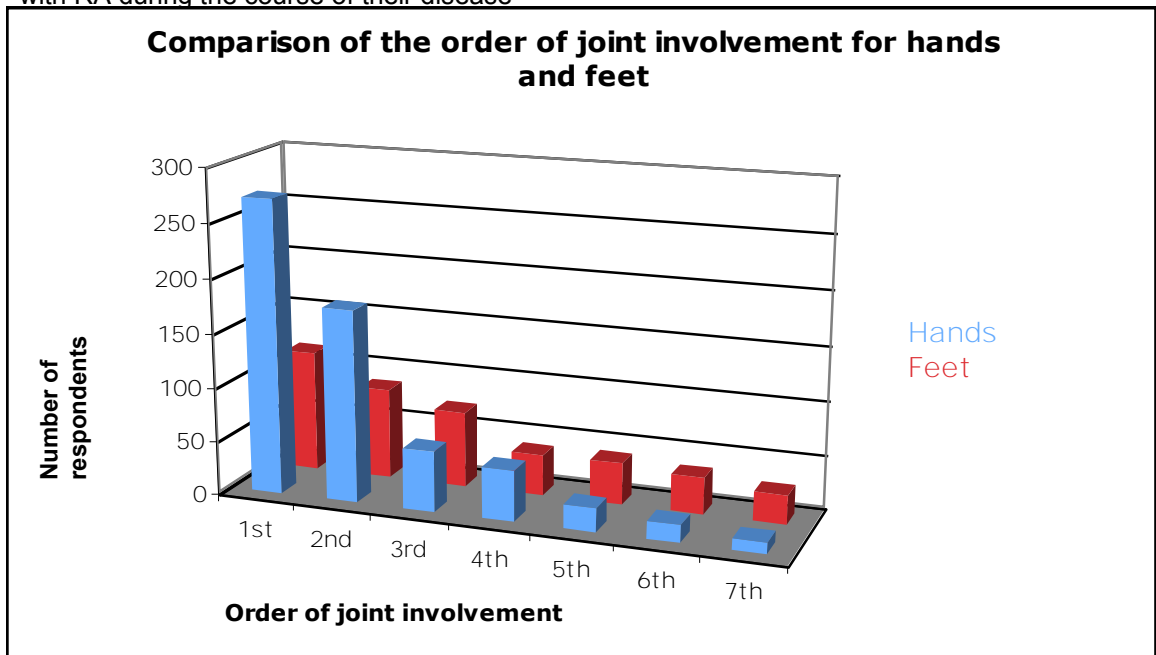
6.6 Chronological order of joint involvement during the course of RA

In describing the order of involvement of joints in the course of their RA, 50.1% of respondents indicated that the hands were the first site where the onset of symptoms were noted, with 35.4% indicating that the feet were the initial site of their symptoms. Even allowing for non-responder bias, this suggests that at least 20% of RA patients would experience foot pain as the first site of their symptoms and if non-responders were similarly affected to responders, then as many as 64% of subjects would have foot involvement first in their disease. Figure 6.2 overleaf illustrates a comparison of the order that hands and feet were affected during the course of the disease. Some subjects provided qualitative data to highlight how symptoms in their feet were the first experience of RA for example,

“The symptoms in my feet were really the first sign of the RA. I initially thought I’d injured my feet from over-exertion on a machine at the gym. For 3 months or so initially before I began drug treatment I would not walk on a hard floor without pain” (subject 205)

In exploring the order that joints were reported to have been affected by RA further, a Students’ t-test was used to determine if those subjects who reported the first symptoms of RA in their foot joints subsequently reported greater levels of foot pain (details in appendix 11 table 4). Those subjects reporting the earliest symptoms of RA commencing in their feet were not found to currently have significantly more severe foot pain ($t=-0.270$, $p=0.911$).

Figure 6.2 - Comparison of the order of joint involvement of hands and feet as described by people with RA during the course of their disease



The distribution of other joints affected by RA during the course of the disease is described in table 6.7 overleaf. The hands and feet were the most commonly affected joints, with both hands and feet being almost universally affected. The knees and wrists were the next most common joints to be affected during the course of the disease, with the hips and back being the least commonly affected joints.

Table 6.7 – The distribution of joints affected by RA in the present study

Joint	N and (%) of patients reporting initial symptoms in this location	N and (%) of patients reporting joint affected by RA ever	N and (%) of patients reporting joint <u>never</u> affected by RA
Neck	65 (11.1)	511 (87.3)	74 (12.7)
Shoulders	111 (18.9)	551 (94.2)	34 (5.8)
Elbows	69 (11.7)	501 (85.7)	84 (14.3)
Wrists	128 (21.8)	574 (98.2)	11 (1.9)
Hands	293 (50.1)	584 (99.81)	11 (0.19)
Back	39 (6.6)	325 (55.6)	260 (44.2)
Hips	40 (6.8)	438 (74.9)	147 (25.1)
Knees	146 (24.8)	556 (96.8)	19 (3.2)
Ankles	102 (17.3)	549 (93.8)	36 (6.2)
Feet	202 (34.5)	572 (97.8)	13 (2.2)

6.7 The reported nature and prevalence of foot complaints

In total, 556 (95.2%) of respondents indicated they had experienced foot pain at some point during the course of their RA. Within the past month 488 (83.5%) of respondents reported experiencing foot pain and 466 (79.7%) reported they were *currently* experiencing foot pain. Using a 10cm visual analogue scale the mean score for current foot pain was 4.9 (\pm SD 2.23, median 5.0). Women reported higher scores for foot pain (mean 5.07 \pm SD 2.2) than men (mean 4.2 \pm SD 2.2), the median values and inter-quartile ranges were also higher for females. A two-tailed Students' t-test (appendix 11, table 6.5) revealed this difference in the severity of foot pain between genders to be significant at the 0.5% confidence interval ($t=-2.992$, $p=0.003$).

Given that the severity of reported foot pain was more marked for women, the prevalence of foot pain between genders was also considered. A Chi square test was used to compare these categorical data. However, this comparison of the prevalence of foot pain between men and women revealed no significant difference ($\chi^2 (1) = 3.575$, $p=0.059$ (appendix 11 – table 6)). This means while women with RA report more severe foot pain than men, women are no more likely to report foot pain in the first place than men. But a caveat should be added here that the significance result was $p=0.059$, which is close to being statistically significant and perhaps suggests a clinical trend towards women being more likely to report foot pain.

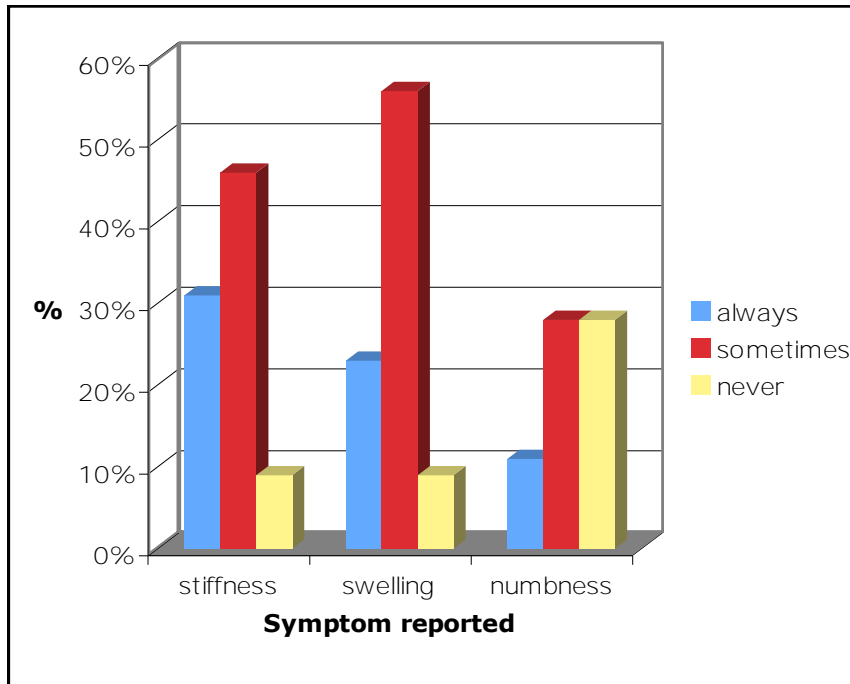
Analysis of variance (ANOVA) was used to test if any relationship existed between the severity of foot pain and the socio-demographic variables of BMI, cigarette smoking and age, as well as the

disease variables of duration of RA and duration of morning stiffness (details in appendix 11, table 7). No significant relationship between BMI ($F=1.295$, $p=0.187$), duration of RA ($F=0.812$, $p=0.693$) or duration of morning stiffness ($F=1.486$, $p=0.092$) and severity of foot pain were noted. However, age was significantly related to the severity of foot pain ($F=1.628$, $p=0.047$), suggesting that as people with RA age, they experience greater severity of foot pain. The relationship between age and foot symptoms was explored further using the Pearson correlation coefficient, ($\rho=0.268$ $r=0.056$ (appendix 11, table 8)). This means some caution is required when interpreting these findings as the relationship between age and severity of foot pain was relatively weak in statistical terms. Equally there is recognition that foot pain experienced by people with RA may vary considerably on a daily basis depending on factors such as activity levels. Employment may also have an impact on foot pain. For instance, someone standing up all day at work may report a greater degree of foot pain than someone who is retired. To investigate this further two groups were created based on whether respondents indicated they were working or currently on sick leave (details in table 9, appendix 11). An inverse relationship was seen between severity of foot pain and employment status such that subjects in full-time employment reported their foot pain as being less severe (mean 4.3, \pm SD 2.2) than those currently on sick leave (mean 5.8, \pm SD 2.2). When tested, this relationship was found to be significant ($t= -3.098$, $p=0.002$). This suggests those people who are working report lower levels of foot pain, whereas those on sick leave reported greater levels of foot pain.

Finally, any relationship between cigarette smoking and the severity of foot pain was explored using a Chi square test owing to the categorical nature of these data (details in table 10, appendix 11). No significant relationship was found between cigarette smoking and the reported severity of foot pain ($\chi^2 (2) = 2.130$ $p=0.345$).

In addition to pain, respondents reported other symptoms were common in the feet. Stiffness was the most commonly experienced symptom followed by swelling and numbness as illustrated in figure 6.3. Of particular note is the consistency with which that the symptoms of stiffness, swelling and numbness (as different to pain) are experienced by respondents in the current study. The majority of people with RA who responded to these questions reported experiencing stiffness, swelling or numbness some or all of the time, with only 5.3% ($n=31$) of respondents indicating they did not experience stiffness, swelling or numbness.

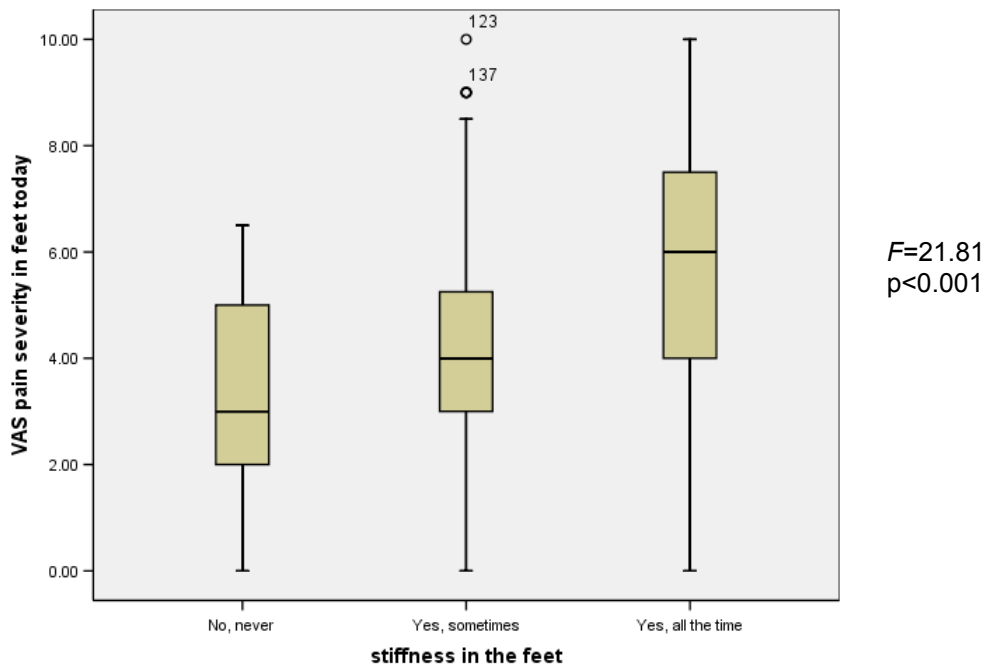
Figure 6.3 - Symptoms reported in the feet in addition to pain



Analysis of variance testing was used to compare the mean severity of foot pain with those subjects reporting stiffness, swelling and numbness. Analysis of variance (ANOVA) was used owing to the need to compare categorical variables with continuous data. An ANOVA revealed a significant association between severity of foot pain and stiffness ($F=22.81$, $p<0.001$, (all details are provided in tables 11a-c in appendix 11). To control for type 1 (false-positive) errors, Tukey *post-hoc* multiple comparisons were applied. This particular post-hoc test was chosen owing to the large numbers of values being compared and the general normal distribution of these data. Overall, it was revealed these symptoms were clearly inter-related such that severity of pain was significantly associated with the reporting of these additional symptoms. The Tukey *post hoc* multiple comparison indicated this relationship was linear in nature, i.e. as the severity of foot pain increases so does the likelihood of stiffness in the feet. This relationship between stiffness in the feet and severity of foot pain is most clearly illustrated by the box plot in figure 6.4.³

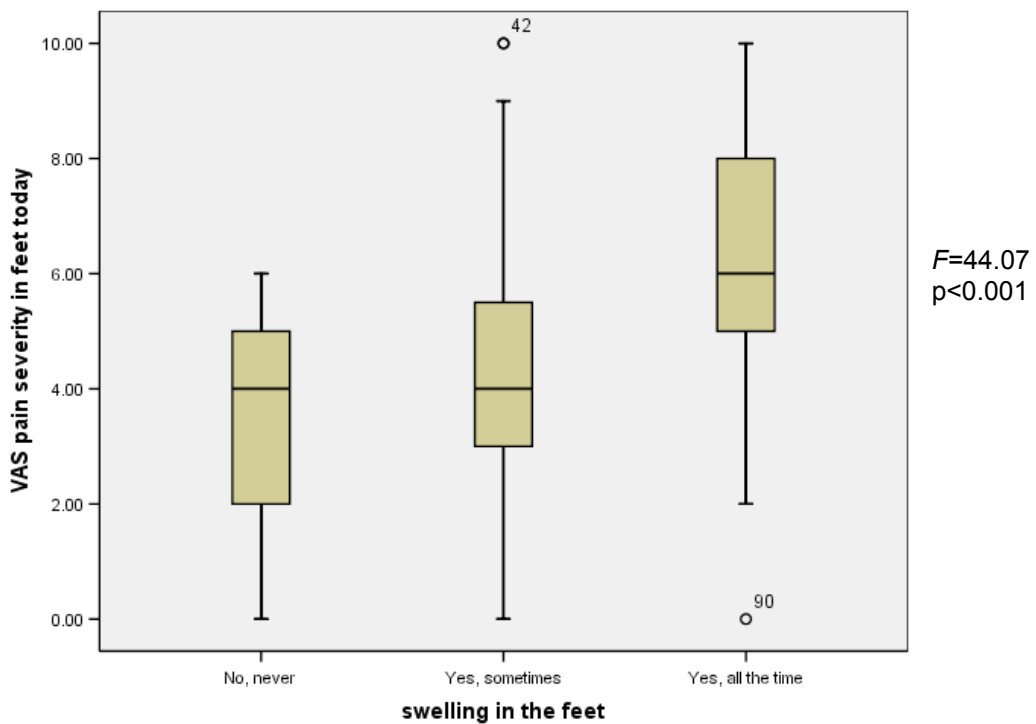
Figure 6.4 - Box plot illustrating the linear relationship between severity of pain and stiffness in the feet

³ A scatter graph and best fit line, are more traditionally used to illustrate such a relationship, however this approach was inappropriate owing to the ordinal nature of these data



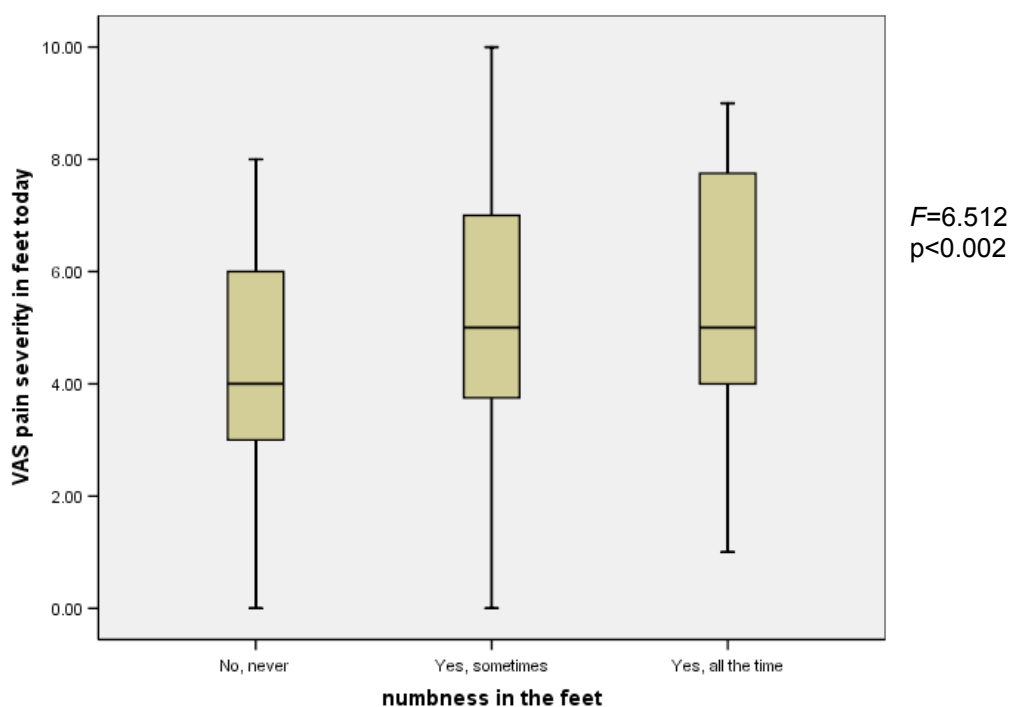
Results for swelling were broadly similar, with a one-way ANOVA revealing a significant association between the severity of foot pain and swelling ($F=44.07$ $p<0.001$, (details in tables 12 a-c in appendix 11)). The Tukey *post hoc* multiple comparison indicated this relationship was linear in nature, i.e. as the severity of foot pain increases so does the likelihood of swelling in the feet. This relationship is most clearly illustrated by the box plot in figure 6.5, which compares the likelihood of swelling in the feet with pain severity.

Figure 6.5 - Box plot to illustrate the linear relationship between severity of pain and swelling in the feet



To compare the severity of foot pain and prevalence of numbness in the feet, a one-way ANOVA revealed a significant association between the severity of foot pain and presence of numbness in the feet, ($F=6.512$, $p=0.002$ (details in tables 13 a-c, appendix 11)). The Tukey *post hoc* multiple comparisons indicated this relationship was linear in nature, i.e. as the severity of foot pain increases so does the likelihood of numbness occurring in the feet. This relationship is most clearly illustrated by the box plot in figure 6.6, which compares the relationship between numbness in the feet with pain severity. It is unclear from these data however, whether the numbness described by people with RA is a symptom consistent with frank sensory neuropathy.

Figure 6.6 – Box plot to illustrate the relationship between numbness in the feet with pain severity



In addition to describing symptoms in their feet, respondents were also invited to list what type(s) of foot pathology they had been diagnosed with. The reported prevalence estimates for each of these conditions is summarised in table 6.8 overleaf. Consideration was given to providing a list of recognised foot pathologies, but this was felt to enhance the risk of bias. Therefore respondents listed their own foot complaints as free text and were able to list more than one complaint and percentages may not total 100%.

The most common foot complaint reported by almost one third of those with RA were bunions, followed by hyperkeratotic lesions (e.g. corns and callous). Although a number of other foot pathologies were listed, perhaps most notable was that 5.95% of those with RA reported foot ulceration. The importance of these findings is discussed further in section 9.4. It should also be noted that 20% of respondents reported no foot pathology (excluding symptoms such as pain) as being present. This provides evidence against the possible assertion that these prevalence estimates are artificially high, with questions only being answered by those with foot complaints.

Table 6.8 – Self-reported prevalence of foot conditions (excluding pain)

Complaint	Prevalence % (n)
Bunion	29.92 (176)
Corn	27.88 (164)
Callous	21.59 (127)
Flat feet	18.53 (109)
Toe deformity	12.92 (76)
Other cutaneous lesion (blister, verrucae etc.)	7.48 (44)
Other subcutaneous lesion (bursa, nodule etc.)	7.31 (43)
Ulceration	5.95 (35)
No foot condition reported	20 (117)
No reply to this question	5 (29)

6.8 The anatomical location and impact of pain in the feet

The location of pain in the feet at different points during the course of the disease (today, in the past month and at any point in the disease) is displayed in table 6.9 overleaf. Foot pain throughout the ankle/foot is clearly common, with most respondents reporting foot pain at some point in the course of the disease. Involvement of the forefoot/toes and ankles predominates at any given point in the disease process. In addition to these trends, the inherent variability in the occurrence of pain is noteworthy, such that although just over 40% of subjects reported forefoot pain on the day of completion of the questionnaire. This prevalence rose by nearly 5% if the whole of that month was considered and was considerably greater (63.9%) during the course of the disease as a whole.

Table 6.9 - Frequency of pain reported at different anatomical sites in the foot

Anatomical location	Foot pain today % (n)	Foot pain within the last month % (n)	Foot pain at any time during the disease % (n)
Forefoot	40.3 (237)	44.9 (264)	63.9 (376)
Ankle	25.5 (150)	30.6 (180)	42.7 (251)
Toes	25.3 (149)	172 (29.2)	45.9 (270)
Hindfoot	13.4 (79)	13.9 (82)	21.8 (128)
Midfoot	8.5 (50)	10.2 (60)	17 (100)

NB Column totals may be more than 100% as subjects could select more than one

The qualitative comments related to foot pain provided by participants in the current study were particularly illuminating in terms of explaining the nature of pain experienced in the feet and the impact this had on respondents' lives. Indeed some respondents reported that their foot pain was the greatest problem, impacting on all other aspects of their lives for example,

"I have had severe problems with my feet... causing bad posture, pain and unable to walk any distance. This has impacted on my way of life, work and sleep" (subject 275)

"of all my joints affected, my foot problems interfere with my life more than any other, they make my life a misery" (subject 203)

A number of respondents with RA (n=39) commented that their feet were particularly painful during weight-bearing activity such as walking, which presented a number of difficulties particularly if, as a result, mobility aids were required. Sometimes this led to feelings of anger and frustration being expressed for example,

"at times one wished one knew how to walk on one's hands" (subject 26)

"I am unable to walk any distance and I have to resort to a wheelchair, which I hate" (subject 172)

Difficulties with weight-bearing activity were so great for some subjects that they were forced to change their chosen occupation, as typified by one respondent who commented,

"pain in my feet/ankles and other joints caused me to give up my career in nursing and take a more sedentary job working for a bank. It has impacted greatly on my life" (subject 306)

When reporting such problems to the medical team, some people with RA felt the difficulties experienced with walking and the impact that this has on their overall quality of life was often underestimated, for example,

“My feet have generally not been of particular interest in my rheumatology care. For me the difficulties I’ve had with both my feet have been the most difficult to cope with. Thank you for your questionnaire” (subject 33)

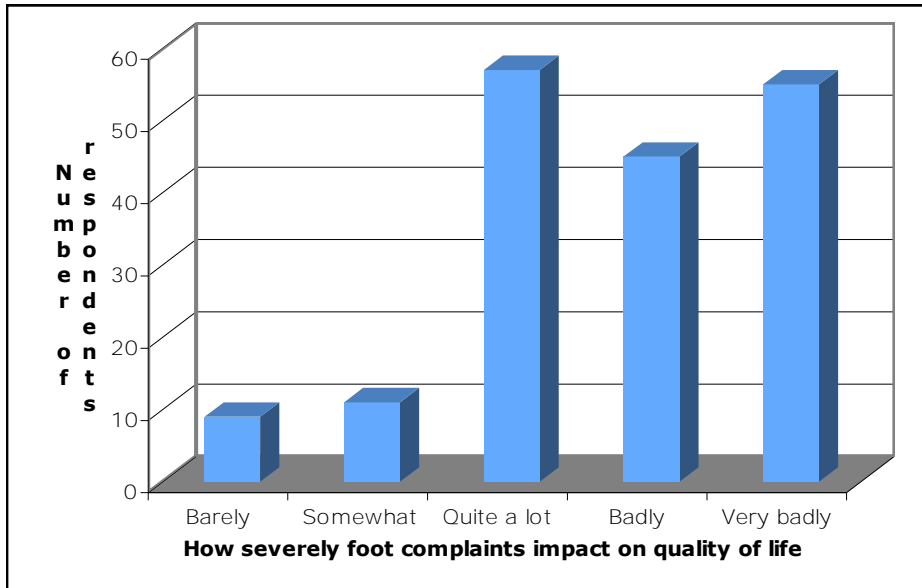
“My feet ache almost continuously and shoes are becoming more of a problem. The hard skin caused by deformities is painful to walk on and I feel that often walking problems are trivialised by medics” (subject 226)

6.9 Sub group analysis – Impact of foot complaints on Quality of Life

An exploration of the impact of foot complaints associated with RA on quality of life was undertaken with subjects who were patients at BSUH. This part of the study was designed as an *a priori* sub-group analysis; with the intention of following up these findings with an in-depth quantitative analysis, which will form a sequel to the work presented here. In total 177 (93.2%) of BSUH patients reported their quality of life was adversely affected by their foot complaint(s). Over half of respondents with RA described their quality of life as being badly or very badly affected as a result of their foot complaint(s), as illustrated in figure 6.7 overleaf.

Respondents who reported that their foot complaint(s) had a negative impact on their quality of life were invited to complete a 10cm visual analogue scale (VAS) to determine how severely quality of life was being affected. The mean score was 5.36 (\pm SD 3, median 5.5), which suggests that people with RA perceive that their foot complaints have a moderate to severe effect on their quality of life. While there appears to be a contradiction here, with over half suggesting foot complaints affect quality of life badly or very badly, but the VAS score only slightly above the mean value of 5, there are two probable explanations. Firstly, the standard deviation was three, which was sizeable given the use of a 10 cm VAS scale and suggests considerable variability with regard to quality of life scores. This variability may lead to a regression to the mean, as suggested with a mean score only slightly above the arithmetic mean of five. Secondly, respondents may have understood the questions differently, finding the descriptions used for the Likert-type scoring of „barely“ to „very badly“ more representative of how they perceive their quality of life to be affected than the 0 – 10 visual analogue scale.

Figure 6.7 - Bar chart to illustrate how severely foot complaints impact on quality of life

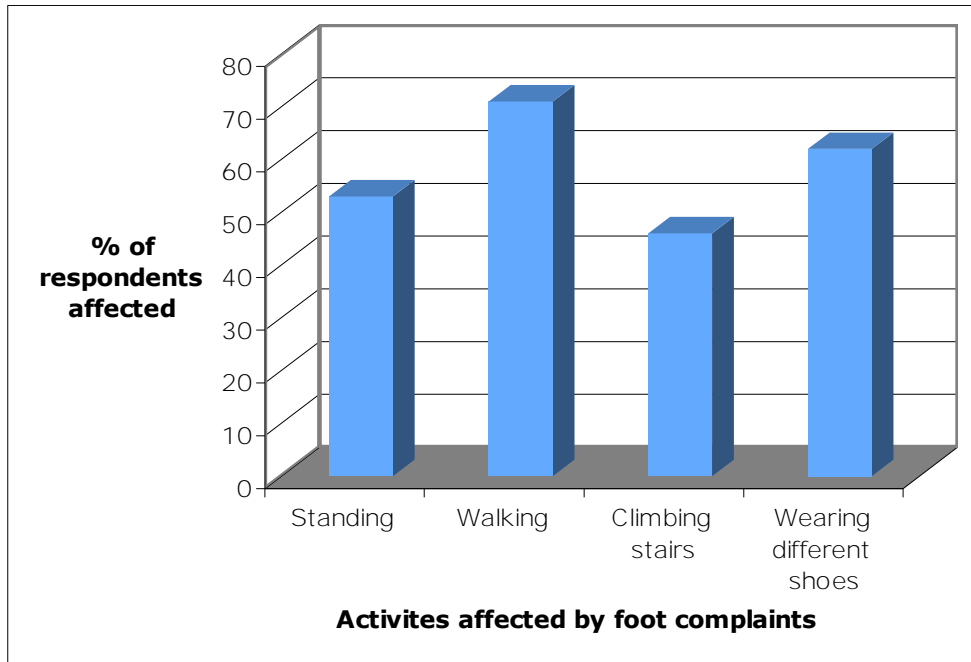


How people with RA characterised the impact of their foot complaints on their everyday activities is illustrated in figure 6.8 overleaf. Clearly the greatest impact of foot complaints was felt by patients to be on their ability to walk, followed by being able to wear different shoes. The findings that foot complaints have a considerable impact on quality of life were strongly supported by analysis of the qualitative data, with respondents continually highlighting the difficulties they have with walking and perhaps more importantly, the impact the restriction in this activity has on their quality of life for instance,

“I cannot walk very far. I miss walking with my family. (I use a wheelchair when we go out with family)” (subject 1082)

“I used to be a long distance runner thirteen years ago. I also loved long walks across hills and dales, mountain climbing, dancing. All finished now. If I do any of these things now I can barely walk next day” (subject 1085)

Figure 6.8 – Aspects of patients’ lives that are affected by RA in the feet



Some respondents used this opportunity to describe the impact that limited mobility and loss of independence had on their social life, as well as on their overall well-being, for example,

“I have to be more selective in my social activities,... RA is always at the back of your mind, it you overdo it you have to rest up the next day. It’s a balancing act” (subject 1143)

“loss of confidence in myself since being restricted in my social life and occupation has affected my general happiness” (subject 1131)

Footwear was also mentioned, with a total of 19 respondents with RA providing additional comments to highlight the difficulties they faced when trying to find comfortable footwear that they felt was also socially acceptable,

“Due to this condition impossible to find shoes. Trainers very uncomfortable and any closed in shoes. Mainly wear mules or cushioned flip flops” (subject 1081)

“My feet problems are probably the most difficult to live with. Finding shoes which fit is an absolute nightmare. Vanity stops me wearing my “hospital” shoes. Every step I take feels like I’m walking on marbles” (subject 1182)

For some respondents the only suitable footwear was that provided by orthotists or only available from specialist manufacturers, two typical comments included,

“My feet are particularly bad. Just been given some shoes from hospital with plenty of padding and support. They are helpful” (subject 1025)

“I can only purchase shoes from specialist supplier at my own expense. Cannot walk around house in socks or bare feet” (subject 1105)

For some respondents the difficulties they faced with trying to obtain suitable, comfortable footwear and/or not being able to wear the shoes they would like to was reported to have a profoundly negative affect on their overall mood and psychological health, two comments that summed up the difficulties those with RA faced were,

“I am glad you are carrying out this research, because I feel it is a neglected area in the treatment of RA. My feet are my biggest problem. It is getting increasingly difficult to find any sort of footwear that fit my deformed feet. I resort to wearing old shoes and trainers, which depresses me greatly. Generally, not much interest has been shown by medical professions in problems with my feet” (subject 44)

“Not being able to wear feminine heeled shoes because of the RA has been a cause of real sadness to me. When my feet do feel bad I feel like a miserable old woman and the effect on my life is immense” (subject 71)

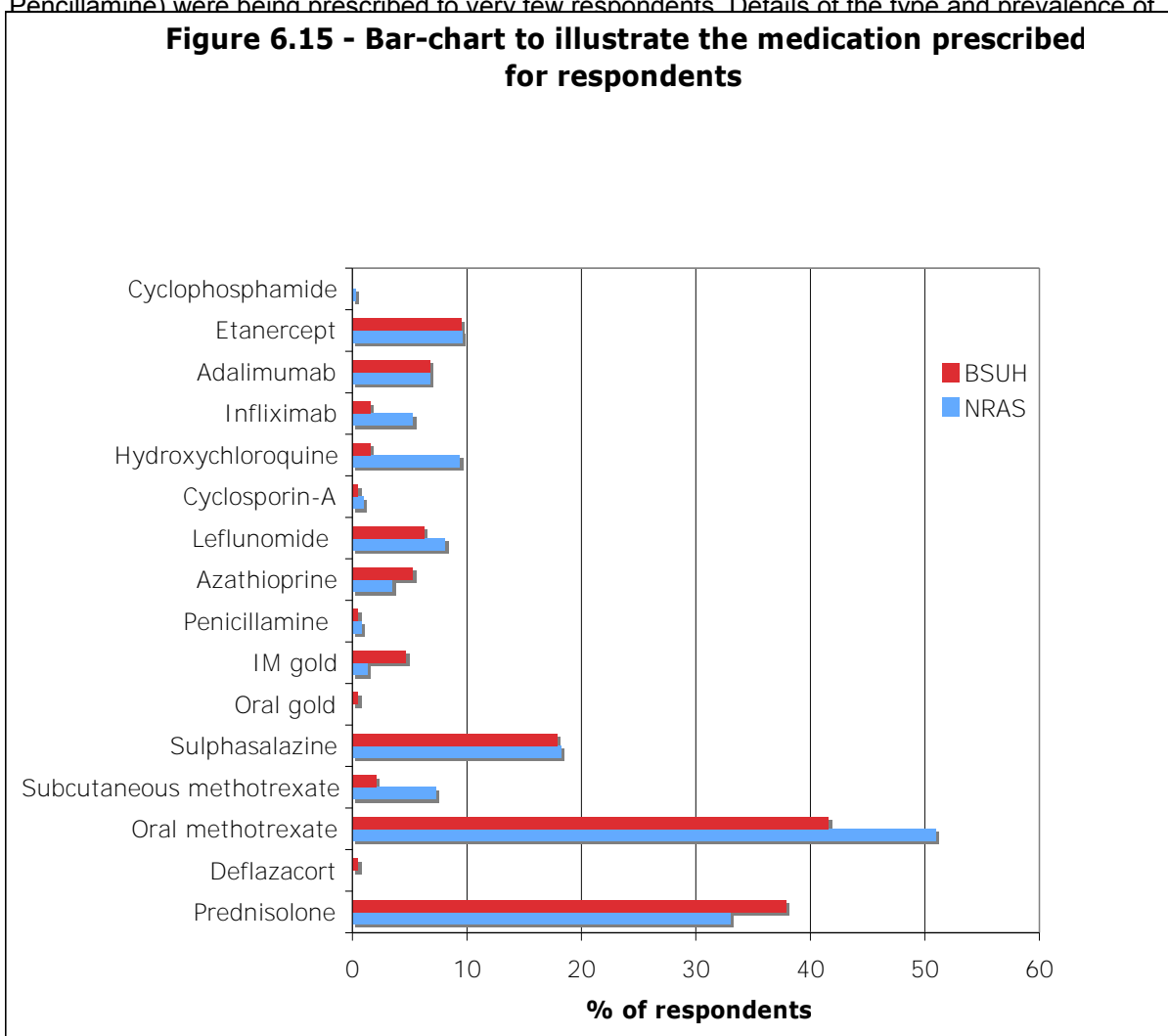
6.10 Medical management of respondents RA – the patients’ perspective

Respondents were invited to indicate whether they were receiving care from a rheumatologist and what medication had been prescribed. This was considered important for three reasons. Firstly, the use of modern disease-modifying medication should in theory lead to an improvement in at least a proportion of foot complaints, allowing for comparison with some of the epidemiological studies carried out previously (detailed in section 4.3). Secondly, the prescribing habits of rheumatologists can be compared to other data to demonstrate the generalisability (or not) of these data. Finally, there may be disparity in the efficacy of different DMARDs with regard to foot complaints, as part of this an *a priori* sub-group analysis was included with regard to biologic drugs, the findings of which are described in section 6.11.

As expected most respondents in the NRAS cohort (95% n=365) did consult a rheumatologist, however only 91% (n=173) of the BSUH cohort reported seeing a rheumatologist. This latter figure was a surprising finding as this cohort was recruited from audit data obtained during out-patient clinics led by consultant rheumatologists, therefore all subjects would have seen a rheumatologist. This finding suggests that either respondents did not fully understand the question and/or do not realise (or could not recall) which specialist they see in the hospital setting for the care of their RA.

The vast majority of respondents, (95% of the NRAS group, 92.5% of the BSUH cohort) reported being prescribed medication for their RA. Of these, almost all respondents (99%) were prescribed some form of disease modifying anti-rheumatic drug (DMARD). The most common DMARD was oral Methotrexate followed by Sulphasalazine. Most of the „older“ DMARDs (such as Gold and D Penicillamine) were being prescribed to very few respondents. Details of the type and prevalence of

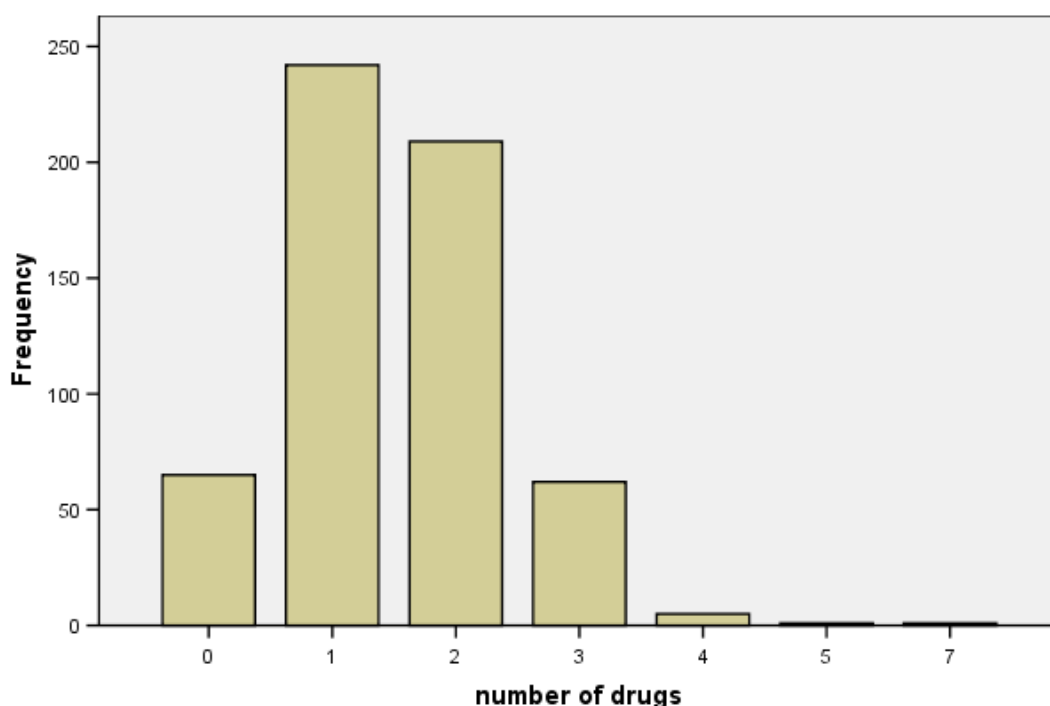
Figure 6.15 - Bar-chart to illustrate the medication prescribed for respondents



The proportions of respondents from the two cohorts taking each of the different DMARDs were similar. The most apparent differences were corticosteroid prescription was slightly higher in the BSUH cohort (37.9% compared with 33.4% for the NRAS group) and methotrexate was more widely prescribed in the NRAS cohort. This lends weight to the suggestion that the findings were broadly generalisable. A total of 47.6% (n=242) took more than one DMARD (this figure includes corticosteroids) and the proportion of respondents taking more than one DMARD is illustrated in figure 6.10 overleaf. Of those respondents who took corticosteroids (n=204), a total of 166 (81%) also took at least one other DMARD. Seven respondents took four or more DMARDs, which while

possible would be unusual. It is however possible these seven respondents listed all the DMARDs they had ever been prescribed rather than the drug(s) there were currently prescribed.

Figure 6.10 - Number of different DMARD's prescribed



A total of 28 respondents (7% of the total cohort) provided qualitative information about their medical care for RA. Opinions were divided regarding the efficacy of the various drugs used by respondents, with 12 subjects opting to report the positive effects of their medication in the qualitative comments, for example

“Thanks to the arthritis clinic at XXX hospital, and their prescribing Methotrexate tablets for me, my quality of life miraculously returned to me” (subject 350)

“Having been prescribed METHOTREXATE TABLETS 1 YEAR ago, my pain has been greatly reduced. Prior to that I was having substantial pain” (subject 1002)

Only 13 subjects with RA reported problems with their medical treatment, most (n=10) being due to side effects associated with DMARD therapy, a typical example being,

“Over the years I have had many different drugs, but all caused skin rashes and/or stomach problems” (subject 70)

6.11 Sub group analysis – Anti-TNF α medication related to foot complaints

Of the 585 usable replies received, 120 (20.5%) respondents were currently being prescribed anti TNF α medication. These newer biologic agents were used in similar proportions in each group, with 21.7% (n = 85) of the NRAS group and 18.8% of the BSUH group (n = 34) using these agents. The demographic characteristics of this sub-group of respondents are outlined in table 6.10 (details in table 11.15 a – d, appendix 11). Demographic characteristics for those taking anti-TNF α and those not taking anti TNF α medication were broadly similar except for gender. The gender ratio was 1 Male:6.5 Females in the anti-TNF group and 1 Male:9 Females in the non anti-TNF group. The high proportion of female responders can be partly explained by the fact RA is more frequent among women. Also, in common with other epidemiological studies utilising a similar methodology (Walker-Bone et al. 2004a), female participants in the current study tended to complete the questionnaire more often than males. Of the 120 respondents prescribed anti-TNF α medication, 16.1% (n=94) were taking at least one other DMARD in addition to their biologic therapy.

Table 6.10 – Demographic characteristics of those prescribed anti-TNF α medication

Characteristic	Anti-TNFα group (n=120)	Non anti-TNFα group (n=465)
Mean age (\pm SD)	54 years (\pm 11.5)	58 years (\pm 12.8)
Gender M:F	1:3.9	1:6.5
Mean duration RA (\pm SD)	12.8 years (9.6)	11.9 years (11.2)
Mean BMI (\pm SD)	25.4 (5.77)	25 (4.6)
Mean duration of morning stiffness (range, (\pm SD))	3 hrs (10 mins – 24 hrs, (5.5))	2.9 hrs (10 mins – 24 hrs, (5.7))
Severity of current foot pain (0-10cm VAS) mean (\pm SD)	4.5 (2.4)	5.3 (4.6)

Of the 120 respondents who were prescribed biologic therapy, eighteen opted to write about their experience, all of who reported notable improvements, one example being,

“Since I have been taking Adalimumab my symptoms have greatly improved. I now experience much less pain and stiffness, also much more productive at work” (subject 102)

For those people with RA for whom conventional DMARDs had been ineffective, newer biologic drugs appeared not only to dramatically improve the physical symptoms associated with RA, but some respondents also recalled marked psychological and psychosocial benefits,

“since being prescribed Humeria there has been a marked improvement – I never really felt I had a life for 12 years – very limited movement and feelings of hopelessness and alienation” (subject 1186)

Although these comments indicated that while biologic medications appeared to make a marked improvement to patients’ lives, other surrogate measures of outcome did not demonstrate similar improvement. For example, the duration of morning stiffness was similar for those taking biologic drugs to those subjects taking conventional DMARD therapy as noted in table 6.11. It is possible therefore that these measures do not fully capture areas of greatest importance to patients.

In terms of foot complaints, as illustrated in table 6.12 overleaf, a significantly greater proportion of subjects in the anti-TNF α group reported currently experiencing pain in their feet ($p=0.012$ - statistical working in table 11.16a - g, appendix 11). However, the intensity of foot pain assessed with a 10cm visual analogue scale was slightly lower in the anti-TNF α group (mean 4.5, \pm SD 2.4) compared with that of the conventional treatment (non anti-TNF α) group (mean 5.3, \pm SD 4.6), although this difference did not reach statistical significance. Other signs and symptoms characteristic of foot complaints in RA (i.e. stiffness, swelling and numbness) were all noted to be significantly more prevalent in the anti TNF α group ($p\leq 0.05$). A higher proportion of foot complaints in those taking anti-TNF α medication were not entirely unexpected findings because, as noted in section 2.6, these drugs are reserved for those with more severe disease.

Table 6.11 - Comparison of foot symptoms in those prescribed anti-TNF α medication with those being treated with conventional drugs

	Prescribed anti-TNFα (n=120)	Not prescribed anti-TNFα (n=465)	Significance
<u>Today</u> do you have pain in your feet due to RA?	Yes = 78%	Yes = 66%	p = 0.012
Proportion of respondents who always or sometimes experience <u>stiffness</u> in their feet	95%	89%	p = 0.050
Proportion of respondents who always or sometimes experience <u>swelling</u> in their feet	97%	88%	p = 0.014
Proportion of respondents who always or sometimes experience <u>numbness</u> in their feet	96%	55%	p = 0.044

In table 6.12 below, the reported need for foot care and the provision of foot care between those prescribed anti-TNF α medication and those with more conventional DMARD therapy is compared.

Table 6.12 – Comparison of the need and provision of foot care in those prescribed anti-TNF α medication with those being treated with conventional drugs

	Anti-TNFα group (n=120) % (n)	Conventional treatment group (n=465) % (n)
Discussed foot complaints with rheumatologist	90 (108)	83 (386)
Discussed foot complaints with GP	54 (65)	55 (256)
Receiving podiatry care	70 (84)	78 (361)

In spite of an overall lower prevalence of foot complaints, a greater proportion of the conventional treatment (i.e. non anti-TNF α) group were currently receiving specialist foot care than those currently prescribed anti-TNF α therapy. However, it should be noted that the conventional DMARD treatment group was far larger than those receiving anti-TNF α , which may skew the findings as there may be a greater proportion of people receiving conventional treatment for their RA who have foot complaints that warrant specialist foot care.

While foot complaints appeared to be more prevalent in those prescribed anti-TNF α medication, patients' feet were examined significantly less frequently ($p < 0.001$) than were their hands. In those taking anti-TNF α medication, examination of respondents' hands was reportedly undertaken more frequently (on average every 4.1 months (\pm SD 5.28)) compared with every 6.6 months (\pm SD 11.3) in those **not** prescribed anti-TNF α medication. In contrast however, examination of the feet was undertaken slightly less frequently in those prescribed anti-TNF α medication (on average every 15.7 months (\pm SD 26)), compared with foot examination every 15.4 months (SD \pm 28.6) for those **not** taking anti-TNF α medication, (details in table 11.17 a and b, appendix 11). Perhaps of greatest importance were the large standard deviations, which suggests considerable difference in practice between rheumatologists. Additionally the discrepancy between frequency of examination for hands and feet was not lost on those with RA, of the 120 subjects who reported they had been prescribed biologic therapies, six noted that the feet were not part of the standard assessment regime for biologics and this was a mystery to them, a typical comment being;

"I cannot understand why feet and toes are not part of the assessment for Embrel" (subject 90)

Whilst it is possible there is a Hawthorne effect regarding such an observation, the language used by participants to describe a lack of foot assessment related to biologic therapy suggests that this is an area of genuine concern. This was particularly apparent among those subjects who reported continual foot pain for example,

"When I have the Infliximab infusion, the feet are disregarded when adding the scores. All the other joints are scored regarding the amount of pain. My feet are never free of pain" (subject 1159)

6.12 Perceptions of foot assessment by clinicians from those with RA

The majority of respondents 82% ($n=482$) reported that they had discussed their foot complaints with their rheumatologist and 52.5% ($n=309$), with their GP. As these figures total more than 585, the total number of respondents, this suggests some respondents discussed their foot complaints with both their GP and their rheumatologist. However, as was reported in the previous section, in spite of this apparent need, respondents recalled a distinct difference in the regularity of hand versus foot examination. On average respondents reported they last had their feet examined by a rheumatologist and/or specialist nurse 16.5 months ago (range 1-228 months \pm SD 28 months); whereas respondents' hands were last examined on average 6.2 months ago (range 1-108 months \pm SD 10 months). Statistical testing (using the Students' t-test) revealed this difference was significant $p < 0.001$ (table 2, appendix 11).

A repeated theme in the qualitative data was the perceived general lack of interest in patients' foot problems. A total of 16 respondents (8% of the 211 who included qualitative comments) suggested their GP and/or Consultant did not take their foot problems seriously, or their feet were not assessed frequently enough, for example,

"I am glad you are carrying out this research because I feel it is a neglected area in the treatment of RA, my feet are my biggest problem" (subject 44)

"after 5 years being under RA consultant...last week was the first time he actually looked at my feet – he got quite a shock when he saw them" (subject 347)

"Rheumatologist dismisses foot pain/swelling as „part of the illness – nothing we can do“ – NEVER examines feet" (subject 129)

Some respondents went further highlighting that in their experience there was not the same level of care available for foot problems as for hand problems, with one respondent commenting,

"nobody is concerned about the feet, although I have had good treatment for my hands, I am so pleased you are researching this" (subject 65)

6.13 The management of foot complaints from the patients' perspective

In terms of the need for foot care, 393 respondents (67%) indicated they had difficulty undertaking basic foot care (defined as difficulty cutting toenails). In total, 370 respondents (63%) reported they had seen a chiropodist or podiatrist. While these data suggest there would appear to be a small gap between the needs of people with RA for foot health services and service provision. It is however, not appropriate to assume those receiving foot care are in the greatest need, particularly as an even greater proportion of respondents report discussing their foot complaints with their specialist. To explore any potential gap between the need for foot care and receiving foot care further, a cross-sectional analysis was undertaken, whereby those respondents who reported signs and/or symptoms in the feet were compared with those who reported receiving podiatry care, the findings are presented in table 6.13 overleaf. The findings in table 6.13 suggest that in general, more people with RA who report signs and/or symptoms in their feet receive podiatry care, than those who report foot complaints but do not receive podiatry care. There are however, still some notable exceptions. In particular 44.4% of those who reported foot pain did not receive podiatry care and between 20-30% of respondents who reported their feet were always swollen and/or stiff did not receive podiatry care. Figures were improved for those who reported numbness with less than 10% of those who reported their feet were always numb did not receive podiatry care.

Although, a much smaller proportion of respondents reported numbness in the first place in comparison to the other signs and/or symptoms (section 6.7).

Table 6.13 – Cross-sectional analysis to illustrate whether those with foot complaints were receiving podiatry care

Sign or symptom reported in feet	% of respondents who report that they received podiatry care
Pain	
Foot pain	66.1
No foot pain	33.9
Stiffness	
No stiffness	8.3
Stiffness some of the time	51.7
Always stiff	40.1
Swelling	
No swelling	8.4
Swelling some of the time	62.9
Always swollen	28.7
Numbness	
No numbness	38.3
Numbness some of the time	43
Always numb	18.8

In the qualitative data those with foot complaints reported mixed feelings about the availability of specialist foot care. Where podiatric/chiropractic care was available, there was a general feeling that regular podiatry was beneficial, with some respondents reported excellent care from NHS podiatry services, typical comments included,

“I am very fortunate that I have excellent care from my GP, Rheumatologist and Chiropodist – the latter I have a regular 4 weeks appointment that “keeps me out of trouble”. I wear surgical shoes with callipers all day and every day. I see my Rheumatologist every 2 or 3 months” (subject 1)

“I now go to see my chiropodist every 10-12 weeks – my feet are greatly improved” (subject 84)

However, access to podiatric care was perceived to be a problem for a minority, with 10 of the 315 respondents who provided qualitative data explaining that they could not get an appointment with a NHS podiatrist, causing some to seek private care for example,

“I have arranged for my own podiatry treatment. Bought my own „New Balance” trainers and gel insoles” (subject 150)

“the NHS Chiropody Service is totally inadequate for anyone with RA” (subject 311)

When invited to comment about the provision of orthoses or footwear, a little over half of respondents (n=323, 54.19%) had been prescribed some form of insole/orthoses, and 122 (20.74%) had been prescribed hospital shoes. Unfortunately, while the majority of respondents were prescribed insoles and/or footwear, a number did not continue to wear them as described in table 6.14.

Table 6.14 – Numbers of subjects who continued to use prescription footwear and/or insoles

	YES	NO	Missing
Still wearing hospital shoes (n=122)	36 (29.5%)	86 (70.5%)	0
Still wearing insoles (n=323)	168 (51.9%)	143 (44.2%)	12 (3.9%)

The reasons for not continuing to wear insoles/shoes were numerous and are summarised in table 6.15 overleaf. Answers were not received from all subjects who were not wearing prescribed insoles and/or shoes.

Table 6.15 - Reasons for **not** wearing shoes and/or insoles

Reasons for not wearing shoes or insoles	Shoes (n=86) N (%)	Insoles (n=143) N (%)
Unattractive (shoes)	48 (56)	N/A
Do not help	26 (30)	30 (21)
Do not fit foot in shoe/insole in shoe	15 (17)	20 (14)
Increase foot pain	10 (12)	27 (19)
Worn out	6 (7)	5 (3)
Resolved foot pain	5 (6)	13 (9)
Undergone foot surgery	21 (24)	9 (6)
Prescribed footwear	N/A	6 (4)

(NB Columns may not add up to 100% as respondents could tick more than one choice)

The qualitative data revealed footwear was a repeated theme for some, with 19 (9%) respondents indicating they were unable to find suitable shoes to wear. This seemed a particular problem for women, where the inability to find smart or fashionable comfortable shoes was a cause of considerable negative psychological symptoms, as illustrated by the following comments,

“I resort to wearing old shoes and trainers which depresses me greatly” (subject 44)

“not being able to wear feminine heeled shoes because of RA has been a cause of real sadness for me” (subject 71)

“It is very difficult to find shoes on the High Street, other than lace-ups which will accommodate orthotics. Not being able to wear a „stylish“ shoe makes a person feel disabled and lowers self-esteem and mood” (subject 105)

A total of 158 (26.86%) of people with RA had been referred to a foot surgeon and of these 120 (20.4 %) had undergone some form of foot surgery. If there is a perceived dissatisfaction with conservative care, this may explain the seemingly high consultation rate for surgery. In the qualitative responses, previous (or impending), foot and/or ankle surgery was often referred to by respondents. The outcomes of surgery were variable with some finding their mobility was much improved for example,

“I have had a replacement right ankle for 9 months now – huge improvements in symptoms and mobility” (subject 286)

For others foot surgery was not successful leading to further problems with joints in their lower limbs, as highlighted by one subject,

"I had a hindfoot fusion on my left ankle/foot one year ago which was not successful as I now have more pain in my ankle, knee and hip" (subject 86)

For some of those with RA the prospect of surgery was a cause of concern, both in terms of the outcome and the necessary alteration to their medical treatment an example of which was provided by one subject who reported,

"I have seen a foot surgeon recently and am on a waiting list for surgery. This will mean stopping medication for 2 weeks. I am a bit worried about the outcome" (subject 170)

6.14 Summary of key findings from those with RA

When comparing the two groups of people with RA who responded as part of the current study, strong commonality was noted for most socio-demographic variables with the exception of age, duration of RA and employment status; differences which were expected given the geographic location of the BSUH group (described in section 6.4). With regard to the characteristics of RA strong commonality was also noted between both groups in the parameters of the mean duration of RA, disease modifying medication prescribed and the duration of morning stiffness (detailed in section 6.5).

The current study has demonstrated a number of facts about foot complaints not previously established:

- Foot pain accounts for a greater proportion of initial symptoms than has been reported previously.
- Foot complaints in RA in this sample were more prevalent than previously estimated.
- Foot complaints have a moderately severe impact on quality of life.
- Foot complaints were not limited to pain, other symptoms (e.g. numbness, swelling and so on) were also common.
- Symptoms were most prevalent in the ankle and forefoot.
- The use of disease modifying medication and/or insoles and specialist shoes did not always alleviate symptoms in the feet.
- Symptoms in the feet prevent some respondents from participating in activities that are important to them.

In terms of these main findings, a greater number of people with RA reported that the initial symptoms of the disease occurred in the feet (35.4%) than has been previously reported. In the only other comparable study in terms of numbers of participants, Vianio (1956) noted foot complaints were the first reported symptom in 16% of subjects. In the current study a greater proportion (50.1%) of respondents indicated the first symptoms of RA were in their hands. However, during the course of the disease, foot pain was almost universal for those with RA such that 95.2% of respondents had reported foot pain at some point. While pain in the feet was generally reported to be moderately severe in nature, women reported significantly higher foot pain scores than men. Additionally, those people with RA who were employed experienced less foot pain than those not in work or on sick leave. After pain, the next most common symptoms in the feet were stiffness, followed by swelling and numbness.

Overall, involvement of the metatarsophalangeal joints and ankles was the most frequent and troublesome. These joints are vital for normal propulsive gait, and dysfunction may lead to reduced mobility and a loss of independence. These losses coupled with the various symptoms in the feet had a negative effect on quality of life, which was moderate to severe in nature. Consequently activities of daily living and perhaps more importantly valued life activities were adversely affected.

Pharmacological management of RA appeared to match national patterns with methotrexate being the most commonly used DMARD, followed by oral corticosteroids. Combination therapy was also common and 20.1% of respondents reported being prescribed biologic drugs. Some respondents commented that their medication improved the symptoms in their feet, however current outcome measures (particularly those measures that exclude the feet) may not capture this improvement. Respondents reported formal assessment of their feet was infrequent, particularly when compared with the frequency of hand examination. Consequently, some people with RA commented that issues of importance to them were not always the main focus of clinical assessments. In terms of the management of foot complaints, a sizeable number of patients did not continue to use insoles/shoes that have been manufactured for them resulting in a considerable drain of resources, but there is insufficient data to comment on this aspect further. However, dissatisfaction with conservative care may explain the 26.8% referral rate for foot surgery.

7.0 Chapter 7 – Results of rheumatologists’ perceptions of the epidemiology of foot complaints in RA

7.1 Introduction

This chapter aims to present the findings of a survey of rheumatologists’ perceptions of the nature and extent of foot complaints in RA, together with how foot complaints are assessed and managed by rheumatologists. These findings are based on a questionnaire forwarded to 414 members of the British Society of Rheumatologists (BSR). The questionnaire developed for the purpose of the current study was comprised predominantly of structured questions generating nominal and interval data as described in section 5.5. Results will be presented in six sections reflecting the overall structure of the questionnaire, these sections are:

- Demographic details.
- Rheumatologists’ perspectives of the epidemiology of foot complaints.
- Rheumatologists’ assessment and examination of foot complaints.
- Referral of people with foot problems.
- Availability of local foot care services for people with RA.
- Rheumatologists’ utilisation of outcome measures.

7.2 Response rates

In total, 414 self-administered questionnaires were posted to rheumatologists and 139 (33.6%) useable replies were received, as detailed in table 7.1.

Table 7.1 – Response rate of the population sampled

	n	%
Number of questionnaires posted	414	100
Post office returns*	30	7.2
Received a questionnaire	384	92.9
Incomplete questionnaires	2	0.48
Unable to complete questionnaire (e.g. no longer a BSR member)	13	3.1
Non-responders	232	56
Completed, usable questionnaires	139	33.6

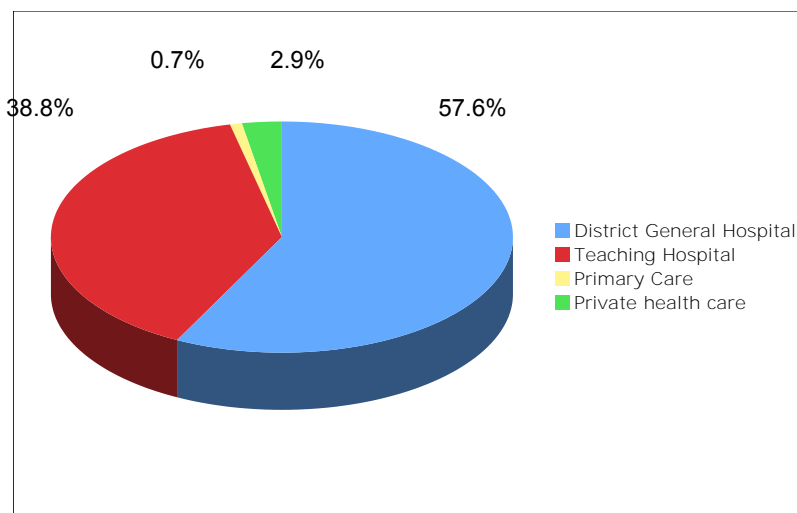
*As this sample was based on a 2003 database some returns were expected

7.3 Demographic Details

The majority of respondents were male (63%) in line with the ratio of Male: Female rheumatologists. Respondents had been practicing rheumatologists for an average of 18.25 years (median 16.5 years, range 3 - 40 years, SD 8.4). A total of 128 (92%) respondents were consultant rheumatologists, 6 (6.5%) were specialist registrars (or equivalent), and the remainder of

respondents were general practitioners with a special interest in rheumatology. In terms of place of work, most were employed in the NHS as illustrated in figure 7.1.

Figure 7.1 - Pie chart to illustrate where rheumatologists were employed



7.4 Rheumatologists' perspectives on the epidemiology of foot complaints

Rheumatologists reported that in their experience, within the first 12 months of diagnosis of RA, a mean of 63.7% (\pm SD 19.5) of patients would report some form of foot complaint to their rheumatologist. Over the course of the disease as a whole, rheumatologists perceived an average of 86% (\pm SD 11.2) of people with RA experienced foot problems that they reported to their rheumatologist. This figure is very similar to the proportion of people with RA described in section 6.12 (82%) who reported that they discussed their foot problems with their rheumatologist. However, rheumatologists were of the opinion that an average of 38.6% (\pm SD 21) of patients would not report their foot complaint(s) to their Consultant. The large standard deviations are worthy of note at this point as this suggests there is considerable disagreement between rheumatologists regarding the epidemiology of foot complaints in RA.

Rheumatologists were invited to list up to 12 of the most common foot complaints their patients reported to them. Not all rheumatologists listed all twelve foot complaints, the most complete data were provided for the three most commonly occurring foot complaints, as detailed in table 7.2.

Table 7.2 – The frequency of the three-foot complaints most commonly reported to rheumatologists
(percentages are used for ease of comparison).

Foot complaint	Most commonly	Second most commonly	Third most commonly

	reported %	reported %	reported %
Metatarsal pain	<u>88.4%</u>	6.5%	2.9%
Heel Pain	0	5.8%	3.6%
Difficulty walking	8%	<u>31.9%</u>	13%
Foot deformity	0	2.2%	8%
Cold feet	0	0	0
Foot swelling	1.4%	9.4%	13%
Arch pain	0.7%	15.9%	17.4%
Ankle pain	0.7%	18.1%	<u>22.5%</u>
Difficulty getting shoes	0.7%	7.2%	11.6%
Ulceration	0	0	0
Corns/Callus	0	2.9%	6.5%
Numbness	0	0	1.4%

The most common problem patients apparently reported to their rheumatologist was metatarsal pain followed by difficulty walking and ankle pain. This closely mirrors the findings from people with RA described in sections 6.7 and 6.8. However there were some notable discrepancies between rheumatologists' opinions and what people with RA reported. For example with regard to numbness in the feet, 11% of people with RA reported this was present all of the time and 28% reported numbness in their feet to be present some of the time. Yet, very few rheumatologists (1.4% n = 6) indicated numbness was a commonly occurring symptom in the feet. A potentially more serious problem is foot ulceration, which no rheumatologists reported as being a commonly reported foot complaint, even though people with RA reported a prevalence rate of 5.95% for foot ulceration. Hyperkeratotic lesions (such as corn and callus) has a reported prevalence of up to 28% according to those with RA, but was only reported by a total of 9.4% of rheumatologists. Whether rheumatologists are tending to base their responses on the symptoms reported by patients as opposed to the findings of clinical examination would be worthy of further exploration, particularly in the light of the frequency of foot examination reported by those with RA previously in section 6.12.

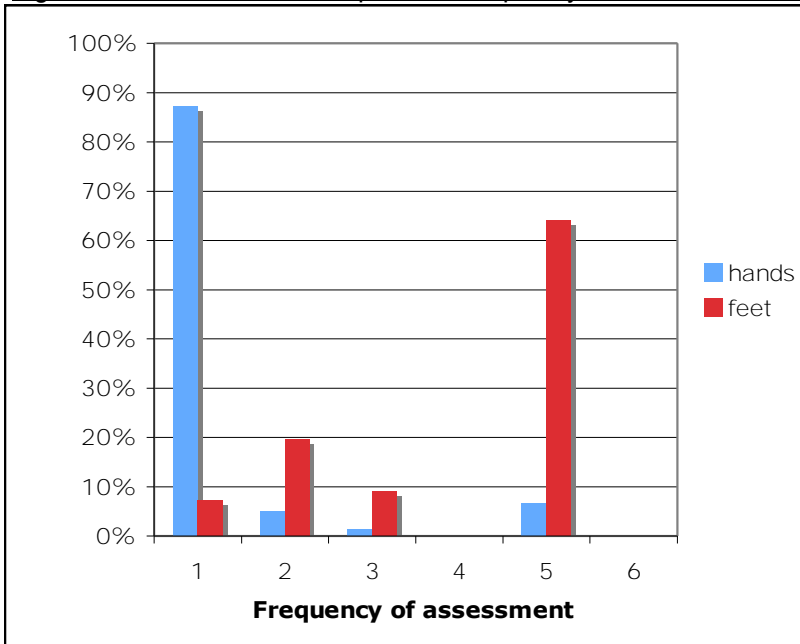
7.5 Assessment and examination of foot complaints by rheumatologists

In terms of foot assessment, almost all rheumatologists (97% \pm SD 10.8) reported they would assess the feet in people with newly diagnosed with RA, but on average only 34% (\pm SD 35.6) would undertake a foot assessment in a patient with long-standing, stable RA (the question assumed there were no reported foot problems). When changing medication to biologic therapy a mean of 68.9% (\pm SD 30) of rheumatologists would undertake a foot assessment. Again, the large standard deviations suggest noteworthy variability in clinical practice between respondents. In

terms of the frequency of foot assessment carried out by rheumatologists, figure 7.2 overleaf compares the frequency of hand examination with the frequency of foot examination.

Data in figure 7.2 suggest the majority of rheumatologists (87%) examine patients' hands at every consultation. In contrast to hand assessment however, only 7% of rheumatologists examine patients' feet at every consultation, with slightly more rheumatologists (19%) opting to examine patients' feet every other consultation. Nevertheless, for the majority of rheumatologists who responded there would appear to be no regular practice for examination of the feet, (reported by 63.8% of respondents).

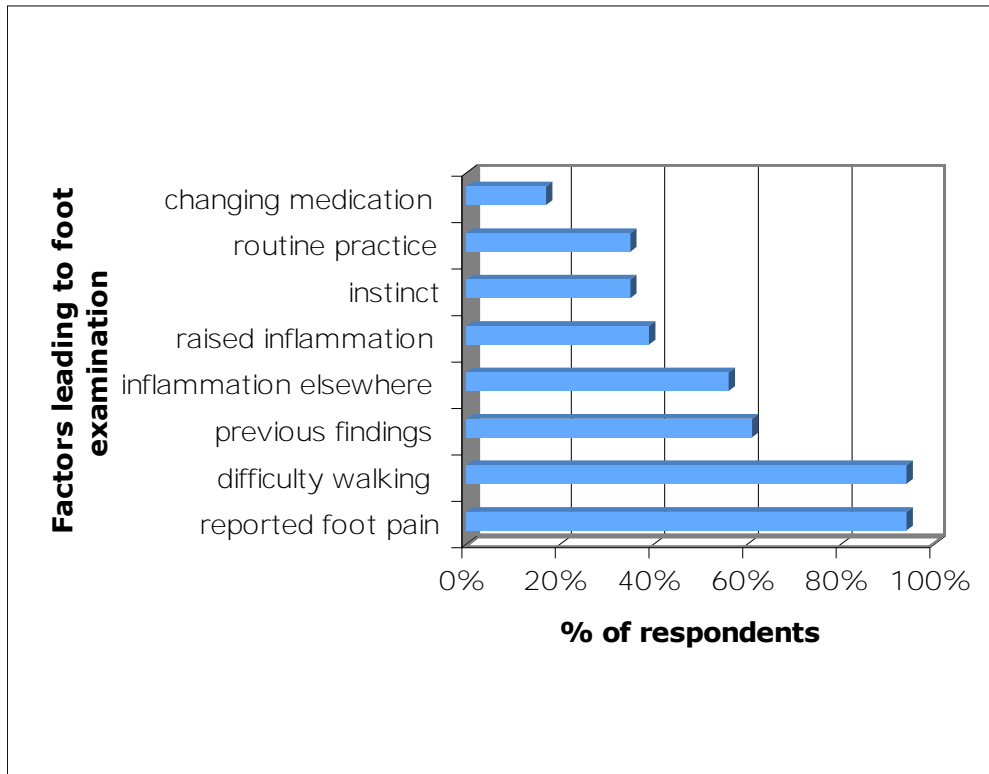
Figure 7.2 – Bar chart to compare the frequency of examination of hands and feet



Key: 1- Every consultation 2 – Every other consultation 3 – Annually
 4 – Every 2 years 5 – No regular practice 6 - Never

The factors that would cause rheumatologists in the current study to examine patients' feet are detailed in figure 7.3.

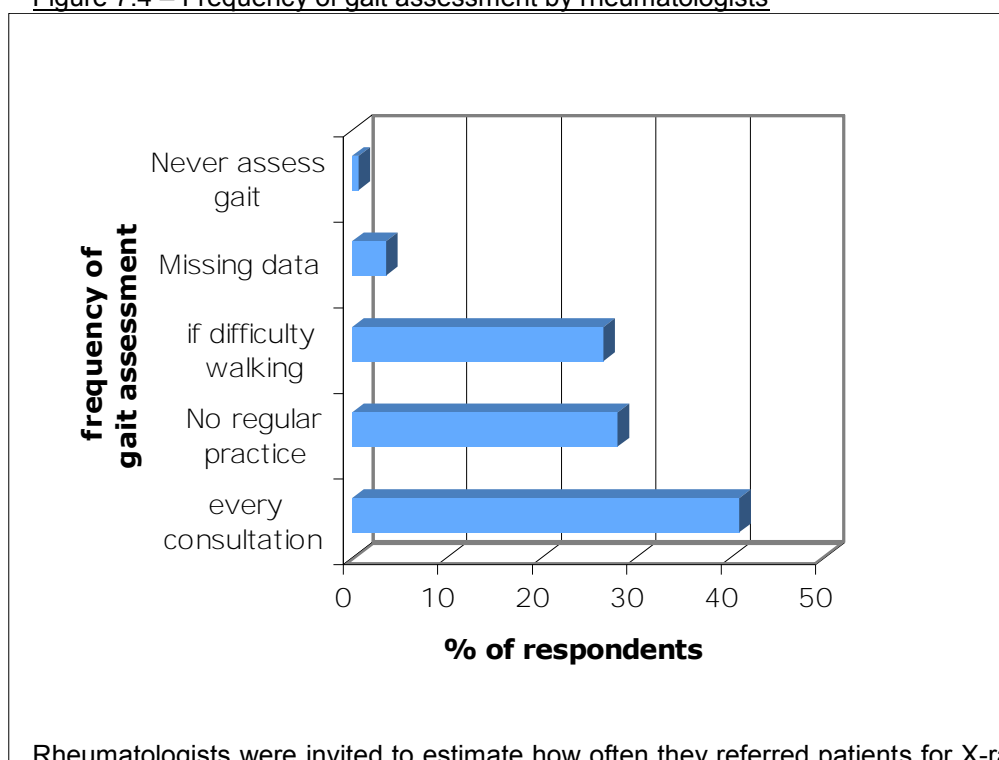
Figure 7.3 - Factors that would trigger rheumatologists to examine feet



Foot pain and difficulty walking were clearly the most common factors that would lead rheumatologists to examine feet. While to some extent these findings might be dependent upon patients reporting these problems to their rheumatologist, the results do correspond with the foot complaints most commonly reported by rheumatologists outlined previously in figure 7.2. The factors that were least likely to trigger rheumatologists to examine feet included changing a patients' medication and instinct, i.e. those clinical clues that suggest a foot complaint that may not be immediately reported by a patient.

Assessment of patients' gait was subject to further enquiry as part of separate questions. Gait assessment was reported to be undertaken far more often than foot examination as illustrated in figure 7.4, with 41% of rheumatologists reporting they would assess a patients' gait at every consultation, whereas only 7% examined the feet at every consultation. In comparison, 63% of podiatrists indicated they would assess gait at every consultation (section 8.4).

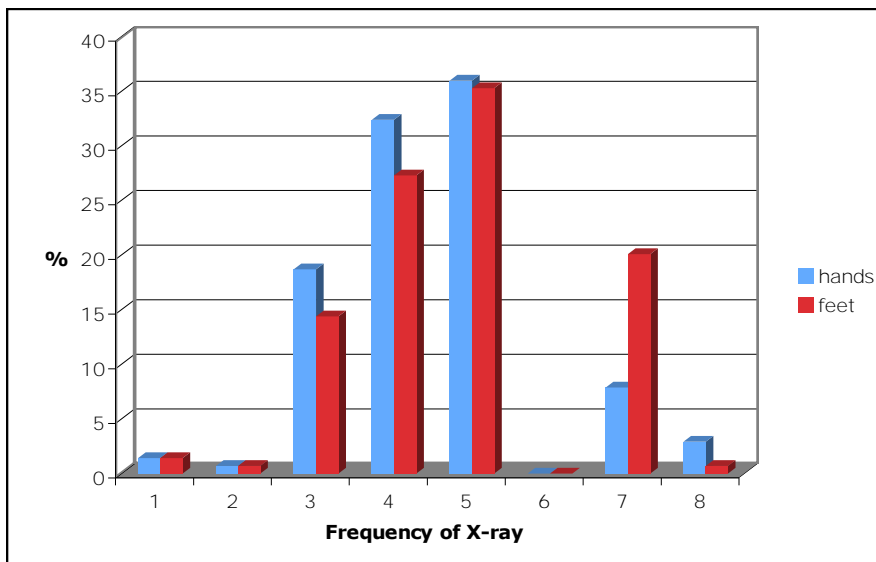
Figure 7.4 – Frequency of gait assessment by rheumatologists



Rheumatologists were invited to estimate how often they referred patients for X-rays of hands and feet (figure 7.5). Unlike the clinical assessment of hand and feet, where hand examination predominated; no overall clear pattern emerges with regard to X-ray. While hands do appear to be X-rayed more frequently than feet, most rheumatologists reporting either having no regular practice, or undertook X-rays of hands and feet routinely every two years. No rheumatologist

reported that they never request an X-ray of the feet and very few (less than 5%) indicated they would order X-rays of hands or feet at either every consultation or every other consultation.

Figure 7.5 – Comparison of the frequency of X-rays taken for hands and feet



Key: 1 – Every consultation 2 – Every other consultation 3 – Annually
 4 – Every 2 years 5 – No regular practice 6 – Never
 7 – If problems reported 8 – If surgery considered

Rheumatologists were invited to indicate the frequency with which more specialist investigations (MRI, ultrasonography and blood tests) were ordered specifically for foot complaints (table 7.3 overleaf). Ultrasonography was the most commonly ordered imaging modality, even though ultrasonography was not available to all the rheumatologists surveyed, which complicates the analysis. Equally, ultrasonography might be used as an initial investigation considering it is considerably less expensive than MRI scans. Blood tests were available to all respondents, but more rheumatologists indicated they would never use this for investigation of foot complaints, presumably because blood tests lack sensitivity for some conditions and/or are not thought specific enough for localised foot complaints.

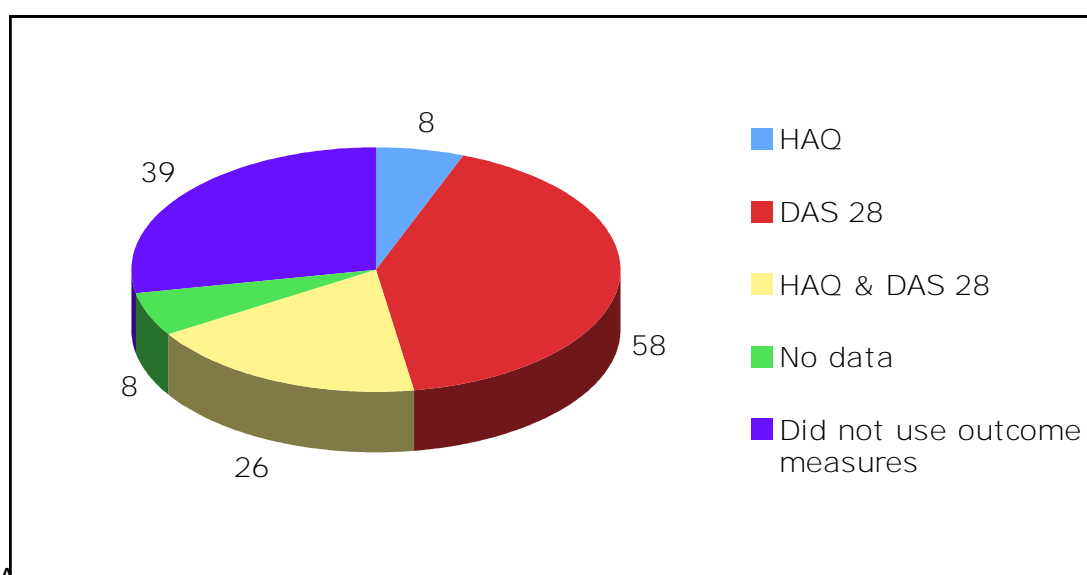
Table 7.3 – Frequency with which additional investigations were ordered for foot complaints

	Yes % (n)	Sometimes % (n)	Never % (n)	Not available % (n)
MRI	4.3% (6)	86.4% (120)	8.6% (12)	0.7% (1)
Ultrasonography	10.1% (14)	69.7% (97)	14.4% (20)	5.8% (8)
Blood tests	8.6% (12)	65.5% (91)	25.9% (36)	0

7.6 Rheumatologists utilisation of outcome measures

A total of 71.9% (n=100) rheumatologists reported they routinely used validated outcome measures in their practice to assess disease activity (figure 7.6). The most commonly reported outcome measures were the Health Assessment Questionnaire (HAQ) developed by Fries and colleagues (1982) predominantly as a measure of disability and the Disease Activity Score 28 (DAS 28) developed by Prevoo and colleagues (1995) to assess overall disease activity.

Figure 7.6 - Routine use of outcome measures by rheumatologists (n = 139)
(number of respondents provided for ease of comparison)



A separate question was used to determine if rheumatologists used foot-specific outcome measures. Only a tiny proportion of rheumatologists (n=3, 2.15%) reported using foot-specific outcome measures. The only two foot-specific outcome measures used were the Foot Function Index developed by Budiman-Mak and colleagues in 1991 (used by one respondent) and the Leeds Foot Impact Scale developed more recently by Helliwell and colleagues (2005) used by two respondents.

7.7 Referral patterns for patients with foot problems by rheumatologists

The vast majority of rheumatologists (93.5%, n=130) reported they referred their patients with RA to a variety of other healthcare professionals for the assessment and management of foot complaints (table 7.4).

Table 7.4 – The health professional(s) who rheumatologists refer patients with foot complaints to
(for ease of comparison all data are detailed as percentages).

Professional Group	Always	Sometimes	Never	Missing data
Occupational therapist	3.6%	28.1%	21.6%	44.6%
Orthotist	21.6%	59.7%	1.4%	15.8%

Physiotherapist	6.5%	53.2%	5%	33.8%
Podiatrist	41%	50.4%	0.7%	6.5%
Specialist Nurse	3.6%	20.9%	26.6%	47.5%

Clearly rheumatologists are of the opinion a number of different health professionals are equipped to manage foot complaints and this was reflected in the results. For example, orthotists feature strongly, with only 1.4% of rheumatologists indicating they would never refer their patients to an orthotist. The comparatively high number of referrals to orthotists may reflect patients' concerns about footwear as highlighted in section 6.13. Whilst some podiatrists may consider themselves to be the pre-eminent specialist in dealing with foot complaints this is not wholly matched by the referral pattern reported by rheumatologists. Although a little over 90% of rheumatologists who responded would consider referring a patient with a foot complaint to a podiatrist either some or all of the time; physiotherapists were considered by over half of respondents, occupational therapists by over a third and specialist nurses by over a fifth. These data may suggest that a range of health professionals are involved in a multi-disciplinary approach to managing foot complaints as part of an overall care pathway. Equally, these findings may reflect the difficulties associated with the availability of foot care services as outlined previously in section 6.13 and again later in this chapter. It should also be noted there was a large amount of missing data in this section of the questionnaire, therefore care should be taken when interpreting results. It is unclear whether these missing data reflect a lack of availability of services for referral, or validates podiatrists concerns (described in section 8.7) that improved links are needed between rheumatologists and the wider multi-disciplinary team. There is an opportunity to undertake further work looking at the nature of referrals received by the professionals listed and how well they perceive they are equipped to manage such referrals.

Rheumatologists were invited to identify what factors would lead them to make a referral to foot health service providers. Although not completed by all respondents, the table below gives an indication of the factors most frequently reported.

Table 7.5 Factors that lead rheumatologists to refer patients for specialist foot care
(for ease of comparison all data are detailed as percentages).

Referral factor	Podiatry service	Foot surgery	Chiropody service
	%	%	%
Availability of foot care service	58.3	44.6	44.6
Severity of foot symptoms	82.7	84.9	51.8
Severity of RA	43.9	38.8	38.1
Drug therapy (e.g. anti TNF)	63.3	63.3	58.3

Lack of skin integrity	64	40.3	53.2
Severity of foot deformity	79	82	50
Age of patient	59.7	54	47.5
Mobility of patient	64.7	67.7	41.7
Co-morbidities (e.g. diabetes)	67.6	46	62.6
Inability to care for feet	70.5	40.3	75.5

There were some themes that emanated from these data. Factors that used to be important in determining a referral, such as a patient's age, now appear to be less important in determining whether a referral is made, with less than half of rheumatologists indicating age was an important factor. Procedural difficulties (i.e. whether foot care services were available) were important issues for some (44-58%), but not for all. Rather other factors directly related to RA in the foot such as severity of foot symptoms (51-83%) and severity of foot deformity (50-82%), were both seen to be more important factors in determining whether a patient should be referred for specialist foot care. This is in contrast to the general severity of RA, which was seen to be a less important factor. These findings need to be viewed in the light of an important caveat: some respondents noted they considered „podiatry“ and „chiroprody“ to be the same, which calls into question the validity of some of the responses in this section. During the questionnaire development and pilot phases this specific issue was addressed and rheumatologists participating in the pilot studies clearly did not deem chiroprody and podiatry as interchangeable titles. In light of the findings presented here there would appear to be a need for further work into the understanding rheumatologists have of the scope of practice of foot health providers. It is equally important to view these results in the light of what foot care services are currently available. Redmond and colleagues (2006) in their survey of 170 rheumatologists highlighted the issue of lack of availability of foot care services. Up to 73% of respondents in Redmond's series indicating there was a lack of availability of adequate basic foot care services. If no specialist foot care service is available, then clearly there can be no referral and this may appear to skew the results in terms of pattern of referral. To explore this potential effect further, the availability of foot care services from rheumatologists' perspective was investigated and is discussed in the next section.

7.8 Availability of local foot care services for people with RA – the rheumatologists' perspective

The availability of foot care services for referral by rheumatologists in this survey is highlighted in table 7.6 overleaf. Again it needs to be noted that some rheumatologists considered podiatry and chiroprody to be interchangeable terms, although this view was by no means universal as highlighted by the pilot study. The lack of availability of foot care services and/or the long waiting lists could be factors that would hinder referral to specialist foot care services for some rheumatologists. Although only a small number of respondents (less than 10%) reported service

were entirely absent, more (43.2% – 48.2%) reported long waiting lists. It should also be noted that figures for availability of foot care services differ between table 7.5 and 7.6. The availability of foot care services highlighted in table 7.6 could be one factor influencing referral patterns. This suggests rheumatologists might be more willing to refer if foot care services were more readily available.

Table 7.6 – Availability of foot care services for rheumatology departments

(for ease of comparison only percentages are provided)

Service	Availability				
	Yes, easily	Yes, but long wait	Not available	Don't know	Missing data
Podiatry	53.2%	43.2%	2.2%	0.7%	0.7%
Foot Surgery	49.6%	48.2%	2.2%	0	0
Chiropody	34.5%	44.6%	8.6%	5.8%	0

Respondents were also invited to outline any factors they felt could delay or prevent referral to specialist foot health services. Of the 137 (98.6%) rheumatologists who answered this question, a total of 44 (31.7%) reported referral to specialist foot care services was hindered by one or more factors and these factors are listed in table 7.7 overleaf. The remaining 66.3% reported no difficulty in referring their patients to foot health service providers. The most commonly reported hindrance to referral among rheumatologists was long waiting lists (n = 17, 12%), although for some (n = 10, 7%) foot health services were simply unavailable. Unlike podiatrists, several of whom reported communication difficulties with the rheumatology team, this was largely not reported to be an issue for rheumatologists.

Table 7.7 - Factors that hindered referral to foot care services

Factor hindering referral to foot care services	Number of respondents' n (%)
Long waiting list	17 (12%)
Service unavailable	10 (7%)
Limited service available	10 (7%)
Don't know how to refer	9 (6%)
Don't know who to refer to	6 (4%)
Difficult in making an appointment	3 (2%)
The following issues were all mentioned by only one respondent; high referral threshold, poor communication, no contract, referral can only made by GP, patient resistance, no combined clinic, ineffective treatment, inexperienced podiatrist.	

7.9 Summary of the key findings from the rheumatologists' survey

Data presented in this chapter from rheumatologists who responded as part of the current study reveals the majority of their patients with RA present with foot complaints. Rheumatologists estimated that approximately 63.7% of patients would report foot complaints within the first year of diagnosis. This rose to 86% of rheumatologists who indicated foot complaints would be reported during the course of the disease; although over one third of rheumatologists suspect foot complaints are not always reported. It is noteworthy however to report a high standard deviation with respect to each of these figures (19.5, 11.2 and 21 respectively) suggesting considerable disagreement between rheumatologists. The complaint most commonly reported to rheumatologists by people with RA was metatarsal pain (88.4%) followed by difficulty walking and ankle pain (31.9% and 22.5% respectively).

Examination of the feet (either clinically or with the aid of imaging modalities such as X-ray) was reported to be carried out significantly less frequently than examination of the hands. The reasons for this discrepancy are not clear, as simple procedural differences in practice (e.g. whether feet were routinely examined every other year whereas the hands were examined every year) did not explain this difference. It is possible that commonly used outcome measures that specifically exclude the feet such as the DAS 28 (used by a total of 84% of rheumatologists) might be one explanation. Equally, the time constraints imposed in busy rheumatology out-patient clinics may be another reason why foot examination is not carried out as frequently as examination of the hands. Difficulty walking and the reporting of foot pain were cited as the two most common reasons that would trigger foot examination. However, this is somewhat at odds with the suspicion by over one third of rheumatologists that their patients did not always report foot complaints to them, but this did not appear to be a trigger for more frequent foot assessment. The issue of foot assessment is

further compounded by the frequency of routine foot examination, in that 97% (SD 10.8) of rheumatologists would assess the feet of someone newly diagnosed with RA, but this fell to 34% (SD 35.6) in someone with established RA who reported no foot complaints, however large standard deviations around these data suggest considerable variation in practice. The ability of people with RA to engage in social or valued life activities due to foot complaints were not reported as assessed but these could be accounted for via an assessment of disability. Only a tiny proportion of rheumatologists reported using outcome measures specifically designed for the feet.

The majority of rheumatologists (91.4%) would always or sometimes refer patients with foot complaints to podiatry/chiropractic services for specialist foot care, with the severity of symptoms and/or foot deformity being the most often used criteria for referral. However, these data somewhat contradict those provided by patients with RA in table 6.11, where a sizable proportion of patients with foot complaints reported they were not receiving specialist foot care. This might be explained by the fact Allied Health Professionals, particularly physiotherapists and orthotists were also a source of referral for foot complaints for up to 59.7% and 81.3% of rheumatologists respectively. It was not clear whether this referral pattern was due to a lack of availability of podiatric care, although a number of rheumatologists (43.4% in total) expressed frustration that when trying to access specialist foot care on behalf of their patients, barriers such as long waiting lists or complex referral procedures in effect limited availability of these services.

8.0 Chapter 8

Results of Podiatrists' perceptions of the assessment and management of foot complaints in rheumatoid arthritis

8.1 Introduction

This chapter presents the findings of a survey of the working practice of podiatrists experienced in treating people with RA. The survey was based on a sample of podiatrists who are members of a special interest group for podiatric rheumatology – the Podiatric Rheumatic Care Association (PRCA). The questionnaire developed for the current survey consisted of a range of structured and unstructured questions providing a mix of quantitative and qualitative data. Results will be presented in a series of five sections reflecting the structure of the questionnaire:

- Static assessment and examination practice.⁴
- Dynamic assessment and examination of the feet by podiatrists.⁵
- Qualitative information from people with RA recalled by podiatrists during consultations.
- The use of outcome measures by podiatrists.
- Provision of specialist foot health services for those with RA - the podiatrists' perspective.

In terms of presenting these data, both quantitative findings and qualitative are combined to develop the themes emanating from this section of the study. It should be noted however, that data from podiatrists who responded is presented in a slightly different format from rheumatologists. Considering podiatrists care for those people with RA who present with existing foot complaints; enquires about the prevalence of foot complaints were considered to be unhelpful, as returns of 100% would have been expected. Additionally, given the relatively small size of this sample group, there was concern that if demographic characteristics were collected this could lead to a potential loss of anonymity and dissuade potential respondents from replying; therefore demographic data were not collected.

8.2 Responses Rates

As described in section 5.7.10, self-administered questionnaires were posted to all members (n=78) of the PRCA. A total of forty questionnaires were returned, (response rate of 55%).

8.3 Static assessment and examination practices

The first group of questions were related to the assessment and examination of foot joints. As part of the development of the questionnaire, podiatrists routinely assessed joint in the feet for pain and

⁴ For the purposes of this study, static assessment is defined as assessments undertaken while the patient is seated on the treatment couch

⁵ Dynamic assessment is defined for the purposes of this study as assessments carried out with active input from the patient e.g. standing and walking

range of motion. With regard to pain, the majority of podiatrists (n=33, 82%) examined joints in the feet to determine both the existence and extent of pain. The factors that led to a particular joint being examined were highly variable as indicated in table 8.1. Routine clinical practice (32.5%), the subjective history from the patient (30%) and the reported pain history (30%) were the three most common factors determining whether podiatrists assessed foot joints for pain.

Table 8.1 – Factors that lead podiatrists to assess a joint for pain

Factor	n (%)	Factor	n (%)	Factor	n (%)
Routine practice	13 (32.5%)	Patient history	12 (30%)	Reported pain	12 (30%)
Swelling or oedema	8 (20%)	Deformity	5 (12.5%)	Inflammation	5 (12.5%)
Annual review	3 (7.5%)	Pathology	2 (5%)	Having RA	2 (5%)
Mobility problems	2 (5%)	Raised HAQ	1 (2.5%)	Trauma	1 (2.5%)
Insole prescription	1 (2.5%)	Change in medication	1 (2.5%)	Changes in joint range of motion	1 (2.5%)

The levels of intensity of foot pain were „always“ assessed by 47% of podiatrists (n=19) with a further 40% (n=16) replying that pain intensity was assessed „some of the time“. Only 13% of podiatrists (n=5) reported never assessing the intensity of pain. The most common method for recording the level of pain intensity was a visual analogue scale, with 62% of podiatrists (n=25) using this method. One fifth of podiatrists (20%, n=8) reported that they recorded written descriptions of foot pain. How detailed these descriptions were however, was not explored. The remainder of respondents (18%, n=7) reported recording pain intensity, but did not report the methods used. The qualitative comments from podiatrists indicated that the majority (43%, n=17) of those who used a visual analogue scale did find it helpful. However, a sizeable minority of respondents (25%, n=10) reported that while they used a visual analogue scale to assess pain, they found such an approach to be unhelpful. The remaining 32% (n=13) of podiatrists reported they found the use of a visual analogue scales to be helpful „some of the time“.

When invited to indicate which joints were examined for pain, most podiatrists reported assessing the main functional joints of the feet as described in table 8.2.

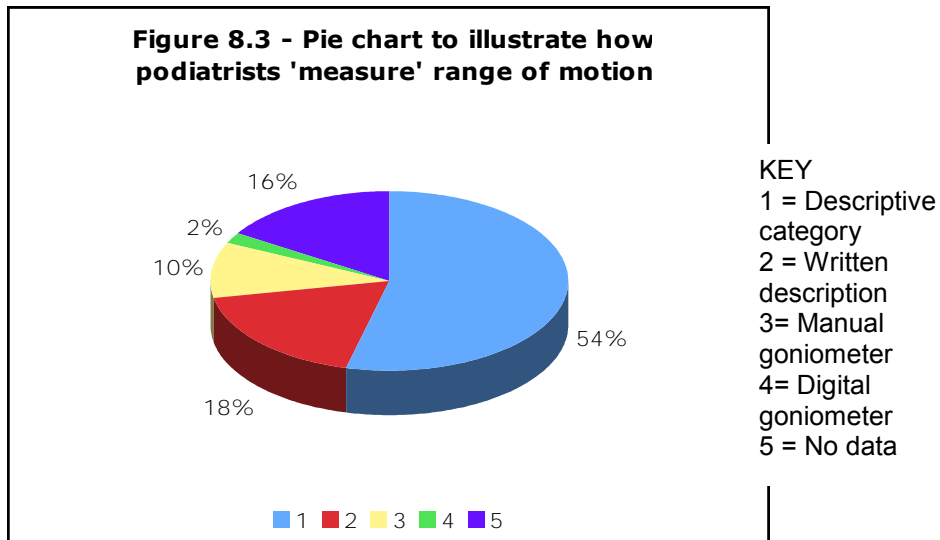
Table 8.2 - Proportion of podiatrists (n=40) assessing joints in the feet for pain and range of motion

Joint(s)	Assessed for pain n (%)	Examined for range of motion n (%)
Metatarsophalangeal	39 (97.5)	38 (95)
Sub-talar	37 (92.5)	39 (97.5)
Mid-tarsal	36 (90)	35 (87.5)
Ankle	35 (87.5)	36 (90)
Interphalangeal	29 (72.5)	26 (65)
Other (not specified)	9 (22.5)	9 (22.5)

As with pain, the most common joints in the feet to be assessed for range of motion were the metatarsophalangeal and sub-talar joints. Slightly fewer podiatrists reported that they assessed the ankle joint for pain less frequently than other joints in the feet, yet as described in section 6.8, the ankle joint together with the metatarsophalangeal joints were consistently the most frequently affected according to those with RA.

Examination of the range of motion in the joints of the feet was apparently undertaken with the same degree of frequency as assessment of foot joints for pain. A total of 83% of podiatrists (n=32) reported routinely assessing range of motion, inferring that podiatrists perceive this aspect of their practice to be as important as pain assessment. As highlighted in table 8.2, the majority of podiatrists examined the major functional joints of the foot for range of motion, with broadly similar numbers of podiatrists examining each joint for range of motion and pain. In terms of how range of motion was assessed, 65% of podiatrists (n=26) indicated they measured the range of motion some or all of the time; with 35% (n=14) indicating they did not measure range of motion. However, of those podiatrists who reported they measured joint range of motion, many respondents interpreted the term „measured“ somewhat loosely, with the use of instrumentation such as goniometers to provide an actual numerical value of the range of motion in different joints being confined to five respondents (12%) as illustrated in figure 8.1. Instead, most podiatrists (54%, n=21) elected to categorise the recording of range of motion into broad descriptive groups such as rigid, normal or hypermobile.

Figure 8.1 – Illustration of how podiatrists measure range of motion in foot joints



The assessment and subsequent recording of presenting foot deformities was routinely undertaken by 92% of respondents (n=37), the majority of whom (n=31, 85%) utilised a written description. Other methods of recording deformities in the feet were also reported. These methods included diagrams (n=3), photographs (n=3), podiatrists' own forms (n=3), one podiatrist apparently used x-rays, a structural index developed by Platto and colleagues (1991) was also used by one podiatrist.

The podiatrists surveyed were invited to report how frequently they undertook routine vascular and neurological assessments/examinations. In total 70% and 52.5% of podiatrists „always“ undertook vascular and neurological assessment respectively, suggesting this aspect of foot assessment/examination was not carried out as frequently as the assessment of pain, deformity and range of motion of foot joints. A total of 25% podiatrists indicated they would „sometimes“ undertake a vascular assessment with more (37.5%) reporting they would only perform a neurological examination „some of the time“. Relatively few podiatrists reported they never undertook a vascular assessment (5%) or neurological examination (10%) of the foot. Finally, in terms of footwear assessment, 80% of podiatrists indicated they examined shoes for both fit and wear patterns

8.4 Dynamic assessment and examination of the feet by podiatrists

Most podiatrists reported they assessed people with RA when both standing and walking, although a rather mixed pattern of practice was noted. A greater number of podiatrists (85%, n=34) reported they would always assess a patient standing, compared with 63% (n=25) who would always assess gait. In contrast, no podiatrists reported they would never assess gait, but 12% (n=5) reported they would not assess a patient standing. A total of 7% and 37% of podiatrists respectively, reported they would assess stance and gait „some of the time“. When invited to describe what was being examined when considering a patient standing, a wide variety of different responses, detailed in table 8.3 overleaf, were reported.

The single most common factor the majority of podiatrists (n=24, 60%) were assessing when observing stance was position of the feet. Position of the knee was the next most common factor considered (by nine respondents, 22.5%) and the presence of foot deformities (assessed by 8 respondents, 20%). This latter figure was surprising given that during the static assessment described in section 8.2 where a total of 37 respondents (92%) indicated they would routinely assess and record existing foot deformities. Foot deformity appeared to be rarely considered by podiatrists when assessing the patient standing. However, a number of responses such as toe and ankle position were reported and these could be interpreted as assessing foot deformity. Fifteen additional factors were considered by at least two or more podiatrists when assessing a patient standing. These factors varied from toe position to overall body symmetry as detailed in table 8.3. A further 12 items were also mentioned (listed in table 8.3), but in each case only by one respondent. Some discord between what podiatrists assess when considering stance and what people with RA consider to be important was also apparent. For example, only one podiatrist reported they would consider assessing pain in the feet when standing, yet in section 6.9, 50% of BSUH respondents reported “difficulty with standing” was adversely affecting their quality of life.

Table 8.3 – Factors podiatrists consider when assessing static stance

(number of responses provided as respondents could choose more than one factor)

Foot position (24)	Knee position (9)	Deformity (8)
Relaxed calcaneal stance position (7)	Toe alignment (7)	Arch profile (7)
Leg length deformity (6)	Hip position (6)	Symmetry (5)
Base of gait (4)	Rearfoot to Forefoot (4)	Rearfoot to leg (3)
Neutral calcaneal stance position (3)	Spine position (3)	Shoulder position (3)
Ankle position (2)	Foot in weight-bearing (2)	Overall posture (2)
The following factors were identified by only one respondent: Foot shape, leg position, facial expression, navicular drop, foot function, head position, muscle imbalance, toe contact, heel raise test, compensation, foot pain, balance.		

The reported assessment of gait was even more heterogeneous with as many as 29 different factors being reported as being considered by podiatrists when assessing gait (table 8.4 overleaf). These factors varied considerably and included consideration of separate sections of the gait cycle (e.g. heel strike or toe off) to aspects of the entire gait cycle such as velocity. The most common items assessed were gait type, heel strike and foot posture – all reported by eight podiatrists. There is however some caution when interpreting these findings as it is difficult to be confident about how reliably some items can be assessed. For example, determining some of the factors

listed (e.g. double support time) can be difficult without gait analysis software (Whittle 1991). This question did not seek to differentiate whether respondents were undertaking visual gait analysis or whether gait analysis technology such as three dimensional motion analyses was being employed. However, these data suggest podiatrists take the time and trouble to try and identify the varying components of the gait cycle that people with RA report are adversely affected.

Table 8.4 - Factors podiatrists consider when assessing gait

(number of responses given for ease of comparison as respondents could choose more than one factor)

Gait type (8)	Heel strike (8)	Foot posture (8)
Toe off (7)	Forefoot loading (7)	Pronation/Supination (6)
Asymmetry (6)	Hip position (6)	Shoulder position (6)
Knee position (6)	Rearfoot:forefoot (5)	Pain (5)
Apropulsive gait (5)	Heel position (5)	Stride length (4)
Subtalar joint motion (4)	Velocity/Cadence (4)	Spinal position (4)
Balance (3)	Compensation (3)	Double support time (2)
Deformity (2)	Use walking aids (2)	MTPJ motion (2)
Rearfoot to leg (2)	Gait phases (1)	Facial expression (1)
General posture (1)	Angle/Base gait (1)	

8.5 Qualitative information from people with RA recalled by podiatrists during consultations

In addition to enquiring what factors podiatrists considered when assessing their patients, respondents were invited to recall what people with RA experienced when reporting:

- Symptoms encountered in their feet.
- How foot complaints affected their mobility.
- How foot complaints affected their ability to carry out everyday activities.
- How foot complaints have affected their quality of life.

Generating these data were a key element of the current study because it is on the recall and interpretation of patients conversations that clinicians base their management of their patients' condition.

Taking podiatrists' responses as a whole, there were two striking aspects. Firstly the variability of responses that podiatrists recalled from their patients was considerable suggesting a wide range of differing foot complaints. This was supported by some of the qualitative information provided by those with RA. Secondly, within this rich, heterogeneous information it was clear that the burden of foot problems for those with RA was extensive and clearly pervaded all aspects of patients' lives. This has implications both for podiatric management of foot complaints in RA and the wider provision of foot care services, because it is important podiatrists are fully aware of the range of foot complaints experienced by those with RA.

When invited to outline the symptoms in the feet that people with RA experienced and described to them, podiatrists reported that their patients used a wide range of terms to describe their foot symptoms, which are listed in table 8.5. The most common descriptions of pain were references to standing on pebbles or glass, which 42% of podiatrists (n=17) reported their patients used. Almost as prevalent, but less commonly reported in the literature, was a description of hot, burning pains in the feet, recalled by 37% (n=15) of podiatrists.

Table 8.5 Descriptions people with RA use to describe foot symptoms to their podiatrist (number of similar responses)

Standing on pebbles or glass (17)	Hot, burning pain (15)
Aching pain (5)	Like walking on hot coals (4)
Sharp pain (3)	Shooting pain (3)
Hurts to walk (2)	Limits choices shoes (2)
Feet feel numb (2)	Feet lack padding (2)
Feet swollen, like they will burst (2)	Throbbing sensation (2)
Walking on bones (2)	Grinding of bones in feet (1)
Feel unbalanced (1)	Feels like bones will snap (1)
Feet don't bend (1)	Unable get out & shop (1)
Tingling sensation (1)	Gnawing pain (1)
Feet are like glass - not soft (1)	Stabbing pain (1)
Joints give way (1)	

From the descriptions recalled by podiatrists, it was also possible to develop an understanding of the severity of foot pain podiatrists recalled their patients describing. Firstly, the nature of the language used by people with RA to describe their foot pain to their podiatrist (e.g. throbbing, shooting or stabbing pains) provided an insight into the nature of the foot pain patients had reported. Secondly, the emotional impact of foot pain as reported by patients (for example, "I just want to cry") also provided evidence that the foot pain patient reported was severe. Finally, the effect of foot pain on patients' quality of life was evident with a number of descriptions highlighting how social and leisure activities are severely limited because of foot pain.

When invited to recall what people with RA reported during the course of their consultation with their podiatrist regarding how foot complaints affected patients' mobility, a similarly wide range of responses were elicited (table 8.6).

Table 8.6 Descriptions people with RA use to describe to podiatrists how foot symptoms affect their mobility (number of similar responses)

Walking is limited (14)	Feet are stiff (7)
Choice of shoes is restricted (5)	Pain is worse in the morning (6)
Restricts sporting activity (4)	Unable to walk to shops (4)
Have to rest more (3)	Unable go up/down stairs (4)
Can't play with children (3)	Mobility is restricted (3)
Like „standing on pebbles“ (2)	Can't walk barefoot (2)
Feel like an old man (1)	Unstable – fear of falling (1)
Unable to go out (1)	

Podiatrists reported the majority of their patients concerns were centred on the restriction of activity. A number of podiatrists reported their patients found their mobility to be worse in the morning; “I feel like a slug in the morning” being a memorable quote from one podiatrists’ practice. Restriction of mobility was important because this adversely affected a wide range of activities of daily living. The most commonly reported limitation was walking, with 35% of podiatrists (n=14) indicating their patients told them their ability to walk was curtailed. However, walking was not the only activity to be adversely affected. People with RA reported to their podiatrist that difficulty with mobility also limited sporting pastimes, the ability to climb stairs and participation in social activities with family and friends. The issues surrounding restricted mobility had broader implications, for example the lack of mobility appeared to limit freedom of choice and therefore resulted in a loss of independence. As one podiatrist recalled a patient saying, “I have to think about where family and friends are going before I say „yes“ – sometimes I go somewhere and I can't get back”.

Separate from information about how foot complaints affect mobility, podiatrists were also invited to comment on what their patients typically reported about how foot complaints affected their patients’ ability to carry out everyday activities. Table 8.7 details the activities podiatrists reported their patients found difficult because of their foot complaints.

Table 8.7 Descriptions people with RA use to describe to podiatrists how foot symptoms affect their ability to undertake everyday tasks (number of similar responses)

Unable to stand (9)	Painful feet limit mobility (6)
Prevent doing housework (6)	Unable to walk to shops (5)
Activities take longer (4)	Feet hurt continuously (3)
Very fatiguing (3)	Limits social activity (2)
Had to change jobs (2)	Can't keep up with family (1)
Unable to use public transport (1)	Can't care for feet (1)
Limits sporting activities (1)	Can't wear shoes of choice (1)
Unable to play with children (1)	

Podiatrists reported a range of limitations people with RA experienced due to a loss of mobility associated with symptoms of RA in their feet. Some podiatrists reported how their patients were now unable to stand for prolonged periods and therefore they were prevented from doing simple household tasks such as cooking or housework. One podiatrist recalled how a patient had commented “my husband has to do most of these chores now”. Other everyday responsibilities such as shopping were also identified by podiatrists as no longer possible for their patients. Podiatrists also described how patients reported that pain in their feet curtailed many activities of daily living and therefore adversely impacted on aspects considered germane to quality of life such as freedom of choice and loss of independence. Similar themes were reported in section 6.9, yet as described previously in section 8.3 and subsequently in section 8.6 few podiatrists appeared to incorporate this information into their assessment process or as part of outcome measurement. Difficulties associated with foot pain and loss of mobility often had the effect of enforced role change both for the patient and for their spouse, this area may be worth further exploration.

Finally, podiatrists were invited to consider if their patients had ever reported that their foot complaints had adversely affected their quality of life. A wide range of activities and limitations of personal choice as well as negative psychosocial feelings and emotions were recalled by podiatrists (table 8.8).

Table 8.8 Descriptions people with RA use to explain to podiatrists how foot symptoms reduced their quality of life (number of similar responses)

Limits walking (9)	Severe foot pain (8)
Restricts choice shoes (7)	Limits social activity (7)
Unable to stand (3)	Don't want to dress up (3)
Housebound (3)	Cause of depression (3)
Dare not go out alone (3)	Unable to care for children (2)
Prevent shopping (2)	Unable to work (2)
Restricts sporting activity (2)	Have to use wheelchair (2)
Avoid everyday activity (2)	Fear of falling (2)
Feet continually painful (1)	Require earlier appt (1)
Unable to travel abroad (1)	Fear not being taken seriously (1)

In addition to limitations placed on mobility and the severity of foot pain in RA, social and family responsibilities were clearly identified as being adversely affected due to foot complaints. These were identified as being curtailed and unfulfilled because people with RA reported being unable to participate in leisure activities or family orientated responsibilities. Loss of mobility combined with severe pain in the feet were reported to be key factors in limiting walking or forcing patients to use

a wheelchair, leading some podiatrists to report their patients were housebound as they dared not go out alone and were unable to travel. One podiatrist summed this up by reporting how a patient had described how foot complaints had “made her a prisoner” in her own home. Loss of freedom of choice was also an important theme as people with RA were unable to select when they undertook activities important to them owing to the loss of mobility. Additionally, reduced freedom of choice was reported in a number of other areas (e.g. footwear selection and leisure activities), which according to podiatrists caused their patients a great deal of distress. Those with RA as described in section 6.13 also identified these areas. Taken together, foot complaints, loss of mobility and subsequent reduced freedom of choice were identified by podiatrists as a cause of negative psychological symptoms such as depression.

8.6 The use of outcome measures by podiatrists

When invited to describe whether outcome measures were used to assess the impact of the disease process or the efficacy of treatment interventions, 50% of podiatrists (n=20) indicated they did not use outcome measures in clinical practice. Of the 50% remaining, half (25% of the total respondents) indicated they sometimes used outcome measures. One person did not respond, leaving 22% (n=9) routinely using outcome measures. The outcome measures that were used in clinical practice by podiatrists are identified in table 8.9.

Table 8.9 – Outcome measures used in practice by podiatrists (number of respondents)

Foot Function Index (9)	Foot pain disability questionnaire (4)	Pain scale (2)
Foot Impact scale (1)	Health Assessment Questionnaire (1)	Muscle strength (1)
Foot posture index (1)		

The pilot studies carried out as part of the development of this questionnaire suggested there were a number of aspects of foot assessment podiatrists wished to record but were unable to do so, therefore podiatrists were asked to identify their „wish list“ and responses are outlined in table 8.10.

Table 8.10 - Aspects of foot assessment Podiatrists wish to record, but are unable to do so (number of respondents)

Objective outcome measure (5)		Foot pressure measurement (4)	
X-ray (4)	Ultrasonography (2)	Swollen joint score (2)	
Foot specific pain score (2)	Foot function index (2)	Activity assessment (1)	
Osteoporosis (1)	Video gait analysis (1)	3D motion analysis (1)	
HAQ (1)	Blood tests (1)	Muscle imbalance (1)	

The aspects of foot assessment identified by podiatrists that they wished to record but were unable to do so fell into three broad categories. Firstly, a total of 10 podiatrists expressed a wish for outcome measures or other assessment tools that they considered were „objective“. The domains to be covered these objective outcome measures varied, but included methods for measuring pain, foot function and activity assessment. The second category was the ability to use more technologically advanced measures, for example foot pressure measurement and three-dimensional video gait analysis. Finally, some podiatrists reported that they were interested in accessing those investigations often undertaken by rheumatologists and described in section 7.5. Notable amongst podiatrists' requests were access to the results of blood tests and imaging modalities such as X-rays or ultrasonography. While podiatrists wished to access blood test results, the majority of rheumatologists reported they would not order blood tests specifically for foot complaints. This might suggest podiatrists are interested in understanding more about a patients' overall disease status.

8.7 Provision of specialist foot health services for those with RA - the podiatrists' perspective

Finally, podiatrists were invited to consider what could improve the overall foot health service they were able to offer to people with RA. A broad range of responses was elicited, outlined in table 8.11.

Table 8.11 – Factors podiatrists considered would enhance podiatric care for people with RA
(number of responses for each item)

More funding orthoses (11)	Early referral (10)	Team approach (8)
All RA pts referred (7)	More time (4)	Education programme (4)
Better links with rheumatologist (4)	Better links with AHPs 3	
Work with orthotist (4)	More GP awareness (3)	Improved footwear (3)
Direct access for patients (2)	Foot pressure measurement (2)	Triage (2)
Larger podiatry team (2)	Referral guidelines (1)	Ultrasonography (1)
The following factors were identified by one podiatrist; standard assessment form, access to a pain clinic, more review appointments, availability of an advanced practitioner		

Perhaps predictably, the single greatest requirement was for more funding, specifically for foot orthoses, which just over a quarter of respondents highlighted. However, the complex area of interaction and communication with other members of the healthcare team was collectively an area that many podiatrists raised. Improved links with rheumatologists, general practitioners and allied health professionals were all reported, as was a team approach and working with other health

professionals in the wider rheumatology team such as orthotists. The expedience with which people with RA were referred to the podiatry service was the communication-based issue reported most often with 25% of respondents wanting people with the early stages of RA to be referred to the foot health service. Some podiatrists wanted all people with RA to be referred to foot health services. Equally podiatrists may not be aware of the hindrances rheumatologists reported when attempting to refer their patients to foot care services, highlighting the need for improved communication between clinicians. Taken together, an improved working relationship with other members of the rheumatology healthcare team (rheumatologists, orthotists and other Allied Health Professionals) was a key issue with 19 podiatrists (47.5%) indicating this was an area of concern for them.

In section 8.6 the use of enhanced technology (such as foot pressure measurement and/or ultrasonography) was suggested by some podiatrists as helpful in aiding assessment of the foot complaints in RA. Again in the current section a number of podiatrists identified the use of improvements in technology to aid assessment and monitoring of foot complaints. However, considering that a number of podiatrists did not report routinely using outcome measures in their practice, there would still be no clear way of knowing that the use of advanced technology (and the investment this would require) would improve service provision and the beneficial effect this might have on patient care.

Finally, only a relatively small number of podiatrists reported that time or the number of available appointments were limiting factors. This suggests that podiatrists appear to be able to carry out the assessments and treatments required in the timeframe permitted. Additionally, it might be presumed that podiatrists have some autonomy over the duration of consultations as only four respondents reported difficulty with scheduling clinical time. In section 6.12 it was reported that some people with RA who experienced foot complaints were unable to access foot care. It may be that podiatrists are not aware of the difficulties some people with RA experience when trying to access foot care services.

8.8 Summary of the key findings from podiatrists

In terms of the process of foot assessment, podiatrists reported the most common assessment was for pain and range of motion at the main functional joints in the foot and ankle. Assessment of foot joints for pain was routine practice for most podiatrists, with the patient's history and/or reported foot pain being the next two most common factors triggering joint assessment. Assessment of peripheral vasculature was more commonly undertaken than assessments of peripheral neurological status. Static stance was observed by 85% of podiatrists at every visit, whereas gait was assessed by 63% at every visit. A diverse number of factors were considered during

assessment of gait or stance suggesting podiatrists were trying to be as comprehensive as possible, although there was considerable variation in practice.

A wide variety of descriptions of the experience of foot pain were reported by podiatrists from their patients, with “standing on pebbles or glass” and “hot, burning pain” being the two most common descriptions recalled. A total of 35% of podiatrists recalled their patients reported limited mobility due to foot complaints, the inability to walk and in some cases an inability to stand for long periods of time affected the ability to carry out activities of daily living such as housework or shopping. Podiatrists recalled how patients had reported that their foot complaints had a profoundly negative impact on their quality of life. However, of the 50% of podiatrists who routinely used outcome measures in their clinical practice, most choose to use instruments that measure pain and deformity (e.g. the Foot Function Index) rather than instruments that could assess wider implications such as effects on quality of life and valued life activities. Some of the measures (particularly those that rely on visual analogue scores) might also be considered to be somewhat mechanistic and reductionist in nature given that subjective experiences (such as pain) are being assessed. Some podiatrists also expressed a desire to use more technologically advanced assessments to determine the effect of RA on the foot.

In terms of service provision, better funding of more expensive interventions such as foot orthoses was requested by a little over a quarter of podiatrists, although the early referral of people with RA and/or referral of all RA patients was an equally widely held need. Many podiatrists also expressed a wish to have more involvement and/or better access to members of the multi-disciplinary rheumatology care team, which may reflect the communication difficulties between predominantly hospital-based rheumatologists and podiatry services based mainly in the primary care setting.

9.0 Chapter 9 - Discussion

9.1 Introduction

The current study is the first known to examine the nature and extent of foot complaints in RA from the viewpoint of those who live with the disease. Previous epidemiologically focussed work (described in section 3.2) into the prevalence of foot complaints in RA has been undertaken using hospital clinic-based or convenience samples as opposed to population based surveys. Such an approach may skew information particularly if data from people with RA are collected during their attendance at foot clinics. It is possible therefore that the prevalence of complaints may be over estimated, as this approach does not take account for those without foot pathology. The population based samples utilised in the current study aimed to address these issues. Furthermore, the self-reported questionnaire contained both structured and unstructured components developed to fulfil the aims identified in section 1.2 of enabling people with RA to report issues of importance to them, compared with the areas of importance from the clinicians' perspective.

Based on the available, searchable literature this work appears to be the largest study of foot complaints in RA undertaken in the UK to date. The only other similar sized study having been conducted over 50 years ago in Sweden (Vianio 1956) and was undertaken before the modern era of disease management. By obtaining data from as large a sample size as economically and feasibly possible, the current study attempted to reduce the error inherent in small samples, which has been an additional limitation of some previous work.

The unique nature of the current study is further enhanced by the integration of data from the clinicians who most commonly manage foot complaints in RA – podiatrists and rheumatologists; this approach enabled the multi-faceted nature of this topic to be explored more fully. As described in chapter five throughout the present study methodological approaches from differing traditions have been combined to make intensive use of the data available to explore the range of foot complaints, facets of which will be discussed further in this chapter.

The current work has consistently demonstrated the considerable and sometimes overwhelming impact that foot disease in RA has on individuals' mobility, quality of life and ability to undertake valued life activities, because of the extent and location of symptoms such as pain and stiffness in the feet. These definitive data are new to the literature. Novel and equally major has been the marked disparity between what is important to patients and the information recorded by practitioners (particularly podiatrists) with respect to the nature and extent of foot complaints in RA. Potential mechanisms to overcome areas of discord are also considered. The discussion that follows will cover each of these points in turn, comparing the findings of the present study with

previous work and highlighting both potential confounding variables and the way in which the methodological design sought to minimise these limitations.

9.2 Analysis and synthesis of the present study's findings

Following the completion of data analysis and the results, findings from each of the three results chapters were reviewed by a process of re-reading and comparison to determine common or inter-related themes. The process of analysis was commenced by returning to the aims and objectives of the study and considering these in the light of the findings reported in the summary sections (sections 6.14, 7.8 and 8.8). As part of this process it was particularly important to map the findings from those with RA against those from podiatrists and rheumatologists to explore similarities and differences. To undertake this process the principles of thematic analysis postulated by Van Manen (1990) and explained previously in section 5.7 were utilised. This process of analysis and synthesis led to the development of a series of themes, which were seen to have been repeated for all three participant groups: although it should be noted that these themes did not necessarily mean there was agreement across all three groups of respondents. More often a theme highlighted potential discord, particularly between clinicians and those with RA. Once developed the themes could be compared with the literature enabling previous work to be compared to the findings of the current study.

The overarching theme evident from all three groups of respondents was the extent of foot complaints experienced, with symptoms such as foot pain being almost universal for those with RA. People with RA found their foot complaints to be so extensive that many other areas of their lives were adversely affected, for example a loss of mobility and consequent loss of independence. For some patients (as noted in section 6.8 and 6.9) this led to the loss of valued life activities, limitation of social interactions, and poorer quality of life. While the extent of foot complaints in RA was agreed by all three groups of respondents, it was equally clear that some patients felt that the extent and impact of these foot complaints was not fully assessed by clinicians. The literature suggests that while loss of valued life activities and reduced social interactions and poorer quality of life have been widely associated with RA, they had not been reported due to foot complaints. When clinicians did assess the feet, aspects such as valued life activities were not included as part of their assessment. This in turn led those with RA to become frustrated about what they perceived to be a lack of interest in the problems they were reporting, as identified in section 6.12. The resultant differences apparent between clinicians and those with RA regarding the impact of foot complaints was just as important as a theme as the shared agreement about the extent of foot complaints in RA. To explore differences and similarities a series of sub-headings were established, which shaped a large part of the discussion as a whole.

When considering assessment and management of foot complaints, there was a theme of discord between those with RA and clinicians, sometimes because patients felt clinicians did not appear to fully appreciate the wider impact of foot complaints. The approaches and instruments used by clinicians to assess these foot complaints lacked the comprehensiveness required to fully elucidate the very constructs that were being assessed, as highlighted by one respondent who commented,

“When I have the Infliximab infusion, the feet are disregarded when adding the scores. All the other joints are scored regarding the amount of pain. My feet are never free of pain” (subject 1159).

It is possible therefore that as a consequence the management of foot complaints might be sub-optimal and a downward spiral of deteriorating foot health for those with RA is a real potential, an area discussed further in section 9.12, where opportunities to enhance the management of foot complaints are also considered. However, before these more complex areas can be discussed, it is essential to have a broader understanding of the extent and nature of foot complaints in RA. Within this, areas of discord between patients and clinicians’ appreciation of what is important are explored, together with how these areas could be assessed more comprehensively. Discussion of these key areas of importance based on the findings of the current study compared with previous research is developed in sections 9.3 - 9.9.

9.3 The nature and extent of foot complaints in RA part 1: foot pain and its assessment

9.3.1 The extent of foot pain in RA

Until recently, the impact of foot involvement in RA has received relatively little attention in the literature, leading some to suggest that foot pathologies in RA have often been largely ignored and sometimes neglected (Korda & Balint 2004). The results of the current study suggest that foot complaints are an almost inevitable feature of RA, such that only 4.8% of 585 people with RA studied reported had never experienced foot pain. The large sample size, in addition to the broad age range and duration of RA for participants (23 - 95 years and 1 month - 63 years respectively), underlines that the current study sampled a wide cross-section of the population of people with RA, giving confidence that the findings are transferable. A number of reports have indicated that pain is the predominant foot complaint experienced by people with RA (Speigal & Speigal 1982, Keenan et al. 1991, Costa et al. 2004), and the current study confirms that foot pain is extremely common, experienced by 95.2% of respondents at some point during the disease. There was also the suggestion from some respondents in the current study that they had become so used to their feet being continually painful that it had become part of their everyday lives. Only when the nature and extent of foot pain was specifically enquired about did some people with RA acknowledge how much difficulty their foot pain caused; one subject commented,

“Now I’ve had to think about it, my feet hurt just about most of the time, but I’m very used to it so hardly notice it” (subject 135).

Comments such as this do require the consideration of the Hawthorne effect, which is discussed further under the limitations of the current study in section 9.14. Nevertheless the almost ubiquitous nature of foot complaints in RA is highlighted.

The estimate of the prevalence of foot pain obtained in the current study (95.2%) is generally higher than those obtained in previous studies (reviewed in section 3.2). In the largest study of its kind, Vianio (1956) reported that up to 89% of people with RA experience foot problems. However, Vianio’s work was undertaken prior to the advent of modern disease modifying treatments for RA. Pharmacological treatment may affect the prevalence of foot pain, therefore Vianio’s work may have represented an over-estimate; particularly as in a series of 100 RA patients, Kerry and colleagues (1994) reported forefoot pain in 59% and hindfoot pain in 61%. Yet, in the same year a much higher proportion of patients (94%) were reported to experience foot symptoms by Mitchelson and colleagues (1994). Most recently, Matricali and colleagues (2006) have noted the presence of forefoot pain in 81% of a sample of 285 people with RA. Similarly, Lohkamp and colleagues (2006) reported prevalence of foot pain of 74% in a sample of 185 people diagnosed with RA in the last four years. However, care has to be taken when interpreting previous work, owing to the nature of the sample and the different definitions used. The current study did not compare foot pain in early and late disease owing to the lack of consensus regarding what constitutes „early” disease (Berthelot et al. 2001, Aletaha et al. 2004). Equally, while some studies report foot pain, others refer to foot „symptoms” or foot „complaints”; in the current study pain was differentiated from other symptoms such as stiffness, which will be discussed in section 9.4. Given that symmetrical polyarthritis of the small joints of the feet (and hands) is one of the hallmark features of RA (Schnitzler 2005, Helliwell et al. 2007, Schon & Logel 2007), such a high proportion of people with RA reporting foot pain would not be unexpected. Even so, the prevalence of foot pain of 95.2% reported in the current study is striking, particularly when seen in the context of advances in disease management reported in section 2.6 and appendix 2.

The severity of foot pain seen in the current study is worthy of further discussion. Respondents with RA reported a mean pain score of 4.9 (SD 2.2) on a 10cm VAS, suggesting that for many foot pain is moderately severe in magnitude (Anaesthesia UK 2006). Previous studies that have considered the epidemiology of foot complaints in RA (outlined in section 3.3) have tended not to report on the severity of foot pain, making direct comparisons with the literature impossible. However, Evers and colleagues (1998) with a sample of 284 RA patients reported a mean overall pain score for RA of 5.18 (SD 2.29) using a 10cm visual analogue scale as part of the Arthritis Impact Measurement Scale questionnaire. Evers and colleagues findings are only slightly higher

than the mean foot pain score reported in the current study, with a similar standard deviation. This suggests that for some people with RA, their foot pain is as severe as pain elsewhere. A further novel finding of the current study was that severity of pain in the feet was significantly associated with other symptoms in the feet; including stiffness, numbness and swelling. As with previous reports relating to foot pain in older people (Gorter et al. 2000), in the present study foot pain in both genders was noted to increase in severity with advancing age.

As expected, respondents with RA in the current study reported considerably more foot pain than did adults in the general population without RA. Similarly, Holden and colleagues (2004) reported 96% of a sample of 50 people with RA had disabling foot pain, compared with only 37% of a population of 100 healthy adults. In non-rheumatoid populations the prevalence of foot pain is markedly lower than reported in the current study. For example, in the USA Leveille and colleagues (1998) reported an overall prevalence of 32% for foot pain in elderly females, and pain on palpation was described by up to 31% of older adults by Dunn and colleagues 2004. In the UK, Garrow and colleagues (2004) found 24% of women and 20% of men aged 18-80 years reported disabling foot pain. Finally, Menz and colleagues (2006) reported the highest prevalence of foot pain (36%) from non-rheumatoid elderly (aged ≥ 70 years) Australian adults. Data from the current study confirmed that foot pain is an almost universal feature of RA and as part of the study design data were collected to provide explanations of why so many people with the disease reported foot pain.

9.3.2 The influence of gender on foot pain

In the current study women reported significantly higher foot pain scores than men. This is not an entirely new finding in studies of foot complaints in RA. For example, Bal and colleagues (2006) reported women had significantly higher scores on the foot function index than did men. This may reflect an increased willingness to report foot pain on the part of female respondents. Previously, authors have tended to attribute the increase in foot complaints reported by women to inappropriate footwear (Munro & Steele 1998, Dunn et al. 2004); however, this view may be over simplistic as some literature reviews and research reports note female gender to be a predictor of disease outcome in RA (Emery 2006, Blom & van Riel 2007, Sanmarti et al. 2007). In an overview by Yaron (1995) of the female sex hormones, oestrogen has both immunostimulatory and immunosuppressive properties, whereas progesterone appears to solely suppress the immune system. Androgenic hormones are also thought to be immunosuppressive: however, attempts to use hormone therapy to alleviate symptoms have been of variable success. This suggests an (as yet) incomplete understanding of how gender influences disease expression in RA that may also extend to foot complaints. In the current study, footwear related issues were found to be important both to those with RA and clinicians and will be discussed further as part of the debate surrounding therapeutic interventions. Nonetheless, there is little convincing evidence that women's footwear is

the major cause of the reported significant increase in foot complaints in RA, particularly as a number of respondents highlighted they were restricted to wearing „comfortable“ shoes as one way of minimising the pain in their feet.

9.3.3 Foot complaints and Body Mass Index (BMI)

Although Helliwell and colleagues (2007) questioned a potential association between BMI and foot complaints, statistical testing of the data from the current study revealed no significant relationship between severity of foot pain and BMI. The BMI data from the current study did suggest more subjects were obese when compared with national trends where 20% of UK adults are overweight (National Audit Office 2001). Levels of obesity rise dramatically among 55-64 year olds, where 76% of males and 68% females are overweight or obese (National Audit Office 2001). As the current study contained a higher proportion of older adults, a higher frequency of obesity was not surprising. Paradoxically, in RA a low BMI is associated with higher mortality (Kremers et al. 2004, Escalante et al. 2005). The reasons for this link remain unclear, but Kremers and colleagues (2004) suggest that lower cardiovascular risks could be responsible and altered levels of systemic inflammation have also been suggested (Escalante et al. 2005). While in general BMI remains a reliable indication of total body fat there are important limitations to the measurement of BMI in chronic diseases. For example, while BMI can be over-estimated among persons who are very athletic and have a large muscle mass, it can equally be underestimated in those who have a chronic disease and have consequently lost muscle mass. It is therefore possible that a loss of muscle mass could have a negative impact on foot function due to changes in gait patterns, just as a higher BMI could cause more foot complaints owing to increased mechanical stress. A further difficulty highlighted in the current study occurs when assessing aspects of foot complaints such as identification and severity of foot deformity owing to differences in perceptions between people with RA and clinicians. While further work is required to develop a more complete understanding, the current study suggests BMI is not as important an indicator of pain as other factors.

9.3.4 Cigarette smoking and foot pain in RA

As discussed in appendix 1 and within the methodology (section 5.4), RA has been shown to be more severe in those who smoke. However, no statistically significant relationship between smoking and the severity of foot pain was found in the current study. To a certain extent this may be because a total of 11.4% of subjects were currently smokers, a lower rate than the current prevalence of smoking in the UK. The Office of National Statistics (ONS) suggest an overall prevalence of smoking in the UK of 24% for the over 16's, but for those over 60 this falls to 14% (ONS 2005). A number of authors have highlighted that socioeconomic deprivation is associated with a worse clinical outcome in RA (Vliet Vlieland et al. 1994, Young 2000, Jacobi et al. 2003) and a much greater prevalence of smoking is noted in lower socioeconomic groups for both genders (Marsh & McKay 1994, ONS 2006). Data were inconclusive in the current two-sample population

to determine whether people who smoked and had a lower socioeconomic status reported more foot pain.

9.3.5 Mechanical stress, inflammatory synovitis and foot pain

Currently, the balance of available evidence suggests that the most common site for pain (and sometimes the site of initial symptoms) from RA in the feet is the forefoot (Cracchiolo 1993, Shrader 1999, Farrow et al. 2005, Trieb 2005). Findings of the current study (section 6.8) supported this and also indicated that more people with RA experienced the initial symptoms in their feet than was previously thought to be the case. The implications of these findings in terms of the diagnosis of RA will be discussed in section 9.5. More recently, Lohkamp and colleagues (2006) in a study of people with early RA (less than four years from diagnosis) found 69% of respondents reported foot pain in the first year, rising to 80% in the second year, falling slightly to 76% and 65% in years three and four respectively. It should also be noted that findings of the current study (section 8.5) indicated that the range of symptoms in the feet is not limited to pain (the nature of foot complaints will be discussed further in the next sub-section).

In general, pain and deformity in the hindfoot and ankle have been reported to occur less frequently and later in the course of RA, but have a more severe impact on foot and lower limb function as a whole (Cracchiolo 1993, Shrader 1999, Farrow et al. 2005, Trieb 2005). The wider issues associated with declining foot health in RA, such as decreasing mobility and increasing loss of function and independence, will be discussed in subsequent sections. The high prevalence of foot complaints in RA reported by the current study does not appear to be explained by factors such as smoking or BMI. As discussed in section 3.3 however, it has been suggested there may be a link between mechanical stress and inflammatory synovitis leading to the high frequency of foot complaints seen in RA (Miller & Nash 1994, Cimino & O'Malley 1998). In part, this hypothesis is founded on the pattern of foot pathologies observed in RA. Although Dixon (1982) and Helliwell and colleagues (2007) remind the reader that there is no such thing as the „typical rheumatoid foot“, the consistency in the types of deformity seen in the feet (described in section 3.3) is remarkable. More importantly however, Aldrich and colleagues (2000) point out that consistency in clinical presentation may well conceal a wide array of different experiences for those with the illness.

Although the interaction of inflammatory synovitis and mechanical stress has been presumed to account for many of the foot complaints seen in RA, to date little work has been undertaken to explore this link further. Tan and colleagues (2003) reported a predilection for synovitis adjacent to the radial collateral ligament of the metacarpophalangeal joints of the hand, which they suggested this might be due to the local biomechanical factors within the joint. This possibility is supported by Liang & Gardner (1999) who propose a link between the inflammatory cascade and cellular mechanical stress via stimulation of a p38 mitogen-activated protein kinase (p38 MAPK) promoting

nuclear factor-kappa B (NF-κB) components. While this work was completed in neonatal rat ventricular cells, more recently (Agarwal et al. 2004) have found chondrocytes subjected to tensile strain utilised the NF-κB transcription factors to aggravate the pro-inflammatory response, suggesting a role for this mechanism in the pathogenesis of arthritis. However, other pathological processes have also been suggested including a role for nitric oxide, which is produced in response to mechanical stress in cartilage tissue (Fink et al. 2001). Sadly, no similar models exist specifically for the foot. Indeed Razeghi and Batt (2002) lament the paucity of empirical evidence that exists to support the various models of foot function (such as the criteria for normality (Root et al. 1971), sagittal plane blockade (Danenberg 1993) and the tissue stress model (McPoil & Hunt 1995), all of which have been proposed during the last 40 years. It should also be noted that these models are designed to be applicable to the „normal“ foot; that is, without co-existing systemic disease such as inflammatory arthritis. Work on the pathological determinants of the rheumatoid foot remains in its infancy, but the availability of newer technologies such as three-dimensional magnetic resonance imaging (Woodburn et al. 2002) may prove promising in the future. While the lack of empirical evidence to support explanations of „normal“ foot mechanics hinders the development of models to explain foot mechanics in chronic diseases such as RA, the findings of the current study may provide a springboard for researchers to consider the nature and location of foot complaints (particularly in the early stages of RA) in more detail, building up a pattern of symptoms that in conjunction with the findings of imaging studies may provide clues to the pathomechanical process.

9.3.6 The nature of foot pain in RA

The nature of foot pain experienced by respondents in the current study was highlighted by the language used by people with RA to convey their experience of pain in their feet (section 8.5). On reflection, the number of respondents with RA who provided qualitative data and in particular the high quality of the information conveyed therein was an unexpected finding and prompted a further search of the literature as part of the iterative nature of qualitative research. This new search (table 9.1) revealed no new work reporting foot complaints from the perspective of those with RA to add to those discussed in section 4.4.

Table 9.1 - Literature search related to foot pain

Databases searched	Pubmed, Science Direct, Cinhal, AMED
Dates included	1996 – 2008
MeSH search terms	rheumatoid arthritis AND pain AND foot OR feet

Four recently published articles reporting on the epidemiology of foot complaints in RA were located (Matricali et al. 2006, Bal 2006, Lohkamp 2006, Firth et al. 2008) and summaries of these

findings were added to table 3.2. However, none of the reports identified in table 3.2 discussed the nature of foot pain in RA as experienced by those with the disease. It could be argued that this is consistent with the experience of those subjects in the current study, fifteen of whom specifically reported a lack of interest by health professionals in foot complaints. Typical comments included,

“No-one is interested in feet, although I have had good treatment for my hands, I am so pleased you are researching this” (subject 65).

“I am glad you are carrying out this research, because I feel it is a neglected area in the treatment of RA. My feet are my biggest problem” (subject 44).

In the current study podiatrists recalled and those with RA used a wide range of adjectives to convey the nature and severity of foot pain. The most common descriptions of pain recorded in the current study were references to “standing on pebbles” or “standing on marbles” with a total of 42% of podiatrists (n=17) reporting that their patients used these descriptions. This closely matches descriptions that have been previously reported in the literature (Dixon 1981, Gibson 1986). However, almost as prevalent in the sample, but far less commonly reported in the literature, was a description of hot, burning pains in the feet, recalled by 37% (n=15) of podiatrists. Analysis of the vivid descriptions which people with RA reported to their podiatrist together with qualitative information directly from those with RA provided an insight into the affective components of foot pain over and above that which could be provided by numerical scales (Thomas 1997). For some, the duration of foot pain was particularly distressing. For example,

“I cannot walk more than 200 yards without orthotics and trainers with support under the balls of my foot, my feet are in constant pain” (subject 231).

Ongoing pain is often perceived as being more severe (Jones 1997); therefore the duration of foot pain may influence its perceived severity. A number of respondents with RA (n=39) indicated in their qualitative comments that their feet were particularly painful during weight-bearing activity. Unsurprisingly, foot pain (particularly increased pain during activity) led sufferers to limit their activities or forced them to use mobility aids. One respondent summed this up saying,

"I use a wheelchair when there's a lot of walking to be done, and I have a small scooter too. When my feet are at their worst the pain is awful" (subject 301).

Consistent with previous research into chronic musculoskeletal pain (Harding et al. 2005), individuals with RA in the current study highlighted the way in which foot pain forced them to accept the limitations placed upon them,

"I cannot walk. I am in constant pain" (subject 331).

"My feet problems are probably the most difficult to live with. Finding shoes which fit is an absolute nightmare. Vanity stops me wearing my "hospital" shoes. Every step I take feels like I'm walking on marbles" (subject 1182).

A minority of respondents (n=4) in the current study reported that they accommodated symptoms in their feet and difficulties these symptoms presented in a more positive light and were determined not to surrender to the pain. Comments characteristic of this small group included,

"I will not submit to this disease and carry on regardless" (subject 1124).

Most respondents in the current study, however, reported that the impact of pain in the feet on activities of daily living and social activities (for example, shopping, walking, meeting friends, participating in sports) were severely curtailed, both because of the duration of pain and the unpleasant nature of the pain experienced. Analysis of the qualitative comments suggested active participation in social events in particular was compromised because of foot pain and for some respondents this tended to lead to feelings of frustration, anger and despair;

"Arthritic feet make life very difficult. Walking is limited and painful and worst of all fashionable shoes are a no no" (subject 217).

"When my feet do feel bad I feel like a miserable old woman and the effect on my life is immense" (subject 71).

Little work appears to have been carried out identifying the effects that a symptom (for example, pain) located in a single anatomical location (the feet) has on the person as a whole. However, previous workers have reported that chronic pain sufferers often have negative thoughts related to pain and its impact (Eccleston 1997, Harding et al. 2005). Findings of the current study make an important additional contribution to the rather small literature base surrounding both the nature and extent of foot complaints seen in RA. Additionally these findings add to the work of Wickman and colleagues (2004) who also identified the profoundly negative impact of foot pathologies on the physical and psychosocial health of people with the disease. Further discussion of the impact of foot complaints in RA as a whole have on psychosocial issues such as social interaction can be found in section 9.10.

9.3.7 The assessment of foot pain in RA

The recording of pain was evidently an important part of practice for the podiatrists in the present study. Previous studies have demonstrated the recording of pain is also important to people with RA (Carr et al. 2003, Hewlett et al. 2005). In total, 87% of podiatrists reported assessing the severity of foot pain, with the majority (62%) electing to use a 10cm visual analogue scale (VAS) with which to record a numerical value. In previous work (Weir et al. 1998), a survey of 83 podiatrists revealed 53% did not formally assess pain, and that only one subject using a VAS scale. In rheumatology VAS scales have been associated with a number of well-known outcome measures, the Foot Function Index (Budiman-Mak et al. 1991) being the most widely referred to in the current study. The widespread use of visual analogue scales in other outcome measures may go some way to explaining why so many respondents were using this type of scale. The podiatrists surveyed also reported that people with RA were able to distinguish a variety of painful symptoms in their feet and used terms to describe their foot pain that do not appear to be commonly used in the literature in the context of foot pain. The nature of the language used by people with RA to describe their foot pain (for example, throbbing, shooting and stabbing pains), is thought to be key to understanding the quality and/or severity of the pain experienced (Melzack & Wall 1988). Whether the detailed nature of the descriptions people with RA used to explain their foot pain to podiatrists, for example; *“walking on marbles”* or *“grinding of bones in the feet”* were formally recorded in patient’s notes or simply memorised was not clear. Nor was it clear if, or how, this descriptive information was used to inform practice. The apparent reliance by clinicians (particularly podiatrists) on a numerical scale to assess the highly subjective element of pain might also suggest a reluctance to accept qualitative information, or alternatively difficulties in recording these types of data. What was not clear from the findings of the current study was how the rich qualitative descriptions podiatrists reported their patients provided that highlighted the emotional impact of foot complaints were recorded. For example, whether comments recalled by podiatrists from their patients such as *“I just want to cry”* and *“it’s like having red hot poker in your foot bones”* were translated into numerical scales or written into the patients’ notes. Equally, it is

possible this transformation of data is not undertaken by podiatrists, rather that people with RA are asked to complete a questionnaire-based outcome measure such as the Foot Function Index where the response format is in the form of a visual analogue scale. Therefore, people with RA may use different ways of translating their complex symptoms into a point on a numerical scale and this would be an area worthy of further exploration. This is particularly pertinent as some podiatrists in the current study questioned the validity of visual analogue type scales. They suggested that a VAS was not always a useful method of recording pain, which indicates that podiatrists may not be able to easily translate numerical scores for use in clinical practice, but are unsure of other methods that would enable them to use this information. Only 20% of podiatrists reported they elected for a written description to record pain intensity and/or severity (the remaining 5% did not specify the method of recording pain) even though some podiatrists indicated that they were able to clearly recall qualitative descriptions given by people with RA. The reporting of activity limitation as a result of foot pain to health professionals and the subsequent frustration this causes appears to be of greater importance to people with RA than simply outlining the *amount* of pain as a numerical score. This suggests alternative methods for recording the foot pain experience of those with RA would be welcomed by both people with the disease and clinicians – particularly podiatrists.

In the literature there appear to be three main categories of instrument used to assess pain in clinical practice. These methods are categorical scales (often incorporated into pain charts or diaries), visual analogue scales and self-administered questionnaires such as the McGill pain questionnaire (O'Hara 1996). The McGill pain questionnaire (MPQ – (Melzack 1975)) provides an insight into the qualities of the pain experience by ranking descriptors into four major groups (sensory, affective, evaluative and miscellaneous) as different kinds of pain are reportedly characterised by distinctive constellations of words (Melzack & Katz 1998). In the clinical setting, where time is often more limited, the short form McGill pain questionnaire (SF MPQ) developed by Melzack (1987), is often used (Melzack & Katz 1998). In table 9.2 the fifteen descriptors in the SF MPQ are compared with the descriptors podiatrists in the current study reported were used by people with RA to portray the pain they experienced in their feet.

Table 9.2 - Comparison of descriptors in the SF MPQ with patients' descriptions of foot pain

Categories from SF MPQ (Melzack 1987)		Adjectives recalled by podiatrists that people with RA use to describe foot pain	
Throbbing	Heavy	Throbbing	Grinding
Shooting	Tender	Shooting	Tingling
Stabbing	Splitting	Stabbing	Bursting
Sharp	Tiring-	Sharp	Swelling

Cramping	exhausting	Gnawing	
Gnawing	Sickening	Hot-burning	
Hot-burning	Fearful	Aching	
Aching	Cruel- punishing		

There is some similarity in that seven of the descriptors used in the SF MPQ match the adjectives recalled by podiatrists (these descriptors are in the left hand columns of table 9.2). This would seem to suggest the SF MPQ might possess the face and content validity needed to be used to assess foot pain in RA, however this would require further work to confirm. The SF MPQ does have advantages over some of the measures podiatrists currently report they use because it assesses both sensory qualities and the affective dimensions of pain (Dworkin et al. 2005).

The SF MPQ is, however, a generic instrument for assessing pain and it may be more appropriate to consider a more disease-specific tool. The Rheumatoid Arthritis Pain Scale (RAPS) was described by Anderson and colleagues (2001) and is designed to assess both the affective component of pain in RA and the cognitive processes associated with chronic pain experiences. While not specially validated for foot pain, items in the RAPS do bear considerable similarity to the descriptions people with RA used to report the experience of pain in their feet. Table 9.3 overleaf outlines the RAPS and highlights similarities between this instrument and the descriptions reported in the current study. Again, it is possible that there is adequate face and content validity for the RAPS or a modified version of this instrument to be used to assess foot pain in RA. It is not entirely surprising to find the RAPS also appears to have properties that could be used to assess pain in the feet in RA, as during the development of the scale, Anderson and colleagues used the gate control theory of pain as a theoretical framework. The gate control theory was first reported by Melzack and Wall (1965) and subsequently led to the development of the McGill pain questionnaire.

The use of tools such as the SF MPQ or the RAPS would appear to be appropriate in podiatric practice in order that the rich qualitative descriptions provided by people with RA, that are not currently captured with the use of visual analogue scales, can be utilised to identify the wider elements that constitute the subjective experience of pain in RA. This increased sensitivity in the measurement of foot pain could be used to monitor interventions more effectively. While the improved assessment of foot pain is clearly an opportunity to enhance practice, pain was not the only symptom of importance, as discussed in the next section.

Table 9.3 - Comparison of items in the RAPS with patients' descriptions of foot pain

Categories from RAPS (Anderson 2001)	Adjectives people with RA and recalled by
--------------------------------------	-------------------------------------------

NB Scored as 0-6 Likert type scale	podiatrists use to describe foot pain
I would describe my pain as gnawing	Gnawing
I would describe my pain as aching	Aching
I would describe my pain as exhausting	Not reported
I would describe my pain as annoying	Not reported
I am in constant pain	“My feet hurt constantly”
I would describe my pain as rhythmic	Not reported
I have swelling in at least 1 joint	[Swelling was common, but not explicitly linked to joints in the questionnaires]
I have morning stiffness for ≥ 1 hr	<u>Mean</u> duration morning stiffness ≤ 3 hrs
I have pain on motion in at least 1 joint	Increased foot pain on walking
I cannot perform everyday tasks because of pain	Did not form part of the current questionnaire
Pain interferes with my sleep	Did not form part of the questionnaire
I would describe my pain as burning	Hot-burning
I guard my joints to reduce pain	Not reported
I brace myself because of the pain	Not reported
My pain is throbbing in nature	Throbbing
I would describe my pain as sharp	Sharp
I would say my pain is severe	Mean VAS score for foot pain 4.9
I feel stiffness in my joints after rest	[Stiffness was common, but not explicitly linked to joints in the questionnaires]
My joints feel hot	Hot-burning
I feel anxious because of pain	Not reported
I would describe my pain as tingling	Tingling
I feel my pain is uncontrollable	Not reported
I feel helpless to control my pain	Not reported

9.4 The nature and extent of foot complaints part 2: stiffness, swelling, numbness and other self-reported symptoms in the feet

9.4.1 Stiffness, swelling and numbness in the feet

In addition to pain, respondents with RA also reported a number of other symptoms that affected their feet. The pilot studies undertaken for the current study, together with the work of previous authors (Speigal & Speigal 1982, Costa et al. 2004) indicated stiffness, swelling and numbness were the most common features in established RA. Table 6.8 (section 6.7) outlined how many people with RA reported experiencing the symptoms of stiffness, swelling and numbness. Of particular note is the consistency with which these symptoms (as different to pain) were experienced by respondents in the current study. Approximately one third (33.2%) of respondents

continually experience stiffness; nearly a quarter (24.6%) noted their feet were always swollen and 10% reported continually experiencing numbness and only 5.3% did not experience these symptoms. Much greater numbers of respondents with RA reported that these symptoms were „sometimes“ experienced in their feet, further emphasizing the unpredictable nature of foot complaints and highlighted that pain was not the only symptom.

Interpreting the meaning and implication of self-reported symptoms such as stiffness and numbness does give rise to some difficulties. For example, in appendix 1 the pathogenesis of RA is discussed and mechanisms for joint damage are outlined. These pathological mechanisms give rise to joint destruction and possibly limited ranges of motion. It is not clear, however, that the description of stiffness is the same as limited joint motion, which the majority of podiatrists included as part of their examination of foot joints. Yet attempting to mobilise joints, whether perceived to be „stiff“ or having an actual limited range of motion, could cause additional pain. Therefore rest may partially control these symptoms. While rest could reduce levels of foot pain, at the same time this limits opportunities to participate in family, social or occupational activities, thus causing people with RA to balance the competing demands of activity and disability.

Rest in itself may also give rise to other difficulties. As noted previously, swelling in the feet was reported to be relatively common. Again it is difficult to distinguish whether this swelling occurs as a result of systemic inflammation which is part of the disease process, or as a result of reduced venous return that may occur when resting to control pain and therefore not optimising the venous calf pump mechanism (Tortora & Grabowski 2003). The presence of oedema/swelling has a number of implications for the feet and lower limbs. In particular, cellular nutrition is adversely affected due to an oxygen deficit stimulating a localised inflammatory response and the release of hydrolase and protease enzymes that may damage the extra-cellular matrix contributing to tissue necrosis and ulceration (Shamley 2005). The prevalence of ulceration noted in the current study will be discussed later in this chapter. Mobility may also be further affected: one litre of fluid weighs one kilogram, and thus significant swelling requires greater effort and energy expenditure to maintain mobility (Matfin & Porth 2005). The greater energy required for gait due to oedema and joint stiffness is likely to have further detrimental effects on the gait cycle as discussed in section 3.5. In addition, difficulty with obtaining suitable footwear, both due to pain and swelling and/or foot deformity, was a widely reported theme by those with RA. It should be noted here that five people with RA specifically reported they had difficulties finding suitable footwear because of the swelling in their feet,

“...suffers terribly with swollen feet. Cannot get proper shoes to fit because of swelling” (subject 1062).

While issues associated with footwear are discussed later in this chapter, the combination of pain, stiffness swelling and footwear difficulties all contribute to reduced mobility.

The prevalence of motor/sensory neuropathy also appeared to be important both to people with the disease and to podiatrists, particularly as both parties need to be aware of the existence of neuropathic symptoms as part of the overall management of the rheumatoid foot. A higher than expected reporting of numbness in the feet was a finding of the data from those with RA. However, numbness was not a feature that was considered to be particularly prevalent by rheumatologists (as reported in section 7.4). Additionally, in the current study 10% of podiatrists (n=4) reported they never undertook a routine neurological assessment, 37.5% (n=15) and 52.5% (n=21) reporting that they sometimes or always undertook a neurological assessment respectively, a smaller proportion than would routinely carry out a vascular assessment. This variation in foot assessment between clinicians has also been reported by Thompson et al. (2004) who evaluated a group of podiatrists undertaking diabetic foot assessments, in which neurological assessment is a key component (Tyrrell 2005). Recent work by Wilson and Kirwin (2006) using a test re-test design utilising both 10g and 3g monofilaments found evidence of reduced sensation in 59% of a population of 51 people with RA with 3g monofilaments compared to 12.5% of controls. Semmes-Weinstein monofilaments consist of 20 different nylon monofilaments numbered from 1.65-6.65, each indicating the common logarithm of 10 times the monofilament buckling force in grams/milligrams. The 5.07 monofilament represents 10g and is the commonly accepted protective sensory threshold (Brike & Sims 1995), and inability to perceive this monofilament indicates peripheral neuropathy of a severity such that there is an increased risk of ulceration (Spadone 2003). Wilson and Kirwin (2006) found a 3g monofilament provided the best balance between sensitivity (58.8%) and specificity (87.5%) for distinguishing sensation and this work suggests the frequency of reduced sensation in the feet of people with RA is greater than previously reported.

The peripheral nervous system is commonly affected in rheumatic diseases (Leventhal & Fundlich 2000), but estimates for the prevalence of neuropathy vary. In one review, neurological involvement as a consequence of RA was reported in 42% of cases (O'Brian et al. 1997), whereas a study of 31 RA patients by Nakar and colleagues (2001) found evidence of peripheral neuropathy in 32.2%. Grabois and colleagues (1981) reported neuropathy in 15% (n=6) of 39 patients with RA using nerve conduction studies for tarsal tunnel syndrome although only 3 patients were symptomatic. In other chronic diseases where peripheral neuropathy is a common feature (such as diabetes), the epidemiology and natural history of neuropathy also remains poorly defined (Rathur & Boulton 2005). These authors cite a review by Walters and colleagues (1992) where the prevalence of distal sensory polyneuropathy in the diabetic foot varies between 14% and 63% depending on the definition used and the population studied.

Neurological complications in rheumatoid arthritis vary from acute (as in cervical cord compression due to cervical spine stenosis) to chronic weakness or sensory symptoms that may be misconstrued as a deterioration of the arthritis (Ferguson and Hollingworth 1998). As indicated in chapter two (section 2.6.7) and chapter three (section 3.5.2) extra-articular features, including peripheral neuropathy, may present in the feet (Harris 1993). According to Nadkar and colleagues (2001) and Leventhal and Fundlich (2000), peripheral neuropathy in RA may present in a variety of different forms:

- Distal symmetrical sensory or sensorimotor neuropathy.
- Mononeuritis multiplex.
- Entrapment neuropathies.

Peripheral neuropathy may be due to nerve entrapment, vasculitis of the vasa nervorum or related to drug therapy (Dudley-Hart et al. 1957, Ferguson & Slocumb 1961, Harris 1993, Ferguson and Hollingworth 1998). In terms of the prevalence of the differing types of peripheral neuropathy, in a study by Puechal and colleagues (1995) of 32 RA patients with necrotising vasculitis, 5 patients (14%) had mononeuritis, 18 (51%) had mononeuritis multiplex and 12 (32%) had distal symmetric sensory or sensorimotor neuropathy. By contrast Nadkar and colleagues (2001) in a sample of 31 RA patients found five cases of symmetrical peripheral neuropathy, four cases of mononeuritis multiplex and one case of entrapment neuropathy. Of those with neuropathy, 5 cases had overt neuropathy whereas 5 cases were sub-clinical, the neuropathy being detected by electrophysiological studies.

Peripheral neuropathy has a number of potential symptoms and patients with chronic diseases often report experiencing negative symptoms such as numbness in the feet (Rathur & Boulton 2005, Foster 2006). Given that a proportion of people in the current study with RA report symptoms associated with peripheral neuropathy and the literature indicates neuropathy is not an infrequent finding, there is a pressing need firstly for all RA patients to receive neurological assessment both at their first podiatry appointment and at subsequent reviews. Secondly, there is a need for further work to understand the incidence and natural history of distal symmetric sensory or sensorimotor neuropathy in RA.

9.4.2 Other self-reported pathologies in the feet

When invited to describe the type(s) of foot pathology they suffered, respondents indicated a range of conditions (section 6.7). Respondents were not provided with a pre-determined list as it was determined this approach might have limited the range of responses. The key finding is not the type of foot pathology respondents described, as these conditions have been widely reported in the literature previously (Vianio 1956, Jacobi et al. 1976, Videgal 1978, Kerry et al. 1994), but rather

the reported prevalence of these pathologies. When compared with the findings of previous studies (described in section 3.3), the frequency with which individual foot deformities (bunions, hammer toes and so on) were reported by those with RA in the current study was generally lower than that reported in studies based on the views of clinicians. For example, the most commonly reported foot condition in the current study was bunions (hallux valgus) with a prevalence of 29.92%, compared to a prevalence of 58% - 70% in reported studies that used a clinical examination and/or X-rays (Vianio 1956, Jacobi et al. 1976, Vidigal 1978, Kerry et al. 1994, Bal et al. 2005). Interestingly, Michelson and colleagues (1994) used both clinical examination and self-reporting by 99 people with RA; reporting a prevalence of hallux valgus of 33% in this sample. In terms of foot lesions such as hyperkeratosis, the self-reported prevalence of plantar callosities (27%, n=105) in the present study was lower than that reported in a recent study of foot problems by Williams and Bowden (2004) who reported symptomatic callus in 58% (n=81) of their sample of 139 consecutive patients attending a rheumatology out-patient clinic. While in some respects Williams and Bowden's finding of symptomatic callus in 58% of subjects was not unusual, as people attending a podiatry department would be expected to present with foot conditions such as hyperkeratotic lesions. Clinicians' opinions may also differ from those of their patients regarding what constitutes a lesion, because of differences in terminology or because people with RA may not be able to see sufficiently well to record lesions accurately. In contrast to the findings outlined in table 3.2, the extent of foot pain (and other symptoms such as stiffness) tended to be under-reported in previous studies utilising solely clinical examination and/or X-ray compared with the results from people with RA in the current study.

One surprising finding regarding self-reported foot complaints was the frequency with which foot ulceration was reported, with 5% of respondents indicating that they had experienced this. In the literature, foot ulceration is usually more commonly associated with diabetes where a prevalence of approximately 5% is reported (Balint et al. 2003, Foster 2006). The findings of the current study were consistent with the prevalence of foot ulceration in RA recently reported by Matricali and colleagues (2006) using questionnaire based assessment coupled with clinical examination of 285 people with RA. Unpublished work by Scanlon (2000) based upon health professional reporting found that 8% of those deemed to have RA had „rheumatoid ulcers“, although it was not entirely clear what was meant by this. Most recently Firth and colleagues (2008), reporting on a postal survey of 883 people with RA, found a validated point prevalence of foot ulceration of 3.39% and an overall prevalence of 9.73%, the latter being almost double the prevalence reported in the current study and that by Matricali and colleagues (2006), as well as almost twice that widely reported in diabetes. Acute foot pathologies such as ulceration do not appear to have been widely discussed in the rheumatology literature, largely due to the suggestion that the absence of complete sensory neuropathy in RA is rare and this tends to protect patients from the type of foot ulceration more commonly seen in diabetes (Saltzman & Vogelsany 1997). However, more recent

research has reported a higher prevalence of sensory neuropathy in people with rheumatoid arthritis (Wilson & Kirwin 2006, Rosenbaum et al. 2006), which may be one of the reasons for the higher than expected frequency of foot ulceration. Authors have suggested a number of other potential explanations that may be precursors to ulceration, including the inflammatory nature of RA and extra-articular complications such as anaemia and vasculitis, pathologies that may play a part in the reduced ability of soft tissues to withstand mechanical stress (Spiegel & Spiegel 1982, O'Brian et al. 1997, Sobel et al. 1998). The impact of peripheral vascular disease and/or vasculitis however, has yet to be fully determined (Crawly 1987), the lack of definitive epidemiological studies being a major limiting factor. Increased pressure on vulnerable areas of the foot, either due to foot deformity or the effect of footwear, has long been suspected to represent a further risk factor for ulceration (Tinley 1987, Dixon 1987, Shrader 1999). Iatrogenic factors such as the adverse effect of long-term corticosteroids and the reduced cell turnover associated with DMARD therapy further place the foot at risk of ulceration (Cracchiolo 1993, Williams & Bowden 2004), particularly when coupled with the difficulties associated with self care due to poor mobility or loss of dexterity due to hand deformities (Keenan et al. 2006, Helliwell et al. 2007, Firth et al. 2008). The comparatively high frequency of foot ulceration is of concern, particularly given the advent of newer biologic agents that are powerful inhibitors of the immune system, which might place patients at greater risk of infection of open wounds or ulceration.

The findings regarding the prevalence of self reported conditions indicate an important emergent theme about what is most important to people with RA in relation to how the disease affects their feet. People with RA appear to be more concerned about the symptoms they experience and the effect this has on their everyday lives in terms of mobility, loss of independence, inability to fully participate in valued life activities, uncertainty and anxiety rather than the presence of pathologies.

The issue of differences between the opinions of clinicians and those with RA underpins the very purpose of the current study. Measuring the prevalence of foot deformities in a population or the extent of a particular pathology in an individual, while of practical interest to the clinician (particularly if surgical intervention is being considered) may miss the issues that are of prime importance to the person with the disease. For example, the apparent failure to address patients' concerns with regard to foot assessment was commented on by some (n=15) respondents with RA for example,

"Apart from providing surgical shoes with insoles the feet seem to be disregarded when assessing RA. When I have the Infliximab infusion, the feet are disregarded when adding the scores. All other joints are scored regarding amount of pain. My feet are never free of pain" (subject 1159).

Failure to address these concerns adequately may have important consequences for the patient/practitioner relationship.

9.5 Onset of symptoms in the feet and repercussions for early diagnosis

In terms of how early the first symptoms of RA were noticed, about half of respondents (50.1%, n=293) reported that the earliest symptoms occurred in their hands/fingers. This finding was not unexpected because RA typically affects small peripheral joints. The hands are often affected both early and late in the course of the disease, often reflecting overall disease activity, with pain having a marked effect on function (Gordon & Hastings 2003). When invited to indicate when symptoms in the feet were first noticed in comparison to other parts of the body, 35.4% (n=207) of RA sufferers reported foot symptoms pre-dated the onset of joint symptoms elsewhere. As explained in section 6.6, the true estimate of in what proportion of patients foot involvement comes first probably lies between 20% and 64% when non-responders are included.

Previous workers have identified the foot as the initial site of symptoms in RA for between 13 and 32% of subjects (Vianio 1956, Flemming et al. 1976, Kerry et al. 1994), and the findings of the current study are in broad agreement with the upper end of these estimates. Direct comparisons with the literature are, however, difficult due to differences in the presentation of demographic data. For example, Kerry and colleagues (1995) reported the previous highest prevalence of 32% in a sample of 100 people with RA, nearly twice the prevalence in preceding reports. However, Kerry and colleagues' report provided virtually no demographic information, nor was the recruitment policy detailed, making it impossible to know how representative their sample was or to make meaningful comparisons with the findings of the present study. In the current study, it is also possible there was some difficulty with the recall associated with the onset of foot pain given that the mean duration of RA was 12 years. For example, respondents in the current study may have ignored important symptoms as being due to everyday aches and pains, and therefore under-reported the true extent of foot complaints in the early stages of RA. This possibility was explored by Locker (1983) who undertook a series of in-depth interviews with people with RA. Locker reported that symptoms often develop slowly or are intermittent in nature and therefore can be explained in the context of other preceding events, thus not leading to a decision to seek medical advice. Symptoms in general including those associated with the musculoskeletal system are relatively common and usually mild, often transient in nature (Petrie & Weinman 2003), and symptoms in the feet are no exception. For instance, most people will experience mild discomfort in the feet after prolonged weight-bearing activity such as a days' shopping, which does not always lead to the need to seek a medical consultation. Furthermore, subjects may not report troublesome foot pain if this is perceived to be a common complaint amongst peers (Kleinman et al. 1996). The current study did not seek to ascertain what factors were considered grounds for seeking medical advice for symptoms in the feet that may be subsequently diagnosed as RA,

particularly as the broad range of disease duration may give rise to issues of recall bias. If however, as the current study suggests, more people with RA reported foot pain as the earliest symptom than was previously thought to be the case, the pattern of these symptoms related to seeking medical advice would be worthy of further investigation, ideally in those recently diagnosed with RA. This is particularly important in the light of the work of Sutter and colleagues (2006) and Feldman and colleagues (2007) both of whom report low consultation and/or referral rates to rheumatologists for those thought to have new-onset RA. This suggests education of health professionals (such as General Practitioners) and the public might improve rates of recognition of early disease.

The difficulties encountered in diagnosing RA are further compounded because there is no single diagnostic test for RA as discussed in section 2.3. In the current study only a very small proportion of respondents (n=3) recalled that the early symptoms of RA in their feet were initially misdiagnosed as localised foot pathology, for example,

“Misdiagnosed as plantar fasciitis. Would like to see a foot surgeon as walking was one of my favourite hobbies – now sadly impossible for any great distance” (subject 212).

Reports of RA being misdiagnosed as localised foot pathologies are also relatively rare in the literature (Robinson et al. 2004), but there may be a need to undertake further epidemiological research in this area given the relative frequency of foot pain in the general population as described previously. The findings of the current study lend weight to the suggestion that examination of the feet could be important in aiding diagnostic sensitivity for RA in a least one third of patients. This is an important area for future research because the recognition of RA as early as possible is considered essential as a significant proportion of patients develop severe disability early in the course of the disease (Bukhari et al. 2001). Early diagnosis is essential to improve longer-term prognosis and prevent severe disability as identified by a number of authors (Emery & Salmon 1995, van der Horst-Bruinsma et al. 1998, Albers et al. 2001, March & Lapsley 2001, Emery et al. 2002). It is therefore, important to take advantage of any early „therapeutic window“ to tailor specific treatments for patients with this potentially debilitating disease. In 1988 The American College of Rheumatology (ARA) developed classification criteria for RA (Arnett et al. 1988 (outlined in section 2.3)). Developed in a population of people with established RA the ARA criteria are intended to separate subjects with established RA from those with other musculoskeletal complaints (Dixon & Symmons 2005, Smolen et al. 2005, Suresh & Lambert 2005) and as such these criteria are used primarily for research purposes to define populations. However, the ARA criteria are reported to perform badly in terms of their diagnostic sensitivity in the early months of inflammatory arthritis (Harrison et al. 1998, Huizinga et al. 2002, Symmons et al. 2003). It can be seen that the ARA criteria have an emphasis on symptoms in the upper limbs

and hands, and this may lead to key symptoms in the feet and lower limbs being over-looked and important features leading to early diagnosis being missed. The opinions and perspectives of people with RA regarding the nature of early symptoms in their feet require greater exploration, as do the approaches taken by clinicians to elicit this information and to incorporate it into their clinical reasoning processes.

9.6 Anatomical location of foot complaints in RA

When invited to identify where in the feet pain occurred, people with RA in the current study were clearly able to localise their pain by using validated mannequins (section 6.8). Pain was clearly widespread throughout the foot and ankle, but the metatarsophalangeal joints and ankles were consistently the most commonly affected areas. This is of particular interest, as anatomically these joints have predominance for sagittal plane motion and thus are vital for normal propulsive gait. Whittle (1991) explains that the foot/ankle contributes to the smooth progression of the gait cycle by way of three rockers. At heel strike the first rocker consists of the rounded posterior tubercle of the calcaneum which allows transition from heel strike to foot flat. Secondly, dorsiflexion of the ankle enables the body to pass over the stationary foot. Finally, the third rocker occurs at the metatarsophalangeal joints during heel lift/propulsion. Both those with RA and rheumatologists responding to this study consistently identified the ankle and metatarsophalangeal joints as being more severely affected than other joints in the feet. Pain, stiffness and deformity in the ankle and metatarsophalangeal joints could be closely associated with reduced mobility as the smooth forward progression needed for efficient locomotion is lost. A small study by Laroche and colleagues (2006) reported that decreased motion in the metatarsophalangeal joints is related to decreases in walking velocity and stride length. As reported in previous studies (Weiner 1971, Stenstrom et al. 1993, Ailinger & Schweitzer 1993, Young et al. 2002), the lack of mobility caused by the severity of foot pain (and consequent loss of independence) also has a profound negative impact on activity levels, leading to feelings of frustration and annoyance as typified by one respondent,

"I have found the problems with my feet very frustrating. I'm unable to walk any distance and I have to resort to a wheelchair which I hate" (subject 172).

9.7 The impact of foot complaints on quality of life

A number of authors have previously demonstrated that RA has a negative impact on quality of life (Whalley et al. 1997, Bartlett et al. 2003, Russack et al. 2003, Lillegraven & Kvein 2007), although this body of work rarely specifically includes foot complaints. Katsambas and colleagues (2005) reported foot complaints impaired a variety of activities associated with quality of life, but this work did not specifically extend to those with RA. This gap in the literature, together with the increasing demand to supplement traditional outcome measures with information focussing on the patients"

concerns (Fitzpatrick et al. 1998), suggested quality of life was an area worthy of further study. Additionally, the potential for foot complaints to adversely affect quality of life was initially indicated during the pilot study phase of this research.

To explore the potential relationship between foot complaints and quality of life further as part of an *a priori* sub group analysis. Participants from the BSUH cohort were invited to indicate if and how foot complaints impacted on quality of life. Quality of Life (QoL) is a multi-dimensional, somewhat abstract topic, which defies simple definition (Bowling 1995, Dijkers 1999). A range of definitions for quality of life have previously reviewed by Farquhar (1995) and contributions to the field are reportedly available in a range of specialist literatures, which include sociology, psychology and medicine (Bowling 2005). Referring to Schipper and colleagues (1996), Fitzpatrick and colleagues (1998) highlight the various viewpoints that underpin the differing definitions of QoL illustrated in table 9.4. Not surprisingly, given the range of domains highlighted in table 9.4, Kaplan (1994) - cited by Ditto and colleagues (1996) suggested that for QoL to be measured, an understanding of the effects of a disease on an individual's ability to function across a range of domains is required. Léplege and Hunt (1997) have expressed concern that some questionnaires used to assess QoL force patients to address issues of importance to physicians or other professionals to fit particular theories. Because of these difficulties, respondents in the current study were not provided with a predetermined definition of what constitutes QoL. Rather, respondents were allowed to interpret quality of life as they wished, based on the assumption that various aspects of function are not equally important to all (Rapkin et al. 1994 – cited by Ditto et al. 1996). This approach was felt to be in-keeping with the World Health Organisation definition of Quality of Life (Kuyken 1995).

Table 9.4 - Various viewpoints that underpin the differing definitions of quality of life
(Fitzpatrick et al. 1998)

Viewpoint	Example
Psychology	Patients' perception of the illness and its impact
Utility	Values attached to health status
Community centred	Extent to which illness affects an individual's ability to integrate into a given community, whether work or home
Reintegration	The extent to which normal life can be resumed
Expectations vs. Achievements	The gap between an individual's expectations and how well these are realised is associated with quality of life

Respondents with RA described how social and leisure activities were severely limited because of foot complaints (section 6.9). When invited to outline to what extent foot complaints affected quality of life, the findings from those with RA were surprising; over half of respondents indicated that their foot complaints affected their quality of life either badly or very badly. In particular,

walking and being unable to wear different shoes were reported as particularly problematic (sections 6.13, 7.4 and 8.5). A simple visual analogue scale [an approach widely used in QoL measurement (Dijkers 1999)] suggested quality of life was moderately to severely affected by foot complaints for respondents in the current study. For respondents with RA, foot complaints were sometimes reported to permeate every aspect of normal life. Qualitative comments from respondents in the current study included,

“I had severe problems with my feet ...causing bad posture, pain and unable to walk any distance. This all impacted on my way of life, work and sleep” (subject 275).

“The problems with my feet have affected my life more than any other problems I have, and it was a long time until it was found that it was the Rheumatoid that was causing it” (subject 1109).

The results from the BSUH respondents were congruent with podiatrists’ descriptions of how foot complaints in RA impacted on QoL, based on their recall of consultations with their patients. Podiatrists recalled how their patients described the impact of foot complaints on their quality of life. For example, one podiatrist recalled a patient saying, *“my feet make me a prisoner”*. The effect of foot complaints on specific activities was also reported by some podiatrists; for example preventing sufferers from undertaking activities of daily living or participating in activities in which prolonged standing or walking were required. For other podiatrists the personal significance of the activity forced their patients to tolerate considerable discomfort. One notable example was, *“it was murder to walk my daughter down the aisle”*.

In spite of the apparent importance of quality of life to people with RA, none of the podiatrists or rheumatologists questioned in this study indicated they used a specific outcome measure to assess quality of life, even though rheumatology as a speciality is reported to have more QoL measures than other branches of medicine (Garrett et al. 2002). The finding that clinicians do not appear to specifically assess QoL was not entirely surprising, as previous studies have reported limited utilisation of QoL questionnaires by rheumatologists (Bellamy et al. 1999, Russak et al. 2003). Many rheumatologists indicated that such instruments were difficult to administer, took up too much staff time and were difficult to score and/or interpret. Skevington and colleagues (2005) reported similar results regarding the use of QoL measures by General Practitioners in the Primary Care setting. Moreover, in a recent review, Haywood (2006) reported that there is little empirical evidence to suggest patient-reported outcome measures (which would include QoL (Bowling 2005)) are utilised or widely understood by Nurses or Allied Health Professionals. Widening the range of clinicians who may benefit from measuring QoL is thought to be a valuable strategy (Greenhalgh et al. 2005). Measuring QoL is thought to be a useful strategy for improving communication because this identifies issues of importance to the patient (Guillemin 2000, Carr &

Higginson 2001, Pollard et al. 2005, Rupp et al. 2006). This could potentially reduce the occurrence of differences of opinion between patients and clinicians referred to in section 3.6. Greenhalgh and colleagues (2005) go on to highlight that recent Government policy attributes increasing importance to communication between patients and clinicians, because of positive findings that using QoL measures can increase discussion during consultations.

It is acknowledged that the lack of a single accepted definition of QoL (Dijkers 1999, Carr & Higginson 2001), together with the diversity of constructs that make up QoL have led to considerable growth in the development of scales for its measurement, these include generic and disease or dimension specific instruments (Garrett et al. 2005). The diversity of measures available and the complexity of analyses possible make it difficult for clinicians to select a single, suitable measure with which to assess the effects of interventions on QoL. The Health Assessment Questionnaire (HAQ) will be considered in more detail later in this chapter, but to illustrate the point in the current context the HAQ contains items related to QoL and is probably the most widely used measure of functional disability in RA (Whalley et al. 1997). However, it was not clear from the data in the current study whether rheumatologists were using the full or shortened versions of the HAQ (the short version being primarily focussed on disability related to activities of daily living); although Cheah and colleagues (1996) are of the opinion that the shortened version is most commonly used in clinical practice. The role of the HAQ in this context is important because a number of authors have used versions of the HAQ as an instrument for assessing QoL (Cheah et al. 1996, Tuttleman et al 1997, Kosinski et al. 2000, Bruce & Fries 2003a). Greenhalgh and colleagues (2005) express concern that standardised instruments where the patient has no input to the item content are better described as measuring patients views of their health status rather than their QoL. Others have suggested the concept of QoL goes beyond the measurement of physical impairment and disability undertaken by the HAQ (Testa & Simonson 1996, Tenant 1995). Indeed, Allege and Hunt (1997) argue that QoL consists not just of separate components brought together, but rather an integration of various components of physical, emotional and social functioning, which have relative objectivity depending on the perspective taken. They further state that to assume physical function is the most important only serves to highlight the misplaced dominance of the medical model. Other authors have highlighted the importance of including emotional and social aspects of a condition as part of QoL (Whalley et al. 1997). Fitzpatrick (1993) and more recently Soon and Chen (2004) suggest QoL can be conceptualised as a construct consisting of four domains:

- Physical function (i.e. ability to carry out activities of daily living).
- Psychological well-being (psychological response to health including depression and anxiety).
- Social function (i.e. ability to engage in meaningful inter-personal relationships).
- Somatic sensation (i.e. disease related symptoms).

In addition to asking people with RA how foot complaints affected their quality of life, podiatrists were also invited to recall the ways in which their patients had reported that foot complaints affected their quality of life (section 8.5). All domains identified by Soon and Chen (2004) were reported by either people with RA or by podiatrists recalling what patients had told them in the course of consultations. Although Soon and Chen's work was originally applied to wound care, the prevalence of foot ulceration in RA described by the current study and that of others (Matricali et al. 2006, Frith et al. 2008), suggests these categories have appropriate face validity.

Walking difficulties and being unable to use a variety of footwear were commonly mentioned as some of the most problematic issues faced by people with RA (sections 6.13, 7.4 and 8.5). Currently, one of the disease specific QoL instruments for RA – the Rheumatoid arthritis specific quality of life instrument (RA QoL; a 30-item self-administered questionnaire that is scored on a yes/no basis) developed by Whalley and colleagues (1997) and extensively validated (De Jong et al. 1997, Tjihuis et al. 2001) includes these two items. The RA QoL also includes a further six items that people with RA identified as being adversely affected by their foot complaints. These are highlighted in table 9.5 overleaf. The outcome measures most widely used by rheumatologists (the DAS 28 and HAQ) tend to focus on function and disease activity and outcome measures most commonly used by podiatrists (such as the Foot Function Index) focus largely on pain and disability. Using the RAQoL could be a useful method of assessing QoL by rheumatologists but could also provide podiatrists with an insight into the degree to which foot complaints are impacting on QoL providing opportunities to more effectively target therapeutic interventions.

Table 9.5 - The RA QoL highlighting items that match findings in the current study

<p>I have to go to bed earlier than I would like to</p> <p>I'm afraid of people touching me</p> <p>It's difficult to find comfortable shoes I like</p> <p>I avoid crowds because of my condition</p> <p>I have difficulty dressing</p> <p>I find it difficult to walk to the shops</p> <p>Jobs about the house take a long time</p> <p>I sometimes have problems using the toilet</p> <p>I often get frustrated</p> <p>I have difficulty using a knife and fork</p> <p>I find it hard to concentrate</p> <p>I have to keep stopping what I am doing to rest</p> <p>Sometimes I just want to be left alone</p> <p>I find it difficult to walk very far</p> <p>I try to avoid shaking hands with people</p> <p>I often get depressed</p> <p>I'm unable to join in activities with friends/family</p> <p>I have problems taking a bath/shower</p> <p>I sometimes have a good cry because of my condition</p> <p>My condition limits the places I can go</p> <p>I feel tired whatever I do</p> <p>My condition is always on my mind</p> <p>I often get angry with myself</p> <p>It's too much effort to go out and see people</p> <p>I sleep badly at night</p> <p>I find it difficult to take care of the people I am close to</p> <p>I feel that I'm unable to control my condition</p> <p>I avoid physical contact</p> <p>I'm limited in the clothes I can wear</p> <p>■ Items specifically affected by foot complaints</p> <p>■ Items people with RA identified were affected by their foot complaints</p>	<p>limited</p> <p>concept</p> <p>authors</p>
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have also suggested that extending the RA QoL to explore individual patient's concerns has the potential to provide more valid and sensitive scores for use in clinical practice. Accepting that quality of life is a dynamic construct, which is altered by one's experience of chronic illness (Allinson et al. 1997, Carr & Higginson 2001), it may be appropriate to use individualised measures of assessing QoL – such as the Schedule for the Evaluation of Individualised Quality of Life (O'Boyle et al. 1992) or the Patient Generated Index (Ruta & Garatt 1994) to explore the construct of quality of life in the context of foot complaints. These measures, according to Higginson and Carr (2003), are designed to detect an individual's problems in clinically meaningful ways. Given the paucity of quality of life data with respect to foot complaints in RA, such instruments may

provide opportunities to identify new treatments, thus enhancing the patient-centeredness of such an approach.

9.8 The impact of foot complaints on valued life activities for people with RA

To gain further insight into the burden of foot complaints in RA and to create a more complete picture of how life is affected, Katz and colleagues (2004) and Katz and Morris (2007) suggest that the assessment of “valued life activities” is worthy of greater attention. Valued life activities (VLAs) include a broad range of activities that individuals find meaningful or pleasurable, as opposed to those that are simply necessary for self-sufficiency (Katz et al. 2004). VLAs may include “any activity an individual finds pleasurable or meaningful, ranging from simple day-to-day tasks such as reading or listening to music... interacting with family and friends or caring for oneself” (Ditto et al. 1996). The loss of valued life activities has been linked to a reduction in psychological well-being in previous studies associated with RA (Katz & Yelin 1994, 2001, Neugebauer et al. 2003). The types of complex life activities encompassed by VLAs are not typically covered by the outcome measures most widely used by clinicians in the current study such as the HAQ, these measures being predominantly concerned with general function or disability associated with day-to-day living in relation to depression, as opposed to more complex or discretionary activities that those with RA are more likely to discontinue in the light of persistent symptoms associated with the disease (Katz et al. 2004, Neugebauer & Katz 2004, Wolfe 2000). Furthermore, measures such as the HAQ do not specify whether the use of specific adaptations or assistance should be taken into account when scoring responses (Katz & Morris 2007).

Analysis of the qualitative data from those with RA revealed the loss of activities that would constitute VLAs was a repeated theme. Some respondents reported that their foot complaints were their greatest problem, impacting on all other aspects of their lives. Typical examples of the comments from people with RA included,

“I used to be a long distance runner thirteen years ago. I also loved long walks across hills and dales, mountain climbing, dancing, all finished now” (subject 1085).

“Pain in my feet/ankles and other joints caused me to give up my career in nursing and take a more sedentary job working for a bank. It has impacted greatly on my life” (subject 306).

On a more positive note, however, a minority of respondents did report that they had learned coping strategies,

“I have to be more selective in my social activities. RA is always at the back of your mind, if you overdo it, you have to rest up the next day. It’s a balancing act” (subject 1143).

Podiatrists also recalled how their patients had reported being unable to undertake all their previous activities. Podiatrists identified household chores such as shopping as no longer possible for their patients and recalled comments from patients such as *“my husband has to do most of these chores now”*. Other responsibilities were also identified as being adversely affected, with social activities being curtailed and family commitments being unfulfilled. One podiatrist recalled a patient saying, *“I have to think about where family and friends are going before I say „yes“ – sometimes I go somewhere and I can’t get back”*.

The types of activities mentioned by both people with RA and podiatrists varied considerably, reflecting the wide range inherent in VLAs, but notably included those activities that involved social interaction, for example, trips out with family or friends and leisure activities such as dancing or sporting pastimes. Table 9.6 outlines the activities included in the VLA disability scale (Katz et al. 2005), and highlights those areas identified by respondents in the current study.

Table 9.6 - Activities included in the VLA disability scale affected by foot complaints reported by people with RA in the current study

Items comprising the VLA disability scale (Katz et al. 2005)	
<p>■ Highlights the activities identified as being adversely affected by foot complaints in the current study</p>	
<p><u>Obligatory activities</u></p> <p>Basic needs (personal hygiene)</p> <p>Walking inside</p> <p>Walking outside</p> <p>Using car/transit to get around</p>	<p><u>Discretionary activities</u></p> <p>Leisure activities inside (for example, watching TV)</p> <p>Religious/spiritual activities</p> <p>Having others visit you in <u>your</u> home</p> <p>Visiting others in <u>their</u> home</p> <p>Leisure activities outside</p> <p>Going to parties</p> <p>Travel out of town</p> <p>Activities with children</p> <p>Volunteer work</p> <p>Hobbies</p> <p>Gardening</p> <p>Moderate physical activity (for example golf)</p> <p>Vigorous physical activity (for example, walking)</p> <p>Social communications (for example, letter writing)</p> <p>Educational activities</p>
<p><u>Committed activities</u></p> <p>Going to appointments</p> <p>Preparing meals</p> <p>Light housework</p> <p>Heavy housework</p> <p>Shopping</p> <p>Child Care</p> <p>Other family care</p> <p>Paid employment</p> <p>Minor household repairs</p>	

The impact of the loss of VLAs due to foot health impairment should not be underestimated. Some recreational activities allow opportunities for socialisation, and this in turn permits opportunities for the emotional benefits of socially acceptable touch, which importantly in this context, are divorced from dependency on others for personal care needs (Young & Dinan 2005). The ability to participate in low-impact aerobic exercise has been shown to have beneficial effects on more traditional outcomes such as walking time and grip strength (Neuberger et al. 2007). Furthermore Katz and Yelin (1995) estimated that a 10% or more loss in VLAs make individuals five times more likely to develop depressive symptoms when compared with those who did not lose such activities. Among people with RA, those who reported three or more VLAs to be affected in one year were significantly more likely to develop depression compared with those who reported less than three activities affected (Katz & Yelin 2001). The prevention and management of mental health complaints (including depression) represents a major target in the UK with the publication of the National Service Framework for Mental Health setting out an agenda for improving mental health

services for adults (Dept of Health 1999). Yet some of the most commonly used outcome measures used in RA such as the HAQ are based on activities of daily living (bathing, dressing and so on). It is possible, therefore, these instruments may underestimate those aspects of disability that are of most importance to people with RA. Katz and Neugebauer (2001) also point out it is not just the ability to perform VLAs that is important to those with chronic disease: the satisfaction with one's ability to perform a particular activity is also important. For example, the need to use assistive devices or the increased time taken to perform a particular activity may decrease an individual's satisfaction to the point where they are forced to relinquish that activity.

A further consideration is the recognition that some work roles require high levels of foot function, for example commuting by public transport, which may not be possible for those with considerable foot pain and may lead to early unemployment. Equally the loss of work roles that signify independence and the positive attributes of achievement can have a profoundly negative impact on self esteem (Abraído-Lanza & Revenson 2006). In such situations maintaining normal activities has to become a conscious effort that can be tiring and/or frustrating, and the effort may not seem worthwhile. This intrusion into everyday life consequently adversely affects psychological well-being (Bury 1982, Locker 1983, Ahlmén et al. 2005, Abraído-Lanza & Revenson 2006). In the current study, foot complaints prevented individuals with RA from holding positions (either social or occupational) that they perceived to be important. It is possible, but beyond the remit of this work, that this may cause more psychological distress than was previously realised, and this underscores the need for further work to determine the wider impact of foot complaints for those with RA.

9.9 Clinicians' assessments of foot complaints in RA: a perspective on current practice

The current study explored the perceptions of foot complaints from the perspective of those with RA, whereas most of the pre-existing studies have assessed the extent of foot involvement in RA by clinical examination or radiology. The findings of the current study agree with the work of Aletaha and colleagues (2006) who have found evidence that clinicians may under-estimate the extent of symptoms in people with RA. This possibility is supported by data from rheumatologists (section 7.4), 86% of who reported that people with RA would report a foot complaint to their rheumatologist at some point during the course of the disease. This latter figure aligns with data from people with RA, 82% of whom reported that they discussed their foot complaint(s) with their rheumatologist (section 6.12). Yet when invited to estimate the proportion of patients with RA that had foot problems but did not report them, up to 38.6% of rheumatologists indicated they thought their patients did not report problems with their feet. There would therefore appear to be a discrepancy between the true extent of foot complaints and the frequency with which they are reported. This is important as the clinical epidemiology of a condition is based upon the observed signs and symptoms (Beaglehole et al. 1993). If the signs and/or symptoms of foot involvement are not being reported to clinicians by patients, then this may help explain the higher frequency of

foot complaints in the current study compared with previous work. However, the situation may also be obscured by other factors. One emergent theme from the qualitative data from those with RA was a perception that foot complaints in RA are not always fully assessed by clinicians. This perception appeared to be partly predicated on the frequency with which their feet were examined in comparison with the hands. While the majority of participants reported discussing their foot symptoms with their rheumatologist, the findings reported in section 6.12 suggest that, on average, foot examination was not performed for more than 12 months. This compared with hand examination, which had on average, been performed within the past 5-6 months.

RA is both a local and generalised disease, so even when the general clinical parameters demonstrate improvement the patient can be troubled by painful foot joints (Balient et al. 2003). There is also some evidence to suggest that early forefoot involvement is indicative of more aggressive disease with a poorer prognosis (Fleming et al. 1976, Priolo et al. 1997), therefore there is a need for increased vigilance with regard to early symptoms in the feet as early intervention can moderate disease severity. Additionally, early foot involvement in RA also suggested a trend for less favourable scores in the arm and hand function domain of the short musculoskeletal function assessment tool (Wickman et al. 2004), suggesting that foot complaints may have considerable impact on the patient as a whole.

The reasons for the paucity of foot examination by rheumatologists are complex. Some authors have suggested that some rheumatologists may be ill-equipped to examine the feet (Helliwell 2003), or may find foot assessment awkward or unpleasant to carry out (Korda & Balient 2004). The inaccessibility of the feet compared to other parts of the body makes foot assessment less straightforward. This may reflect time constraints in out-patient clinics, where removing shoes/socks may take a great deal longer than assessment of hand joint synovitis. While most rheumatologists appear to agree that foot assessment is an important part of clinical practice (Smolen et al. 1995, Hulsmans et al. 2000, Kapral et al. 2007), the importance of assessing foot joints as part of validated outcome measures remains debatable. For example, Cabral et al. (2005) reported that the importance of foot involvement in RA in terms of assessing its severity did not reach agreement in a Delphi panel exercise. This is in contrast to other inflammatory arthropathies (for example, psoriatic arthritis), where including the foot joints in assessment increases the sensitivity of outcome measures, particularly in milder forms of the disease (Mease et al. 2005). The data from the present study clearly indicates this is a debate that needs re-visiting, particularly in the light of Landéwe and colleagues (2007) who reported that the cut-off point for remission as assessed by the DAS 28 has insufficient construct validity. These authors concluded this was mainly due to the fact that the feet/ankles are omitted from the assessment. However, Kapral and colleagues" (2007) suggest reduced joint counts (not involving the feet and ankles) are appropriate and valid tools for assessing disease activity. It should be noted, however, that Kapral and

colleagues" study (2007) combined the metatarsophalangeal joints as a block on each side, which gives rise to questions about the validity of such an approach as the metacarpophalangeal joints of the hands are scored individually and thus contribute a greater proportion of the overall score.

A considerable proportion of rheumatologists (58%) who participated in the current study were using the DAS 28 as a measure of disease activity. In the algorithm for the DAS 28 (table 2.6), items such as tender joint counts are weighted differently from swollen joint counts. Bukhari (2007) points out that symptoms such as joint tenderness may be mitigated by important psychosocial factors such as anxiety or depression, more so than clinical signs such as swelling. The DAS 28 is currently widely used as a measure of current disease activity (van Riel et al. 2003, Moots & Jones 2004). It has the advantage of minimising the number of items that are required to be measured as well as being more sensitive to change because the constituent items have a smaller standard deviation than each of their component parts (Symmons 1996). However, in section 3.6 the work of a number of authors (Carr et al. 2003, Ahlmen et al. 2005, Hewlett et al. 2005) indicated that the most important themes for those with RA were:

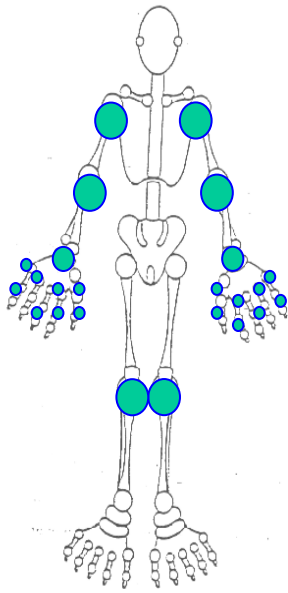
Independence	Pain	Mobility
Well-being	Emotional Impact	Fear of the future
Return to normality		

While it could be argued the DAS 28 does include pain, other domains listed above that have been suggested to be important to people with RA are not covered by this measure. Measures of quality of life and valued life activities however, discussed in sections 9.7 and 9.8 do cover some of the issues listed above. Scott and colleagues (2003) argued for the universal adoption of joint counts as part of routine practice, particularly given the costs associated with biologic agents increasingly being used in rheumatology. Now measures such as the DAS 28 have been almost universally accepted as tools for disease activity assessment and are seen as best practice in clinical trials (Leeb et al. 2005). Although measures of disease activity are clearly important, a critical perspective is required. As reported in section 2.7, examination of foot and ankle joints currently does not form part of the DAS 28, as illustrated in figure 9.1 overleaf. Omitting the feet when assessing disease activity may reduce opportunities for identifying issues of importance to those with the disease as highlighted by comments from some respondents with RA, two of which were,

"I cannot understand why feet and toes are not part of the assessment for Embrel. Hands and feet are routinely x-rayed for "progress" of disease and feet are so important for posture and walking," (subject 90).

"It seems stupid that feet are not included in the DAS score used in assessing anti-TNF□ treatment. The effect of RA on my feet makes it difficult to walk on uneven ground and seems to affect my balance" (subject 116).

Figure 9.1 - Joints assessed for tenderness and swelling as part of the DAS 28



The Health Assessment Questionnaire (HAQ) is a measure used by rheumatologists in the current study (either on its own or in conjunction with a DAS 28) was the Health Assessment Questionnaire (HAQ), the domains of which are outlined in table 9.7 overleaf. This finding is in accordance with Scott and colleagues (2003) who reported that it is important to supplement measures of disease activity (such as the DAS 28) with measures of disability and they suggest the HAQ.

The HAQ is defined as a self-administered, questionnaire-based index of disability (Moots & Jones 2004). The full version of the HAQ covers five dimensions: disability, economic consequences, pain/discomfort, adverse effects of medication and death (Bruce & Fries 2003). These domains represent the original five Ds of patient outcomes – disability, dollars, discomfort, doctor (iatrogenic) and death (Lillegraven & Kvien 2007). Additionally, Bruce and Fries (2005) highlight the HAQ was one of the first patient-centred instruments, and as such played an important role in the shift away from the reliance on biochemical and physical measurement described in section 2.7.

Table 9.7 - Structural dimensions of the 2-page or Short HAQ (Items 1 and 2) and the Full HAQ (Items 1–5) (Bruce & Fries 2003)

<u>1. Disability</u> Dressing Walking Arising	Reach Eating Outside activities	Hygiene Grip
--------------------------------------------------------	---------------------------------------	-----------------

<u>2. Discomfort</u> HAQ VAS pain scale and Patient Global VAS Supplemental dimensions also included in the Full HAQ
<u>3. Drug side effects</u> Medical Toxicity Index
<u>4. Dollar costs</u> Direct costs (medical/surgical costs, for example, medication) Indirect costs (loss of productivity)
<u>5. Death</u> Time to death and cause of death

Disability is an important outcome of RA as discussed in chapter two. Wolfe (2000) suggests that the functional impairment as seen over the long-term is an important outcome associated with RA. In contrast to disease activity, rheumatologists tend to over-estimate disability (Carter et al. 2007), therefore formal outcome measures may provide a more accurate representation of disability. The HAQ was designed to capture the long-term influence of RA and the reliability, sensitivity and validity of the HAQ have been well established (Ramey et al. 1992, Bruce & Fries 2003, 2003a). Despite the clear advantages provided by the HAQ, much of the variability in HAQ scores is reportedly explained by factors such as pain, depression, disease duration and disease activity (Wolfe 2000). Additionally, the HAQ does not capture some domains of importance in RA such as psychological ill-health, social networking or emotional impact (Talamo et al. 1997). These areas were noted to be important to those with the disease in the current study (section 6.8 and 6.9). In spite of some of these limitations associated with patient-reported disability, the HAQ remains one of the most widely used methods of assessing outcome in RA (Fitzpatrick 1996, Wolfe 2000).

More recently however, the HAQ has come under further scrutiny. While the HAQ as a measure of disability does measure pain and function and implies assessment of factors such as independence and return to normality, the latter two are not formally measured (Bukhari 2007). This is important as Häkkinen and colleagues (2005) have shown pain and range of joint motion have the greatest effect on sub-dimensions of the HAQ score. Additionally, like the DAS 28, the HAQ has been reported to place more emphasis on physical activities of daily living involving the upper limbs with fewer questions relating to lower limb function (Talamo et al. 1997, Bal et al. 2005). Although this perspective has been challenged by Walker and colleagues (2001) who suggest walking, rising and outdoor activities have obvious face validity for lower limb function, but hygiene and dressing are also important, as good lower limb function is required to bathe and

dress oneself. Therefore of the eight subscales contained in the HAQ, at least five are pertinent to the lower limb. It is possible therefore, that clinicians who use the HAQ perceive it to measure lower limb function. Most recently though, Katz and Morris (2007) reported that in a sample of 467 people with RA, while some can use assistive devices and personal assistance to help with activities, these accommodations are not clearly accounted for in the HAQ. Additionally, the limitations placed on valued life activities were the most frequently cited difficulties in their sample, again an area not encompassed by the HAQ. Wolfe (2000) suggests the biopsychosocial approach of incorporating a range of factors that importantly include patient individuality and appraisal may be a better model. This debate has led some to suggest that rather than the condition specific instruments such as the HAQ it may be more valuable to consider function specific tools (Stucki 2003). This debate has led one of the original developers of the HAQ to suggest that four sub-domains (mobility, dexterity, axial and compound) may provide greater sensitivity and specificity (Fries et al. 2006).

More importantly however, importantly neither the DAS 28 nor the HAQ requires visual assessment or examination of the feet/ankles – a factor attested to by some comments from those with RA,

“Rheumatologist dismisses foot pain/swelling as „part of the illness – nothing we can do“ – NEVER examines feet” (subject 129).

“Even after each visit to him he [the rheumatologist] only ever looks at my hands then moves my elbows and I keep saying my feet cause me more problems than my hands. He got quite a shock when he saw them [the patient’s feet] and sent me straight to x-ray” (subject 347).

Moreover, while 97% (\pm SD 10.8) of rheumatologists in the current study reported they would assess the feet in people newly diagnosed with RA, only 34% (\pm SD 35.6) would undertake a foot assessment in a patient with long-standing, stable RA (in this context the questionnaire used stated there were no reported foot problems). The majority of rheumatologists (87%) in the present study examined patients’ hands at every consultation, but only 7% of rheumatologists examine patients’ feet at every consultation, with more rheumatologists (19%) opting to examine patients’ feet every other consultation. Yet, the visual assessment and examination of the feet may be particularly important as patients’ appraisals of changes in the shape or appearance of their feet have been shown to be significantly better predictors of loss of valued life activities than self-reported changes in the shape or appearance of the hands (Katz et al. 2006). Woodburn and Helliwell (1995), and more recently Korda and Balient (2004), reported that foot problems in rheumatology are often neglected. This appears to be in spite of the high prevalence of foot complaints reported in the current study. Some of those with RA stated their foot complaints were sometimes trivialised,

"I was a patient for trial for anti-TNF□ and my feet were never discussed. This is important research" (subject 8).

"My feet ache almost continuously and shoes are becoming more of a problem. The hard skin caused by deformities is painful to walk on and I feel that often walking problems are trivialised by medics" (subject 226).

"Generally not much interest has been shown by medical professions in problems with my feet" (subject 44).

Taken together therefore, it is clear that more emphasis is needed in medical training on the relevance and importance of foot/ankle assessment as well as other joint assessment in RA, an issue compounded by the lack of appropriate post-graduate courses available (Helliwell 2003). The outcome measures used in clinical practice such as the HAQ or DAS 28 that do not necessitate foot examination are reportedly not used in isolation; that is, they are only a part of a consultation (Wolfe et al. 2001, Aletaha et al. 2006). The results of the current study suggested that the infrequency of foot examination and the use of outcome measures that discount the feet led people with RA to perceive less interest from their clinicians in their foot symptoms than symptoms occurring at other anatomical locations. Indeed, respondents with RA estimated the time since last hand examination was approximately six months, whereas the time since last foot examination was greater than one year (section 6.12). This apparent discrepancy may reflect a trend among clinicians that they are not as comfortable with foot examination as hand examination, or may reflect time constraints in outpatients, where removing shoes/socks may take a great deal longer than assessment of hand joint synovitis. The lack of interest in foot examination perceived by patients often leads to feelings of frustration and anxiety as highlighted by the comments from those with RA (section 6.12). Given the relatively recent advent of the British Society for Rheumatology foot and ankle course, it would be valuable to assess the impact of this course on rheumatologists' practice.

People with RA have to live with the disease on a daily basis and understanding their views is essential, particularly if, as previous authors have suggested, comparison of the patients' experiences of the disease may be of equal importance to measurement and recording of the levels of disease activity measured by clinicians typically using objective outcome measures (Fries 1993, Long 1996). Differences in perception between patients and clinicians have been reported previously as discussed in section 2.6, but rarely has this been specifically explored with foot complaints. In section 7.8 podiatrists/chiropractors were identified by rheumatologists as the most likely point of referral for people with RA who were suffering with foot complaints, with only 0.7% of rheumatologists indicating they would not consider referring to a podiatrist/chiropractor. It is worth re-iterating that these figures need to be considered in the light of foot care services not being

available in all regions either for those with musculoskeletal foot complaints (Redmond et al. 2005) or for the wider population (Harvey et al. 1997). In section 6.3 the practice of podiatrists in respect of the assessment undertaken to determine the nature, severity and extent of the characteristic features of foot complaints in RA was presented. The approach taken while detailed and meticulous could be equally considered to be reductionist and mechanistic in nature, in that there was an emphasis on the foot alone rather than moving beyond the individual to their role in wider society (Helman 2007). Such criticism could of course be due to the structure and content of the questionnaire and not a true reflection of podiatrists' practice. However, the results were consistent with the focus group work carried out as part of the pilot process and the work of others such as Clarke et al. (2006) who found that detailed information regarding the range of motion available at individual joints in the foot was one of the most important clinical considerations podiatrists use when prescribing insoles/orthoses. This type of approach by podiatrists was also continued into the assessment of functional activities such as gait. While podiatrists' assessment of stance and gait was much more heterogeneous, suggesting that they were attempting to capture the wide array of problems reported by their patients, gait assessment was largely confined to the mechanisms of the gait cycle. When invited to suggest assessment tools/instruments or outcome measures not currently available, (a „wish-list“), podiatrists suggested methods of assessment that were seen as being more objective or perceived to be more valid because of their objectivity. Yet the use of instrumented measurement equipment can lead to practical difficulties in terms of the expertise required to operate it and to interpret findings; there are also issues of repeatability, reliability and validity with such equipment (Otter et al. 2004). Of greater importance from the perspective of this study, however, is the apparent reluctance by podiatrists to accept qualitative information as useful or valid. Not only are rich qualitative descriptions from those with RA translated (or reduced) to a point on a VAS scale, there also appears to be an emerging belief that findings are somehow more valid if more complex technology is employed. This point is not lost on those with RA, one of who commented,

“Have had feet x-rayed several times, but when I tell nurse or doctor at hospital about problems and pain with feet, they say there are too many bones in the feet to look into it! So they only x-ray them to see any deterioration” (subject 93).

This finding is not all together surprising as a number of authors have commented that in all health disciplines measurement priorities tend to be focussed on the measurement of clinical health status, which by its very nature is sensitive to the natural history of the disease and/or its treatment, as opposed to the preferences of those with the disease (Mirin & Namerow 1991, McHorney 2000, Carr et al. 2003). There is currently a reliance by podiatrists and rheumatologists on quantified measurement scales, which are seen as being more valid, reliable and accurate – a feature alluded to in recent reviews in the podiatric literature (Wrobel 2000, Parker et al. 2003) and by the findings

of the current study (section 8.6). Some authors suggest this is because of achievements in the physical sciences and go on to contend that such measurements are in reality imprecise because they do not always fully account for the complexity of the construct being measured (Kuiken and Mail 2001, Lempp & Kingsley 2007). McHorney (2000) points out that there is a consistent practice in healthcare of separating out physical health from psychological health perpetuating the mind/body dualism originally hypothesised by Descartes some 400 years previously (Clarke 2003), which Turner (2000) suggests has been added to over the ensuing centuries by the works of a number of influential scientists such as Isaac Newton and William Harvey.

Adding to the complexity of this debate is the ontological position in relation to the education of health professionals. Law and Britten (1995) contend that the educational system for medical practitioners is firmly grounded in the framework surrounding the medical model, a critique that could equally be applied to other health professionals. In the past decade in particular, however, there has been evidence of a shift in this ontology with a greater emphasis on a more patient-centred approach, which will be discussed in more depth in section 9.13. The debate regarding the history and traditions within professions cannot be ignored. Podiatrists have a professional culture and tradition of undertaking practical tasks (such as callus reduction), which generally require a high degree of psychomotor skill. There is much less of a history in podiatry of using a consultation purely to focus on the patients' concerns without undertaking at least minimal 'treatment'; a position no doubt reinforced by the expectations of those seeking care. Of course, during the consultation (often lasting for 20 minutes or more) podiatrists will discuss a range of topics and in many cases will discover information about the inter-relationship between the person and their disease, information which will be of interest and importance to other members of the multi-disciplinary team. The breadth of information that can be acquired during consultations was alluded to in section 8.5, where podiatrists recalled what people with RA had told them about the course of their disease and its impact on factors such as mobility and quality of life. What is less clear is how reflexive podiatrists are regarding the nature of these encounters.

Reflexivity is a contested term, its definition depending on factors such as the methodological tradition and perspective being considered (Finlay 2003). For example, reflexivity is defined by some as attending to the context of the construction of knowledge (Malterud 2001), while others see it as a heightened sense of self-awareness, allowing individuals to reflect on their own cultural and social background (Helman 2007). For the purposes of this discussion the latter definition is preferred as this is within the purview of developing one's own clinical practice through the practice of reflection. The tendency towards an apparent mechanistic approach to foot assessment by some podiatrists has already been discussed in section 9.3.6 and 9.3.7. This approach was in sharp contrast to the rich, textual descriptions people with RA apparently provided to their podiatrists (section 8.5). A formal culture of reflection and reflexivity is relatively new to podiatric

practice, whereas it has been part of other professions (notably social work, occupational therapy and nursing (Taylor and White 2000)) for a number of years. Podiatrists may therefore be unsure both how to record this information and how best to use it to inform practice. This uncertainty is further compounded by the feeling expressed by some podiatrists in section 8.7 that they are divorced from the wider multi-disciplinary rheumatology team. Conceivably, even when podiatrists have uncovered important information that could be used to augment patient care, there may be no clear mechanism for sharing this with other members of the team. These findings would seem to support the work of Williams and Bowden (2004) who reported that there is a need for rheumatology teams and podiatry services to collaborate further with the aim of improving the foot health service to rheumatology patients. The issues associated with improving inter-disciplinary communication have been a recurring theme in both texts and policy documents (Moots & Jones 2004, Dept of Health 2006a), although the incorporation and sharing of assessments for quality of life and valued life activities discussed in previous sections could also enhance communication.

The possibility that some podiatrists may not consider the subjective information provided by their patients to be important enough to share must also be addressed. Podiatrists in the current study expressed the wish to access more technologically advanced methods of undertaking assessment. This suggests the possibility that these respondents perceive such procedures as being more accurate and valid, presumably because they are more objective when compared with the subjective histories provided by patients. The findings of the current study strongly support the contention that the person best placed to explain the impact of the disease is the patient (Sullivan 2003). There is a clear and direct link between persistent synovitis and the development of erosions (McGonagle et al. 1999, Dixey et al. 2004), although Wolfe and Pincus (1999) report that patients often realise there is a change in their disease before this is reflected in objective features of the disease. The early detection of synovitis may enable the institution of treatment sooner than would be the case when relying on clinical features. In terms of foot care, there is preliminary evidence that early intervention with foot orthoses is beneficial in reducing pain and improving mobility (Woodburn et al. 2003). The information needs of podiatrists may differ depending on whether the early identification of pathology is the primary aim as opposed to reviewing outcome of treatment, although in both cases the impact on the patient needs to be acknowledged and understood. It is not clear from these data whether objective and subjective information were fully integrated in these different contexts, but findings tended to suggest a reliance on information from clinical tests. Key to understanding this debate is the principle that information from tests should inform rather than drive practice – as illustrated in the case of outcome measures such as the DAS 28 that exclude the foot. The findings of the current study suggest the use of outcome measures like the DAS 28 may compound the gap between the need for expert foot care and its provision. If differences in perception between those with the disease and their clinicians could be identified and overcome this might considerably improve overall management.

During the last 10-15 years there has clearly been a shift in emphasis away from uni-dimensional instruments purely measuring joint range of motion without explicitly considering the impact of findings, to questionnaire based instruments which include a broader range of constructs including pain, function, quality of life and choice of footwear. Initially, these instruments were developed purely from the healthcare professionals' perspective as in the case of the Foot Function Index (Budiman-Mak et al. 1991) and the Foot Health Status Questionnaire (Bennett et al. 1998). Latterly, instruments have been developed from the patient's perspective, for example the Bristol Foot Score (Barnett et al. 2005) and the Leeds Foot Impact Scale (Helliwell et al. 2005). This change mirrors the shift in outcome measurement described in section 3.5 and highlights the importance now placed on actively considering the patients' perspective. A less encouraging finding was the extent to which clinicians in the present study reported using the outcome measures developed from the patient's perspective now available. Data from the current study (section 8.6) and evidence of the lack of research with which to compare the performance of existing measures (appendix 4) suggest that although these instruments have undergone extensive testing, they are still not widely used by podiatrists. The greater involvement of patients when developing measures, and health professionals who will utilise the information provided by outcome measures (whether new or existing), is required as part of clinical governance programmes; otherwise the development of new outcome measures becomes little more than an academic exercise, with no real benefit to patient care.

9.10 Limitations on social interaction: a new perspective on foot complaints in RA

There is a progressively large and important body of literature (not just in rheumatology) highlighting the importance of social interaction and engagement, areas that often require sufficient mobility to engage in social activities. Adequate social interactions are increasingly seen as key mediators/protectors for maintaining psychosocial health in a range of conditions (Bassuk et al. 1999, Mendes de Leon et al. 1999, Berkman 2005, Boden-Albala et al. 2005, Glass et al. 2006, Loucks et al. 2006). Of particular relevance to the current study is the accepted understanding that RA is associated with an increased frequency of disability, extra-articular co-morbidities including cardiovascular disease, reduced quality of life and psychological impairments (Blom & van Riel 2007, Scott & Steer 2007). Previous researchers have expressed the opinion that social concerns are largely predicted by physical disability, therefore the involvement of other professionals (occupational therapists, social workers, and so on) is of key importance to those with RA (Neville et al. 1999). While the impact of physical disability on social engagement cannot be denied, this perspective appears to be grounded in the epistemological viewpoint of a Western medical model, and does not fully take account of the socially constructed realities of those living with chronic disease.

Chronic illnesses such as RA not only impact on sufferers' daily lives and their social relationships, but also on their identity and sense of self (Nettleton 2006). Charmaz (2000) argues that these issues are as problematic to manage in the social context as symptoms are in the medical context. Murphy (1999) writes that those who are disabled "enter the social arena with a skewed perspective, not only are their bodies altered but ways of thinking about themselves have been transformed". Previously Bury (1988), basing much of his work on discourses with people with RA, distinguished „meaning as consequence" and „meaning as significance". The former referring to the impact of chronic disease on everyday living, the disruption of occupational and domestic activities. This was an area people with RA in the current study commented upon; for instance,

"Pain in my feet/ankles and other joints caused me to give up my career in nursing and take a more sedentary job working for a bank" (subject 306).

Meaning as significance refers to the imagery associated with chronic conditions and how this disrupts life at every level. Frank (1999) writes of "pain being one of the first experiences an ill person has of being cast out, a loss of coherence from one's normal environment". Examples of meaning as significance were also noted in the current study. One person with RA spoke of how,

"RA has dictated my lifestyle for the last 30+ years. After the initial period of being very unwell and in a lot of pain until it was correctly diagnosed and treated, I had long periods in remission when I was younger, though my life was restricted by the damage to feet, hands and wrists in the early stages. My RA has become more difficult to control now I am older" (subject 1058).

Murphy (1999) highlights the way the dominant features associated with chronic diseases such as RA cannot be simply ameliorated by occupational or social roles. Instead, the negative perceptions associated with chronic disease on both the physical body and metaphysical self can be further reinforced by society. Lonsdale (1990) and Caddick (1995) discuss how, in Western culture in particular, there is a pre-occupation with self-image, which is not only based on but also constantly compared with the images portrayed by the diet, fashion and advertising industries. This tends to lead to a negative self-image, which Murphy (1999) argues can lead to a propensity for social isolation. This might be because of a tendency to avoid social situations either due to a fear of embarrassment or sense of guilt or shame that may occur if those with chronic illness see themselves as not being able to cope in the social arena (Murphy 1999, Charmaz 2000). One participant in the current study commented,

"...now entirely dependent on care in the home through rheumatoid arthritis... Feeding only with specialised cutlery" (subject 1123).

The feelings of not being able to cope in the social environment can be a particular problem in RA. Charmaz (1999) points out that while visible disability (such as hand deformity) may lead to questions or feelings of empathy, an invisible disability (as may occur with the feet) could lead to false assumptions by friends or family or a fear on the part of the individual about failing to meet the expectations of others. Alternatively there could be concerns regarding fitting into one's peer group. In her autobiography of a young adult with RA, Peterson (2001) writes, "I feel like Cinderella's ugly sister as I try to squash my feet into trainers." Murphy (1999) suggests that reactions, and sometimes hostility evident in society towards those with chronic disease, reinforce these issues. In effect this further stigmatises those with chronic disease magnifying their sense of loss (Charmaz 2000). Indeed, one participant in the current study when discussing people's reactions to their feet summed up the feelings of others by saying,

"I'm afraid to say that I have the kind of feet that you would bury in the sand if you were on the beach. I can see from the expression on people's faces that I need to hide them". (subject 302).

Social contacts were seen as being of great importance and foot complaints made this valuable aspect of daily life particularly difficult for many respondents in the current study. These difficulties were summed up by one podiatrist who recalled a patient saying how her feet "*made her a prisoner*". What was less clear from the descriptions provided by podiatrists is if, or how, this valuable qualitative information from their patients is used. Social interaction is rarely considered by existing outcome measures specific to foot complaints, yet the results from the current study suggest not only is it important to people with RA, but it may be useful to explore the significance of considering the fulfilment of social activities as part of treatment planning.

Loss of mobility, inability to participate in valued life activities and reduced social interaction due to foot involvement may also contribute to co-morbidities other than depression. RA is associated with a marked increase in risk for cardiovascular disease (Hayton 2006), with a 60% increase in congestive heart failure and 40% increase in myocardial infarction reported (Gabriel et al. 1999). The pathogenesis for cardiovascular disease in relation to RA has been widely reviewed by a number of authors (Mikulis 2003, Sattar & McInnes 2005, Snow & Mikulis 2005). The contention here is that if patients' mobility is limited and function impaired due to foot involvement they are less likely to participate in social and leisure activities that may confer a protective effect against cardiovascular disease. The reduction of morbidity and mortality from cardiovascular disease remains a high priority in the UK as evidenced by a range of publications from the Department of Health including national service frameworks (Dept of Health 2000a), improvement programmes (NHS 2005) and briefing packs (Dept of Health 2007).

9.11 Foot complaints in RA and the need for social support

In addition to social interaction/engagement, studies have also demonstrated the importance of social support to people with chronic musculoskeletal complaints throughout the course of the disease (Griffith & Carr 2001). Indeed Fitzpatrick and colleagues (1991) have suggested adequate social support may be just as important as more conventional interventions. Evers and colleagues (1998) reported that those people with RA who had a smaller social network shortly after diagnosis were at risk of a greater decline in mobility within the first year of the disease compared to those with larger social networks. Others (Weinberger et al. 1990) have found that social support is important for maintaining functional status and therefore sense of worth in the later stages of RA. Minnock and colleagues (2003) reported positive associations between social support variables and quality of life indicators. It would appear therefore that social support moderates the severity of impact of RA to some extent (Neugebauer & Katz 2004). The mechanisms for this mediation are, however, complex and include the inter-relationship of cognitive/emotional responses, coping strategies and the availability of functional help (Evers et al. 1998, Berkman 2000, Evers et al. 2003). Previously in this chapter the importance to people with RA of living a „normal life“ has been stressed and this has been reported to include no limitations when managing household tasks and engaging in social functions (Ahlmén et al. 2004). Some reviewers have suggested social support is an aspect of wider integration into society as a whole (Vilhjalmsson 1993). Whereas others have divided social support into subgroups that include emotional, instrumental, informational and appraisal (Weiss 1974, cited by Berkman et al. 2000), though it is also suggested separating social support into these subgroups can be problematic owing to the inter-relationships between the subgroups. Within this framework it is also acknowledged that social support is not always positive and difficulty with social interactions may be more strongly related to both physical and psychological distress in the absence of support from family and friends owing to the lack of positive experiences to cancel out the negative ones (Revenson et al. 1991, Holtzman & DeLongis 2007).

In the current study three respondents with RA chose to specifically discuss issues of social support in their qualitative comments one example being,

“In 1999 I moved from X to Y to live with a very caring and lovely man, my partner, and so had to change hospitals” (subject 301).

As such, these comments cannot be linked to the discussion on social support with any confidence. Instead more respondents with RA elected to expand upon the various difficulties associated with everyday living owing to the extent of foot complaints and some chose to report the social issues related to foot complaints in much more general terms for instance,

“Foot problems cause everyday living to be very painful” (subject 371).

This was possibly a reflection on the structured part of the questionnaire, which predominantly focussed on the nature and extent of foot complaints rather than their broader impact on social issues. Nevertheless, seven people with RA commented on how difficult they found it to stand up for any period of time. For example,

“Its even painful to stand barefoot on thick carpet” (subject 145).

Considering that many domestic tasks (cooking, cleaning, washing-up, and so on) require considerable periods of pain free standing (as previously suggested by Strahl et al. 2000), it is conceivable that those taken for granted aspects of daily life would be adversely affected. Work by Ryan and colleagues (2003, 2003a) indicated that continuing with household activities is important to those with RA and that loss of these roles has a negative effect on self-esteem. This supposition is also supported by data from podiatrists, when invited to recall how patients everyday activities were affected by foot complaints, nine podiatrists recounted that their patients found it was very difficult to stand for long periods and a further six podiatrists revealed their patients reported that they were unable to complete housework. Neugebauer and Katz (2004) reported that if people with RA receive help with their daily tasks, this makes them more likely to be able to participate and maintain their valued life activities, with the benefits this confers as described previously in section 9.6.

Although those with RA did not always mention social support directly, the issues surrounding social support did appear to be discussed as part of consultations with podiatrists and that the need for social support was not always adequately fulfilled (section 8.5). This was particularly evident in the light of enforced role change, either domestically or in employment. For instance, nine podiatrists recalled their patients reporting that their foot pain limited their ability to walk. This aspect was also clearly important to people with RA as in total 33 respondents chose to discuss how RA either prevented or limited their ability to walk in their qualitative comments. For example,

“Very painful if I walk too far. The pain is bad; my feet burn and swell” (subject 1134).

Prolonged experience of chronic pain is reported to lead to a higher level of awareness about one’s own body, which in turn has a negative effect on everyday thinking whereby patients may start to worry about the constant pain (Aldrich et al. 2000). Anxiety about pain is associated with a tendency to report further symptoms in some, but not all patients (McCracken et al. 1998). Evers and colleagues (2003) suggested that cognitive responses that consist of fearful or catastrophizing beliefs about pain are thought to bring about a pre-occupation with symptoms and an avoidance of

activity. Others (Minnock et al. 2003) have suggested that close support from friend and family may help prevent avoidance of physical activity and have a beneficial impact on quality of life.

Overall, the reduced opportunities for social engagement due to foot complaints revealed by the qualitative data in the current study would appear to lend further credibility to the argument that loss of social support contributed to poorer overall health in addition to the physical limitations caused by foot pain and deformity. Few of the available outcome measures specific to foot complaints have directly considered the area of social support as being important. This is possibly a reflection of the preoccupation of the medical model with alleviating symptoms and maintaining functional status (Evers et al. 1998), and the use of traditional measures of functional capacity (Neugebauer & Katz 2004). More recent instruments have begun to recognise these issues and have included questions on social engagement/support (Barnett et al. 2005, Helliwell et al. 2005, Dawson et al. 2006). However, data from the current study (section 7.6, 8.6) suggests these measures remain under-used at the present time. A number of authors make the case for cognitive restructuring and coping-skill training to be instituted early in the course of RA to enable people with the disease to develop appropriate compensatory strategies for enabling continual engagement in activities (Evers et al. 1998, Evers et al. 2003, Savelkoul et al. 2001). Traditionally, such interventions have not been part of the podiatrist's role, but given the time they often spend with people with RA on a one-to-one basis (for example when undertaking psychomotor tasks such as the reduction of painful lesions via sharp debridement), opportunities exist to implement such approaches. However, undergraduate education and postgraduate continuing professional development would need to reflect this requirement and the wider multi-disciplinary team would need to embrace this extension of role.

9.12 The management of RA: local and systemic measures and their impact on foot complaints

9.12.1 The role of disease modifying anti-rheumatic drugs

Respondents with RA were invited to detail their current disease modifying anti-rheumatic drugs (DMARD) from a pre-determined list. These data were gathered as part of the demographic data to describe the population under investigation, but also to explore the impact of DMARD medication on foot complaints in the light of recent changes to the pharmacological management of RA described in section 2.6 and appendix 2. Non-steroidal anti-inflammatory drugs were not included predominantly for pragmatic reasons as so many of these compounds are available. The most commonly used DMARD was Methotrexate, which was prescribed to just over 50% of respondents. This finding was not surprising as Methotrexate is considered to be an „anchor drug“ with a good efficacy/toxicity ratio reported as well as being relatively cost effective (Blom & van Riel 2006). Corticosteroids were the second most commonly prescribed agent with 35.65% of the total cohort reporting their use, although most were taking a concomitant DMARD. Although this study did not determine the dose of corticosteroid used, O'Dell (2004) suggests low dose corticosteroids (<10mg/day) are used in 30-60% of the RA population owing to their potent suppression of inflammation; the finding in the current study being at the lower end of this estimate. Corticosteroids are also useful as a „bridge therapy“ when switching DMARDs and in high doses in times of increased disease activity or „flare“ (Blom & van Riel 2006). Against the widespread continual use of corticosteroids are the well-recorded side effects associated with protein catabolism, osteoporosis and increased cardiovascular risk factors (O'Dell 2004). Other DMARDs were reported, used in varying rates, with the older, less efficacious agents such as Gold (Simon 2004) being sparsely utilised. The choice of DMARD strategy is reported to be largely due to empirical clinical practice in individual patients. Therefore trials comparing different strategies are relatively rare (Blom & van Riel 2006). Some people with RA in the current study reported that their DMARDs did improve their foot complaints and collecting this type of data would seem worthwhile in future trials of local and systemic interventions for foot complaints.

9.12.2 The role of biologic agents

In spite of reported concerns about the difficulties accessing newer biologic agents, such as TNF α inhibitors (Econopouly 2006), in the current study a greater proportion of respondents than expected by the researcher. A total of 21.7% (n=85) reported they were prescribed some form of biologic agent. The results from the current study (section 6.11), also suggest that patients with RA who are prescribed anti-TNF α drugs report a higher incidence of foot problems compared to those who are not. These findings are not entirely surprising, given that anti-TNF α drugs are reserved for patients whose active RA is resistant to conventional DMARD therapy. Yet, when

adjusted for non-responders the picture changes (section 6.11). The findings based on actual responses received indicated that those patients prescribed anti-TNF α reported a greater prevalence of foot complaints than those who do not receive anti-TNF α . However, if it is assumed that all the non-responders reported no additional foot symptoms, then those not prescribed anti-TNF α would have a greater prevalence of foot complaints, notably pain and stiffness; although swelling and numbness would still remain more common in the anti-TNF α group. These potential variations may account for why more patients not prescribed anti-TNF α receive chiropody treatment, even though initial responses suggested the need for foot care was not as great in this group.

It is, however, difficult to make accurate predictions regarding the uptake of foot care and frequency of foot assessment in those who are prescribed anti-TNF α , not only because the true figure probably lies between the two estimates indicated in table 6.11, but also because the recollection of foot examination may also vary. Furthermore, recent reports from some centres (Davys 2006) are beginning to suggest that foot lesions (particularly those that may lead to infection, such as in-growing toenails), show a higher prevalence in those patients who take anti-TNF α . This might be because patients have a greater degree of mobility as a result of the effectiveness of these agents coupled with the increased potential for damage to structures weakened by RA. Invasive procedures used by podiatrists and others to treat lesions such as in-growing toenails (for example, nail wedge resection) need to be discussed with the rheumatology team prior to the procedure to determine the need for antibiotic prophylaxis or temporary withdrawal of TNF α therapy (Pisetsky 2000, Otter et al. 2004). There does, however, remain uncertainty in respect of the impact of anti-TNF α on rates of infection as some centres have reported an increased risk in infections (Kroesen et al. 2003); while others contend no statistically significant increases have been seen (Bongartz et al. 2005). Given the higher than expected reporting of foot ulceration in the current study and that of others (Matricali et al. 2005), the subsequent potential for serious infection resulting from these lesions (such as the case reported by Otter and colleagues in 2005), it seems reasonable to highlight the role of the multi-disciplinary team where a podiatrist or extended scope specialist nurse could undertake routine foot assessment as part of a defined care-pathway. Equally it is important to remember that the current study presents a cross-sectional „snapshot“ of current practice. The earlier use of biologic agents in the course of RA may decrease the need for podiatric care, as patients may not develop deformities that place the feet at risk of developing lesions.

9.12.3 Fulfilling an unmet need for foot care

In terms of the need for foot care, 268 respondents (69.4%) indicated they had difficulty undertaking basic foot care (for example, cutting toenails) and 249 (64.2%) had seen a chiropodist

or podiatrist, indicating that there is a gap between the needs of people with RA for foot health services and service provision. These figures need to be seen in the light that 95.2% of respondents with RA reported foot pain and 82% reported having discussed foot complaints with their rheumatologist (section 6.12), which suggests an even greater unmet need. Furthermore, as reported in section 6.13, not all those with foot complaints reported they were receiving specialist foot care. The gap in provision of foot care services for those with RA may be further complicated by the finding that not all rheumatologists in the current study reported they were fully aware of referral criteria and mechanisms of referral for foot care (sections 7.7 and 7.8). The findings regarding knowledge of referral criteria and mechanisms by which to refer patients for specialist foot care support previous work (Redmond et al. 2005) where less than half of rheumatologists reported that basic foot care needs were being met and fewer than one in ten had local agreements for standards of care or mechanisms/criteria for referral. In part, this may be due to historical arrangements where rheumatology services are largely based in secondary or tertiary care facilities whereas foot care is typically delivered in primary care; this can cause difficulties as acknowledged in the Musculoskeletal Service Framework (Dept of Health 2006a). However, in the current study, access to podiatric care was not only commented upon by rheumatologists, but also by a proportion of those with RA; with 10 respondents providing qualitative comments that they were unable to obtain appointments with NHS podiatrists, causing some to seek private care,

“There does not seem to be the same level of help available for “foot” problems, as with “hand” problems with RA” (subject 21).

“I have arranged for my own podiatry treatment. Bought my own “New Balance” trainers and gel insoles” (subject 150).

In the recent annual review by the National Rheumatoid Arthritis Society (NRAS 2006), 58% of people with RA saw a podiatrist less than once per year, even though annual reviews are recommended by the Arthritis and Musculoskeletal Alliance standards of care (ARMA 2004). Even when foot care services were available, some respondents felt these were insufficient, often due to the infrequency of appointments available. This issue was summed up by one respondent, who reported,

“The NHS Chiropody Service is totally inadequate for anyone with RA” (subject 311).

However, where specialist foot care was available in an appropriate and timely manner, there was a feeling that regular podiatry was beneficial and some respondents reported excellent care from NHS podiatry services,

“I am very fortunate that I have excellent care from my GP, Rheumatologist and Chiropodist – the latter I have a regular 4 weeks appointment that „keeps me out of trouble” (subject 1).

“I now go to see my chiropodist every 10-12 weeks – my feet are greatly improved” (subject 84).

“Without insoles that my podiatrist dispenses I would be unable to walk without pain” (subject 1019).

Taken together, the lack of foot care received by some people with RA and the difficulties this causes referrers, as well as the benefits that comprehensive foot care can provide all of which are reported in the current study, confirm the findings of previous research (Williams & Bowden 2004, Redmond et al. 2006). Sadly some of these issues are not new. In 1994 a Department of Health report highlighted the issues of disabling foot complaints in arthritis and the need for specialist care. The need for foot care has been reinforced by a series of policy documents (Dept of Health 2000b, 2005). In particular the Musculoskeletal Service Framework (Dept of Health 2006) has proposed a key role for podiatric/chiropodial intervention in the maintenance and improvement of locomotor function of the feet and legs, pain management and reduction of disability. Yet the lack of foot health provision for this group of patients has recently been highlighted by the Commission for Healthcare Audit and Inspection (2006) and Age Concern (2007), both of whom, in a series of recommendations, request improved access to good quality foot care services, and NHS Trusts to commission adequate provision of these.

Perversely, the need to improve availability of care for those with RA may be prevented by the very criteria used to identify those in greatest need. In response to disinvestment in foot care services many podiatry departments based in NHS Trusts use referral criteria to identify those with greatest need (Campbell 2000, 2002). It is conceivable that those with early RA may not meet these criteria and therefore would be ineligible for treatment. Podiatrists in the current study have expressed a desire to have people with RA referred sooner to foot clinics for assessment and monitoring (section 8.7). In line with the opinion expressed by Helliwell and colleagues (2007), podiatrists in the current study felt early referral presented a greater window of opportunity to provide more effective foot care by identifying the potential for foot pathology sooner. The value of early referral would not appear to be a new idea to most podiatrists (at least anecdotally), although there has been little published data to support this view. Paradoxically, difficulties in achieving early referral and thus capitalising on the extended window of opportunity to provide more efficacious treatments include not only the long waiting lists or the lack of foot care services. There may also be conflict with the very criteria used to identify the need for foot care particularly as such criteria are usually based on the medical model of the existence of pathology. Typically these criteria do not take

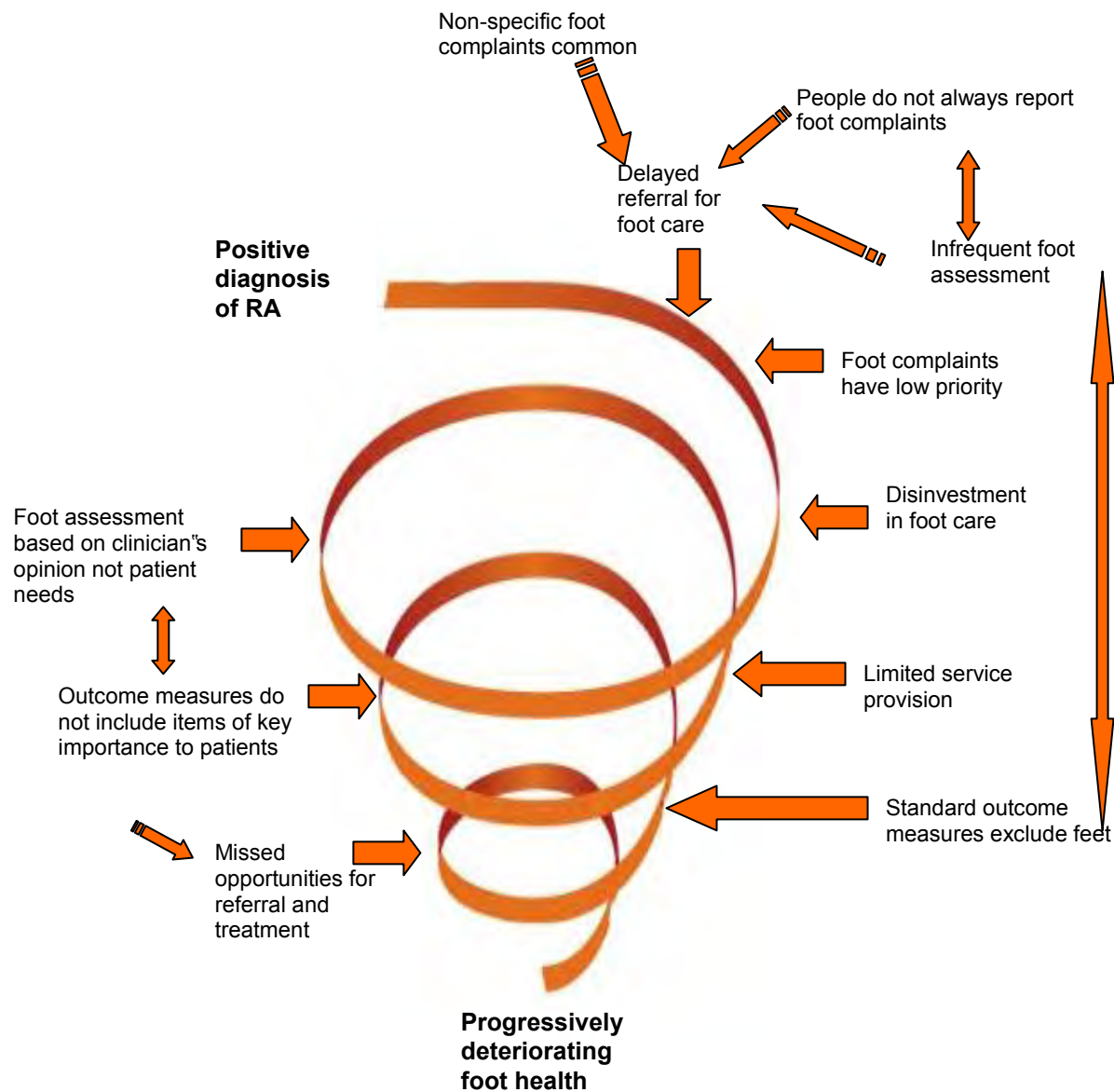
account of the social implications and quality of life issues that the findings of the current study highlighted throughout this chapter as being important to those with RA.

The gap between the potential unmet need for specialist foot care and those with RA actually in receipt of this care, highlighted by the current study, is in sharp contrast to other conditions where there is significant foot involvement. This is notable among patients with diabetes, where multidisciplinary foot care has been found to effectively reduce amputation rates (Larsson et al. 1995, Van Houtum et al. 2004). Therefore national guidelines recommend podiatric involvement (Dept of Health 2001a). In rheumatology, however, previously although some local guidelines did exist (for example the North West Clinical Effectiveness Guidelines for the Foot in Rheumatic Diseases (Lonrigg & Mainwearing 2002)), Redmond and colleagues (2005) pointed out that “the absence of nationally agreed guidelines and poor awareness of local standards appears to be detrimental to the provision of basic foot care for rheumatology patients”. While this may be true, there are other factors that need to be considered. For example, in the current study some podiatrists clearly felt that they were not part of the multidisciplinary rheumatology team (even where such a team existed). Access to both the rheumatologist and other members of the health care team was felt to be a barrier to providing high quality care. Recent government initiatives such as the Long Term Conditions White Paper (Dept of Health 2005) appear to be moving towards a Primary Care based service for all but the most severe cases, thereby providing an impetus to improve the barriers surrounding team working and referral. Furthermore, the Musculoskeletal Service Framework (Dept of Health 2006) recognized the need for closer collaboration among primary care physicians, nurses and Allied Health Professionals. The management of long-term conditions in the Primary Care setting is a key recommendation of the interim report by Lord Darzi – Our NHS Our future (Dept of Health 2007d).

However, as mentioned in section 7.8, rheumatologists reported that the availability of foot care services was somewhat variable, long waiting lists being a notable problem, confirming the findings of previous workers (Jacobi et al. 2004, Redmond et al. 2006). The issues of availability of foot care services may explain the variability of referral patterns for RA patients with foot complaints to health professionals described in section 8.7 just as much as medical practitioners knowledge of referral criteria, because rheumatologists may not refer their patients if they know patients face a long wait. There is also a further over-arching argument that if the infrequency of foot examination remains, medical practitioners might be unaware of the need for foot care, consequently there will not be a particularly high volume of referrals to highlight the necessity for obtaining these services. Campbell (2007), while modeling deterioration in foot health, noted that decreasing independence and increasing age were associated with a rising probability of developing medium/high risk foot pathologies. Both decreasing independence and increasing age can be applied to those with RA; the issue of increasing age being a risk factor for deteriorating foot health has already been alluded

to in the current study. The confluence of these various factors is highlighted in figure 9.2 overleaf, where the potential for continued disinvestment in foot care services is an additional and serious possibility.

Figure 9.2 - Schematic diagram illustrating factors leading to progressively deteriorating foot health in people with RA



9.12.4 Effecting change to foot care services, the role of footwear and orthoses

The Musculoskeletal Service Framework (Dept of Health 2006a) has proposed a key role for podiatric/chiropractic intervention in the management and improvement of locomotor function of the feet/legs as well as a role in pain management and reduction in disability for those with musculoskeletal disorders. To achieve improved care for those with foot complaints Helliwell et al. (2007) have developed the work of Steiner and colleagues (2002) and further conceptualised the ICF framework (outlined previously in section 2.7); and have suggested podiatric management currently largely occurs at the level of structural and functional impairment. The improvement of functional limitations is particularly pertinent when foot symptoms severely limit activities that are

important to those with RA (Sangeorzan et al. 2005). A decrease in foot/lower limb discomfort, coupled with increased mobility, has the potential to improve a variety of aspects of health – social, occupational and psychological. In this context, benefits should not just been seen in the localised context of foot/lower limb morbidity. This view was supported by Katz and colleagues (2006) who found that changes in the feet were more strongly predictive of disability for activities valued by people with RA than changes in the hands. To reduce pain and improve foot/lower limb function insoles and orthoses (with or without specialist footwear) can be prescribed by a variety of health professionals (Kavlak et al. 2003, Woodburn et al. 2002).

The current study opted to determine to what extent insoles/orthoses were prescribed, establish if devices were still being worn and whether people with RA thought their insoles/orthoses were helpful. In total 54.19% (n=323) of people with RA were reported to have been prescribed foot orthoses/insoles, yet of this group 44.2% (n=143) reported that they were not currently using their prescribed device(s). Although of concern, the proportion of respondents not using their orthoses is not dissimilar to the rates reported in some pharmacological studies (Donnan et al. 2002, Benner et al. 2002). It should also be noted that some patients discontinued using insoles/orthoses either because their foot complaint had resolved (n=27, 8.4%) or because additional treatment such as surgery was required (n=19, 5.9%), leaving only a relatively small number who found their orthoses either did not fit their shoes (n=41, 12.7%) or did not improve their foot symptoms (n=56, 17.3%).

Reasons for the limited uptake of orthoses identified in this study are complex, multi-factorial and intrinsically linked. As demonstrated by the current study, people with RA report a wide range of symptoms in their feet, including pain, stiffness, swelling and numbness. However, considerable variation in the location of, the intensity, character and severity of symptoms was also reported. Currently available orthotic materials may not have the pre-requisite properties to ameliorate such a wide range of symptoms and this suggests opportunities to undertake further research into the development of new materials. Recent work has shown that when people with musculo-skeletal complaints are provided with orthoses, their activity levels/mobility tends to increase until pain and/or discomfort become a limiting factor (Springett et al. 2007). Although the work of Springett and colleagues was not carried out specifically in people with RA, it is conceivable that similar patterns may occur. Indeed increased levels of activity could be more marked in those with RA because of the concomitant medication prescribed as part of multi-disciplinary care. This may improve overall foot symptoms in conjunction with orthoses, which of course is consistent with the aim of management outlined in section 2.6. There is, however, an important caveat to consider, as the use of immunosuppressive medication together with the foot deformities that occur as a result of the disease process places patients at risk of skin breakdown which may occur earlier due to the presence of foot deformities or reduced tissue vitality (Otter et al. 2005). The increase in activity levels permitted by the use of orthoses may also lead to ulceration if care is not taken to ensure

orthoses fit correctly and are not causing skin lesions. These issues lead to conjecture that compliance issues with orthoses may also be because of a lack of training on the part of the healthcare practitioner prescribing the device, or may result from poor education of the patient. For example, Woodburn and colleagues (2003) reported that initial discomfort might occur with rigid orthotic devices for a minority of RA patients. Springett and colleagues (2007) found similar problems when issuing over the counter orthoses. Although in both cases these problems tend to be short-lived, patient education is paramount in preventing premature discontinuation of orthotic use. If there is a perceived dissatisfaction with conservative care, as suggested by the proportion of subjects who do not continue wearing orthoses/insoles prescribed by health professionals, this may also explain the seemingly high consultation rate for foot surgery, with 26.9% of respondents having seen or waiting to see a foot surgeon.

In conjunction with orthoses, the issues related to finding comfortable footwear were a repeated theme throughout the current study, and were commented upon by 19 (9%) respondents, all of who indicated they were unable to find suitable shoes to wear. Additionally the difficulties people with RA had in finding suitable, comfortable shoes was a recurrent theme in the qualitative comments which podiatrists recalled hearing from their patients; “impossible to get suitable shoes” and “cannot get shoes to fit” were typical of these. The difficulties experienced because people with RA were unable to find suitable footwear fell into a number of different categories. Footwear was clearly important for relief of foot pain and to improve mobility, especially since 39 people with RA specifically mentioned that their foot pain was worse when walking. These areas are also important for quality of life, as reduced pain and improved mobility will enable those with RA to participate in activities important to their quality of life. Footwear was also important in terms of its effect on overall appearance. The concerns associated with footwear seemed a particular problem for women; the inability to find smart or fashionable shoes that were comfortable was a cause of negative psychological symptoms. For example,

“Not being able to wear feminine heeled shoes because of RA has been a cause of real sadness for me” (subject 71).

“I resort to wearing old shoes and trainers which depresses me greatly” (subject 44).

People with RA also commented that not being able to wear fashionable shoes was an area they found particularly troublesome. This difficulty was summed up by one respondent who said,

“Not being able to wear a “stylish” shoe makes a person feel disabled and lowers self-esteem and mood” (subject 105).

Some podiatrists also indicated that their patients found their choice of footwear was limited because of their RA and this affected their perception of being able to enhance their appearance - "can't wear nice shoes - don't want to dress up", was a typical comment recalled by one podiatrist.

Recent research by Monaghan and colleagues (2007) highlighted that both concerns about appearance as well as levels of disability were both predictive of depression in people with RA. The widespread concerns about footwear revealed by the present study suggest such issues contribute to negative psychosocial appraisals by those with the disease.

Given the extent of foot complaints often reported in RA, footwear is often seen as a valuable therapeutic modality (section 4.8). A recent Cochrane review (Egan et al. 2004) concluded; "there is preliminary evidence to support the use of extra-depth shoes with or without insoles to relieve pain on walking and weight-bearing". However, this review also noted that research in this area is in its infancy with few studies suitable for inclusion. The compliance with wearing prescribed footwear is an important area for consideration, partly because of the expense of these items, but more importantly the potential benefits to patients when the correct footwear is provided (Williams & Meacher 2001). Previously, Harold and Palmer (1992) found that in a sample of 97 subjects with RA, half had surgical shoes and most found these to be of benefit. However, this is a complex area to investigate. Stewart (1996) in a satisfaction survey of subjects with RA reported that while most participants were satisfied overall, when asked about specific aspects of their shoes (for example, weight, appearance, comfort, and so on) rates of satisfaction were noticeably reduced. Boer and Seydel (1998) also reported that the rate referral for prescription footwear was more likely to depend on the satisfaction with the footwear as perceived by clinicians, rather than their beliefs about its therapeutic advantages. These issues have led Emery and Borthwick (2002) to recommend that there is a need to develop standard measures of outcome for this aspect of clinical care.

The issue of footwear was highlighted in the literature review (section 3.8), therefore the current study also enquired about the frequency of footwear provision and the continued use of prescribed footwear. It was found that specialist „hospital“ footwear had been prescribed to 20.74% of respondents (n=122). It was also found that where footwear had been prescribed, 70% did not continue to wear the shoes provided. Although fewer people with RA felt their shoes did not help their foot complaint or actually increased foot pain when compared with orthoses, a smaller proportion reported that the shoes provided had actually helped to resolve their foot complaint compared with orthoses. All of these could be reasons for discontinuing to use prescribed footwear. However, the most common reason respondents did not continue to wear the shoes (n=48, 41.28%) was because they were unhappy about the cosmesis of the footwear provided. The amount of involvement patients have in the prescription of bespoke shoes is often limited and

may explain why recent research suggests that for footwear, patient involvement in the design process is a key factor. Greater patient involvement in this process appears to yield a higher level of satisfaction with the end product (Williams et al. 2007).

To be effective, foot care services need to be integrated and include elements that cover all the aspects encompassed by managing and living with foot complaints. This includes clinical, social, psychosocial, employment and educational inputs, suggesting that a more patient-centered approach to providing foot care is required in RA.

9.13 A novel patient-centred approach to the assessment and management of foot complaints in RA

The concept of patient-centred medicine appears to be widely attributed to the writing of Balint in the 1960's (Stewart et al. 1999, Mead & Bower 2000, Armstrong 2003). Balint (2000) combined general medical practice with psychoanalysis, concluding that often illnesses were as much psychosocial in their origin as organic, biological pathology. Thus patient centeredness represents a move away from thinking about disease solely in terms of pathology and moves towards considering people and their problems (Henbest & Stewart 1990, Mead & Bower 2000). Some have described such an approach as "entering the patient's world and seeing the illness through the patient's eyes" (Law & Britten 1995). In taking such an approach, it is argued that a greater personal relationship between the doctor and patient is afforded, that allows a greater exploration of the presenting complaint in the broader context of life (Mead & Bower 2000). A wide range of concepts has been considered to be part of a patient-centred approach, a model of patient-centeredness (outlined in table 9.8 overleaf) has been proposed.

Table 9.8 - The patient-centred clinical method

(adapted from Weston and Brown 1995 and Little et al. 2001)

<p>Exploring both the disease and illness experience</p> <ul style="list-style-type: none"> • Physicians' understanding – for example explaining differential diagnosis • Dimensions of the illness - ideas, feelings, expectations and impact on function
<p>Understanding the whole person</p> <ul style="list-style-type: none"> • Context of life setting and development of that person • Knowledge of work, family, culture and beliefs
<p>Finding common ground</p> <ul style="list-style-type: none"> • Nature of problems and their priorities • Goals of treatment • Roles of the clinician and the patient
<p>Incorporating prevention and health promotion</p> <ul style="list-style-type: none"> • Screening and early detection of disease • Opportunities for risk reduction • Enhance health • Reduce impact of disease
<p>Enhancing the patient-doctor relationship</p> <ul style="list-style-type: none"> • Sharing the therapeutic relationship • Methods of improving communication • Developing reflexivity
<p>Being realistic</p> <ul style="list-style-type: none"> • Consideration of both clinician's and patient's time and resources • Utilise wider team

In rheumatology, many of the items considered germane to the patient-centred approach not only have a major impact on people's lives but also have been reported not to be routinely collected during consultations with people with rheumatic diseases such as RA (Carr 1993, Wolfe & Pincus 1999). Indeed, in the findings of the current study, outcome measures utilised by the vast majority of both podiatrists and rheumatologists were predominantly based around assessments of pain, function and disease activity and not the wider psychosocial aspects of the individuals' life. Whether this information was entirely missing from the consultation or represents shortcomings in the content of outcome measures remains to be seen. Moreover, Kvien and Heiberg (2003) contend that the lack of a patient-centred approach may lead to a lack of knowledge about the key issues that are of innermost importance to the individual. This deficiency may be because clinicians tend to value „objective“ or clinician-centred outcomes more highly than self-reported or „subjective“ outcomes (Bijlsma 2004). Interestingly, in the current study (as reported in section

8.6), a number of podiatrists reported that an “objective outcome measure” was something they perceived to be lacking from their practice. This was despite the widespread publication of several such instruments in recent years, as reviewed in section 4.6 and appendix 4. However, the importance attributed to „objective” assessments may be misplaced in this context, particularly as some studies report that a considerably greater proportion of patients (compared with clinicians) perceive psychological and social factors as being more important to their presenting complaint (Helman 1985, Peppiatt 1992). From the patient’s perspective, the primary focus of a consultation is not just to elicit symptoms, but for the practitioner to find out what the real problem is by listening (Armstrong 2003).

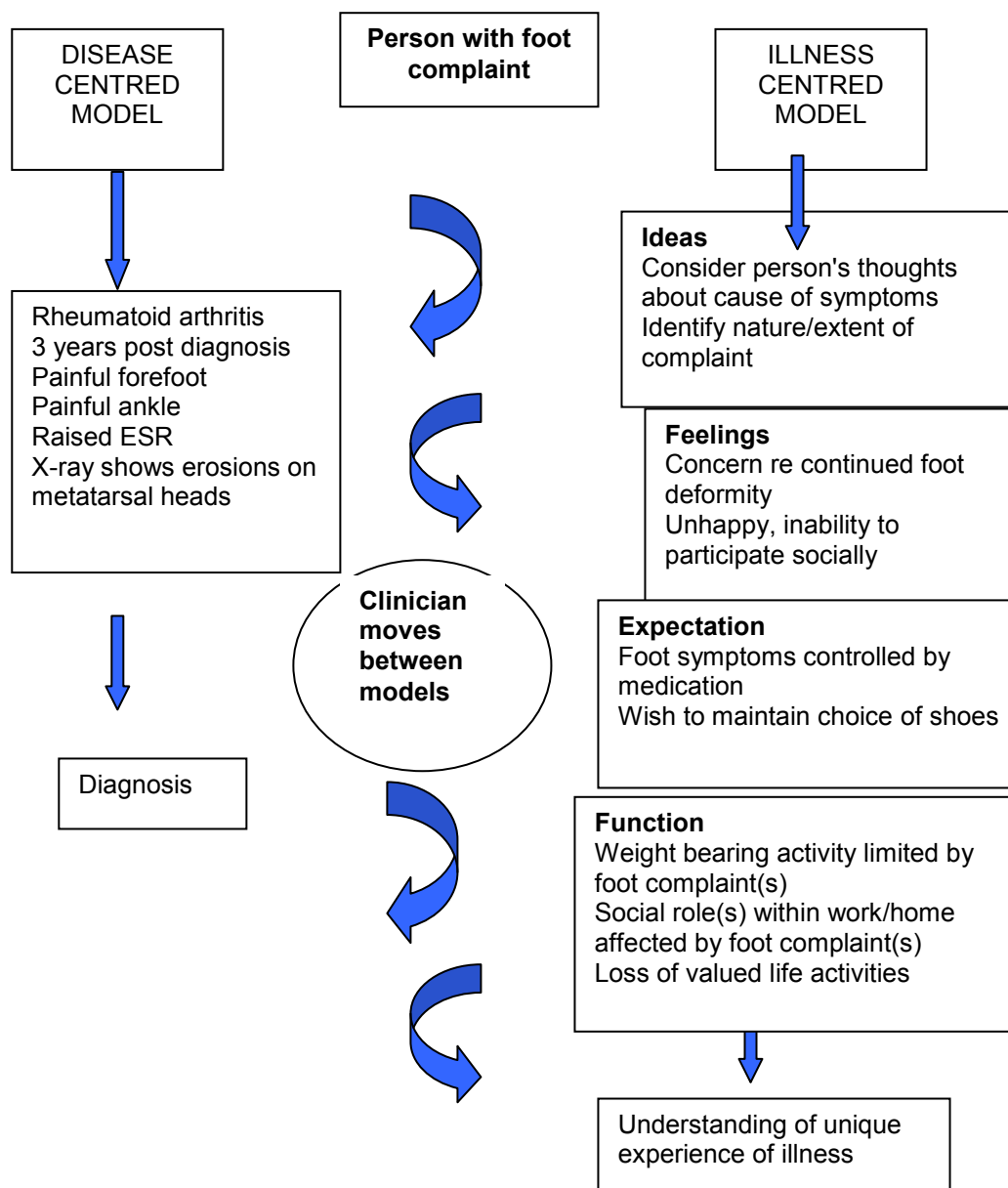
The measurement of patient reported outcomes has been gaining popularity in recent years (Fries 2004), although there are some authors who argue, “patient-centred outcomes cannot substitute for pathobiologic information to judge efficacy and effectiveness of targeted anti-rheumatic therapy” (Mittleman & Lipsky 2006). This opinion appears to suggest it is appropriate to reduce illness to a set of signs and symptoms to be interpreted in a positivist, biomedical manner (Mead & Bower 2000). In the current study, the data particularly from podiatrists (section 8.6 and 8.7) where the broader outcomes of the impact of foot complaints on activities such as social function did not appear to be routinely considered, suggests a similar positivist approach. Whereas Weston and Brown (1995) point out that although the characteristic features of a disease like RA are common to all those who have it (for example, pain and swelling of peripheral synovial joints), the experience of the illness is unique to the individual. The argument of Mittleman and Lipsky (2006) also appears to ignore the evidence that the integration of psychosocial factors that are important to the individual (but not usually gathered in the clinical examination) will lead to improved care. There is growing recognition, both from those with the disease and from policy makers, that actively engaging individuals in the processes of diagnosis and treatment leads to better outcomes (Wolfe & Pincus 1999, Mead & Bower 2000, Kvien & Heiberg 2003). Furthermore, Little and colleagues (2001) in a Primary Care based study, reported patients expressed a desire for a patient-centred approach. The findings of the current study discussed so far in this chapter highlight a number of opportunities for a more patient-centred approach to the assessment and management of foot complaints in RA. How such an approach might be used in clinical practice is illustrated in figure 9.3 overleaf. In this model, greater emphasis has been placed on identifying the nature and extent of foot complaints from the patients’ perspective and linking this with the impact on the person’s social, domestic and occupational roles. Additionally, how a person with RA might feel about their foot complaint(s) and the impact this has on function is considered alongside their expectations of the aims and objectives of management strategies.

A key goal of recent reforms to the National Health Service is to make services more patient-centred (Dept of Health 2007a). Concerns, however, have been voiced that for the majority of

patients services are still being delivered in a paternalistic manner (Richards & Coulter 2007) and some reforms are particularly unhelpful for some at-risk groups like the frail elderly who need long term care (Rowland & Pollock 2004). Whilst there would appear to be some room for improvement, there also appears to be a political expediency for more patient-centred approaches such as the one described overleaf that is based on interpretation of data from the current study.

Figure 9.3. - Comparison of a potential patient-centred approach to foot complaints in RA with a disease-centred model

Based on the model by Weston & Brown (1995)



9.14 Summary of the discussion

The current study is the first to consider the nature and extent of foot complaints in RA from the perspective of those with the disease as well as clinicians and this chapter has integrated these findings. As RA progresses the prevalence of foot pain is almost universal at some point during the disease process as noted in section 6.8, which suggests greater involvement than previously reported. The ankle and metatarsophalangeal joints are particularly badly affected, which is a novel and important finding as these joints are vital for normal propulsive gait. Foot pain in RA appears to be worse in those who are elderly, female and present with additional symptoms in the feet including stiffness, swelling and numbness. The nature and extent of these foot complaints leads to a series of difficulties for those with RA, including limitations of obligatory and, more importantly, valued life activities, a restricted choice of footwear, social isolation and reduced quality of life. The considerable impact of foot complaints on these latter issues is a new contribution to the literature and worthy of further investigation. However, the assessment of foot complaints, when they are carried out, appear to be mechanistic and reductionist in nature. Clinicians typically do not report fully recording and incorporating rich qualitative descriptions into clinical assessment. Where validated tools exist to aid assessment of complex phenomena such as pain, these tools are rarely used in practice. Moreover, some validated outcome measures that are routinely used in clinical practice specifically exclude the feet, which may contribute to assessment of the feet being missed from the overall examination. This leaves those with RA feeling frustrated because they perceive that their concerns are deemed to be unimportant.

Foot complaints appear to persist even with the use of modern disease modifying and biologic agents as highlighted in section 6.10 and 6.11. While high quality foot care appears to be available for the majority, with noteworthy number of those with foot symptoms did not appear to be receiving specialist foot care. Referral patterns for specialist foot care were noted to vary, which clinicians in section 7.8 and 8.7 attributed to factors such as practical difficulties with the referral process and long waiting lists. Additionally, some of the cornerstone therapeutic modalities for foot complaints in RA, such as the provision of orthoses and footwear were noted in section 6.13 to have limited concordance. Taken together, these factors can lead to a progressively deteriorating picture of foot health for people with RA, further distressing those with this disease because of the progressive nature of symptoms and the impact this can have on mobility and therefore independence. This points to an urgent need for clinicians need to work more closely with those with RA to develop a comprehensive patient-centred approach to the assessment and management of foot complaints by all those involved in the care of people with RA.

9.15 Limitations of the current study

9.15.1 Introduction

The present study was designed using a mixed methods approach to both the development of instruments with which to generate data and within the instruments themselves. Qualitative methodological approaches were used in conjunction with reviews of the literature to develop three questionnaires to explore foot complaints in RA from the perspective of those with the disease and to collect the views of podiatrists and rheumatologists. Within the questionnaires, both structured and unstructured approaches to data generation were included. This mixed methods approach provided two distinct advantages. Firstly, new perspectives can be gained on the subject matter being studied. Secondly, the use of different methods overcame some of the shortcomings associated with a single methodological approach (Malterud 2001a). In the current study the quantitative data allowed the statistical testing of results to determine associations between data and identify clear differences in practice and experience between the three groups being studied. Qualitative data enabled the exploration of some of these differences and generation of new ideas and theories. Qualitative and quantitative methods provide different approaches to different types of data, but both can be used to explore the same phenomenon. Importantly, this combination allowed the emergence of an entirely new emphasis; namely the identification of the significance of the socially constructed reality of those with foot complaints. This had not previously been a core assumption on the part of the researcher, or identified within the literature. However, the findings of the current study do need to be considered in the light of a number of limitations.

9.15.2 Construction and content of data collection instruments

To the external observer it may seem from the final questionnaires (appendix 7) that quantitative data were paramount in the current study. However, in reality the richness of the qualitative data and the social contextualisation those data provided were such that neither paradigm was more important than the other. Indeed the philosophical discussions that underpin the findings of the current study are largely due to the manner in which differing methodological paradigms have been combined to capitalise on their respective strengths. In retrospect there may have been opportunities to develop the generation of qualitative data further. For example, people with RA were given an opportunity to provide information they felt was relevant, but it may have been possible to create a more structured approach for this section. More detail about how foot complaints affected quality of life and social activities would have been of particular interest as was the case in the podiatrist's questionnaire where information about patients' quality of life and activity limitation were actively sought. However, the importance of uncovering these data only came to light because of the unstructured nature of the qualitative information provided by participants.

Recognising that such biases may occur, the researcher has considered the interpretation of the data accordingly.

There is also a risk inherent in asking for specific information (qualitative or quantitative) because the perspective of the researcher can be afforded more importance than the information the participant actually wishes to impart. Initially it was intended that the current study would allow for some further qualitative research in the form of interviews or focus groups from each of the three groups of respondents, with the purpose of exploring some of the emergent themes. However, partly due to the practical and fiscal constraints of a PhD, but also the implicit need to ensure the subjects selected are representative of the relevant populations, this work will form part of the post-doctoral work outlined in chapter 10.

In many ways, the importance of the qualitative data and how these could be used to explore the quantitative findings challenged the ontological position of the researcher. In a recent review, Lempp and Kingsley (2007) report that the majority of research in peer-reviewed rheumatology journals is almost exclusively quantitative, save for a relatively small amount of research typically relating to quality of life. In the present study, the time and effort participants (particularly those with RA) took when completing questionnaires was entirely unexpected. For example, some respondents added long detailed letters others included photographs of their foot complaints, some admitted they were unable to write sufficiently well to complete the form and so dictated responses to family/carers. These data provided a series of rich contextual descriptions allowing visualisation of how foot complaints impacted on people's daily lives; an account that a purely quantitative survey would simply not have permitted. Additionally, some respondents also included contact details and indicated they were happy to participate in further research should the opportunity arise. These factors possibly suggest saturation has not been achieved in previous research on this topic. Therefore the researcher realises that in spite of the quality of the information provided, there is the possibility that the „full story“ has yet to be uncovered. For example, the focus of the questionnaire for those with RA was on the nature and extent of foot complaints. This could, in itself, influence some respondents into only making additional comments related to these areas and excluding other aspects regarding the impact of foot complaints on social activities, the importance of VLAs, and the need for social support that appear to be equally important to those with RA, but have remained largely unrecorded in the podiatric rheumatology literature. These topics provide a starting point for further research.

Having collected these data, in retrospect some potentially important items were omitted from the instruments used to generate information from all three groups of respondents. For those with RA some socio-economic factors, which are important indicators of outcome in

the disease (Young 2000), could have been more strongly represented. In retrospect the importance of socio-economic factors may have been underestimated. Jacobi and colleagues (2003) suggest RA patients with a low socio-economic status have particular difficulties accessing care provided by Allied Health Professionals. The types of socio-economic factors that did not form part of the questionnaire for those with RA included marital status, aspects of employment and level of educational attainment, all of which could affect response rates, concordance with treatment and prognosis.

In respect of co-morbidities, neither people with RA nor clinicians were invited to comment on the prevalence of other disorders that might affect the prevalence of foot complaints. For example, the existence of diabetes in addition to RA might influence the occurrence of foot ulceration. However, Firth and colleagues (2008) reported the prevalence of foot ulceration seen in RA was largely unchanged when diabetes was excluded. To single out diabetes when other pathologies that can be associated with RA, such as peripheral vascular disease or peripheral neuropathy that could conceivably affect the prevalence of pathologies such as foot ulceration seemed inappropriate.

9.15.3 Response rates to the questionnaires

The overall 56% response rate from those with RA, although slightly disappointing, was similar to that obtained among other similar populations using comparable methodology (Jordan et al. 2004, Walker-Bone et al. 2004). That said, a response rate exceeding 50% in a population not known to the researcher is thought to be satisfactory (Gillham 2000). A process of reminders often consisting of both telephone calls and further mailings, although recommended by a number of texts specialising in questionnaire survey design (Bourque & Fielder 1995, Magione 1995, Gillham 2000), was intentionally not utilised. Underpinning the recommendations for reminders is the somewhat positivistic philosophy that findings can only be valid (and importantly generalisable) if a certain response rate (some (Magione 1995) suggest 75% is required to inspire confidence in the data) is achieved. Within this context the concept of generalisability also merits further discussion. If the philosophy accorded by the findings of the current study that a patient-centred approach could achieve improved outcomes (as has also been suggested by some reviewers Law & Britten 1995, Lempp & Kingsley 2007) is accepted, central to this approach is the recognition that an individuals' experience of illness is unique and therefore cannot be generalised to others in the same population. This is not to say that themes and experiences cannot be common to a group of individuals, but how the particular experience affects one person will vary depending on their unique cultural, social and occupational situation. For example, in the current study, while the vast majority of people with RA who responded reported experiencing foot pain, the timing, character, location and impact on their lives varied

considerably. In this context, the term transferability (sometimes referred to as external validity) would be more appropriate, as this seeks to identify the wider range of applications (and limitations) for study findings (Malterud 2001). Against this argument is the consideration that the current study did not seek to code questionnaires, largely to maintain respondents anonymity therefore it was not possible to determine the demographic characteristics of those who did not respond.

The response rates from podiatrists and rheumatologists (50% and 36% respectively) were more disappointing. As discussed previously, on one level this could be seen to support the contention of some with RA that clinicians are not interested in foot problems. However, given that a podiatrist's role is to manage foot complaints, the idea of disinterest seems curious. Equally, the poor response rate could be due to the volume of questionnaires practitioners receive and the time they have available to complete these instruments. In addition to the epidemiological aspects of foot complaints, questionnaires enquired about how foot complaints in RA were assessed and managed by podiatrists and rheumatologists, despite reassurances regarding confidentiality and anonymity some clinicians may simply not wish to divulge such information about their professional practice. The poor response rate from clinicians, particularly rheumatologists, suggests these data should be interpreted with caution, as it is possible that only those clinicians with an interest in foot complaints completed a questionnaire, thus giving a skewed perspective of rheumatologists' practice.

9.15.4 Questionnaire validation, validity of findings, bias and Hawthorne effects

One of the biggest challenges encountered when developing the questionnaires used to generate data were issues related to validation of these instruments. The current study appears to be the first to consider foot complaints from the patient's perspective and compare these data with the views held by clinicians. Previous studies have used validated outcome measures (for example, the American Orthopaedic Foot and Ankle Society (AOFAS) scales (Matricali et al. 2006)), but many of the outcome measures available for foot and lower limb complaints in RA have been criticised by a number of authors. For example, the AOFAS scales are reported to have poor construct validity compared with established generic measures such as the SF36 (SooHoo et al. 2003) and inherently limited precision due to the small number of response intervals for each item (Guyton 2001). Other outcome measures developed for the foot have similar limitations as detailed in appendix 4. Therefore comparison of the questionnaires developed for the current study with existing measures was felt to be inappropriate. Additionally, concern has been expressed regarding the cross validation of outcome measures for the foot and lower limb either with each other and/or with earlier original instruments. This is because some of these instruments have key methodological/psychometric flaws (Saltzman et al. 1998). For example, those developed

wholly by clinicians without input from people with RA such as the Foot Health Status Questionnaire (Benett et al. 1998) being used to validate instruments designed to ascertain the views of those with the disease. More recent outcome measures, such as the Leeds Foot Impact Scale (Helliwell et al. 2005), represent considerable methodological improvement in terms of development and testing for validity, but were not available for consultation when the instruments for the current study were being developed. Furthermore, these newer instruments were not designed with the aims and objectives of the present investigation in mind and may not have captured the information obtained by the current study.

The development process for questionnaires used in the present study, described in chapter five together with the broader issues of validity and trustworthiness (outlined in tables 5.3 and 5.4), represented a rigorous approach to the criticisms of previous instruments described in section 3.8, 4.5 and appendix 4. In addition to validating the instruments used to generate data, self-report data is not perfect, with Wolfe and Pincus (1999) questioning whether information given by those with the disease is true or accurate. To some extent this depends on the perspective of those asking the question and the location of the sampling. For instance, clinic-based samples might over-estimate the prevalence of a particular pathology because patients with the very conditions of interest are attending the clinic for treatment. Similarly, community or population based samples might under-estimate the prevalence of a particular pathology depending on the definitions used. During Firth and colleagues (2008) work on the prevalence of foot ulceration in RA a false positive (that is, no foot ulcer when one was reported) rate of 10.76% was noted and a false negative (that is, a foot ulcer existing but not reported) rate of 11.76% was reported. Clearly this may affect the validity of the prevalence of self-reported foot complaints such as bunions or foot ulceration in the current study. However, the purpose of the current study was to determine the nature and extent of foot complaints from those who experienced these and those responsible for their management, in this context both perspectives are equally valid.

A series of additional factors may also have a bearing on how accurate prevalence estimates can be. March and colleagues (1998) using a questionnaire-based survey in Northern Sydney, Australia found almost all self-reported diagnoses of osteoarthritis were confirmed on subsequent clinical examination. In contrast, Kleinman and colleagues (1996) undertaking a survey of the homeless in Los Angeles County, found superficial skin complaints were likely to be under-reported using questionnaires alone. Of course these two studies used very different populations in terms of the socio-demography, but this only serves to highlight how important other factors such as the level of education, perceived importance of the complaint being investigated, and prevalence among peers are in

determining the sensitivity and specificity of self-report instruments. As discussed in sections 3.6, 4.2 and 9.3, differences in perception between patients and clinicians have been widely reported, and the current study, in comparison with the literature, demonstrates that such discrepancies can equally apply to foot complaints. From a strict epidemiological perspective a combination of self-report and physical examination affords the best estimates of prevalence (Kleinman et al. 1996). However, one of the most important aspects of the current study was to determine whether what clinicians perceive to be important differs from what people with RA consider to be significant as it is on the basis of recall and interpretation that they base the management of their patients condition. Recognition of the differences in opinion that occur between people with RA and clinicians highlighted by the current study when developing clinical practice (for example using alternative outcome measures) will facilitate a more patient-centred approach which is important as part of the overall enhancement of care.

Questionnaire-based surveys can be prone to different elements of bias and in the current study many of the questions relied on recall of clinical information. For example, the order of involvement of particular joint groups might have an inherent risk of recall bias. Recall bias is defined as a “systematic error due to differences in accuracy or completeness of past events or experiences” (Last 1995). It is possible that some recall bias may have occurred, but there is no reason to believe that this would lead to patients over-estimating foot involvement, as compared with that of any other anatomical site. Recall bias may however be a more complex phenomenon. Affleck and colleagues (1992) and Ruggieri (2003) point out that recollection of previous painful episodes can be distorted by pain and situational factors at the time of completing the questionnaire, cognitive status, and experience, which may partly explain the very high numbers of people who reported foot pain. Others (Strating et al. 2006) have noted that pain often occurs when undertaking activity (for example, during walking, as was reported in the current study); therefore the actual perception of pain is not always measured, rather the combination of pain and activity, which might more properly be considered to be disability. Furthermore, the relative importance of symptoms may change with time. Carr and colleagues (2003) report that pain may be more important early in the disease whereas mobility and independence are more imperative later. Future work, however, (particularly prospective studies), may be able to make more use of technology, for example the use of electronic pain diaries has been shown to be valid, in addition to improving response rates and easing data transfer (Jamison et al. 2001), although there is clearly a greater inherent cost as well as potential for error due to hardware or software malfunction.

A further limitation associated with self-reported questionnaires may be reflected in bias of the interpretational processes of respondents. For example, a tendency to over-emphasise physical symptoms due to pain-related patterns due to heightened somato-sensory responses such as fear or catastrophizing (Evers et al. 2001). Several authors have reported that catastrophizing (expecting or worrying about adverse outcomes from a given situation) leads to increased pain as well as physical and psychosocial dysfunction (Turner et al. 2000, Ciechanowski et al. 2003, Vowles et al. 2007). In the current study attempts were made to control for some of these issues, in terms of separating items enquiring about current pain from previous pain experience. The present study sought to generate as large a data set as economically and feasibly possible was important to reduce as many of these elements of uncertainty as possible and to make estimates more stable.

Another type of bias that may account for some of the findings in the current study is response bias: that is, those RA patients with existing foot pain were more likely to respond to this survey (Last 1995). Against this assumption is that 119 (20.3%) of those with RA who completed the questionnaire reported they did not currently have foot pain. Furthermore, a number of respondents (n=59, 14.8%) who reported experiencing only mild foot pain (defined as less than 2 on a visual analogue scale) also opted to complete the questionnaire. Additionally, the effect of non-response bias was explored by assuming that all non-respondents were never affected by foot pathology. Even allowing for this, minimum estimates from the present study suggest that 56% of RA sufferers would experience foot pain at some time during their disease and 54% of RA patients would currently suffer with foot pain. Given that absence of foot pain did not appear to be the sole reason for not responding, it is likely figures for foot pain would be higher. While this does not completely discount the possibility of response bias occurring, there was no reason to suggest this was a major factor.

The possibility of a Hawthorne effect being present (that is, being part of the current study may have affected the behaviour and reporting characteristics of those in the sample (Last 1995)) was also considered. While the implications of such an effect may be related to some of the issues discussed in relation to recall bias, a greater concern was that the questionnaire was primarily concerned with foot complaints. It was felt that enquiring exclusively about foot complaints could influence respondents (whether people with RA or clinicians), risking a strong Hawthorne effect being exerted. Therefore questionnaires were carefully designed to include information related to other anatomical areas such as frequency of hand examination and order of joint involvement. This provided useful comparative information at the same time as removing focus from foot complaints alone.

9.15.6 Analysis and presentation of data

One of the difficulties associated with single investigator research is the risk of inherent personal bias. Some authors contend this is unavoidable, that researchers cannot divorce themselves from the cultural, social and political context of their work; indeed this contextualisation may make the work more meaningful (Bowling 2002, Kock 1996). The nature of Doctoral study potentially increases the risk of bias as data are analysed and themes derived by one person and while supervision aids methodological rigour, it may not always provide multiple perspectives (Fereday & Muir-Cochrane 2006). Mindful of these potential pitfalls the current study utilised techniques based on the work of Bryman (1988) and Coyle and Williams (2000). Firstly, to highlight the perspective of participants, direct quotations were included. As highlighted in section 5.7.3, the use of direct quotations is seen as strengthening the presentation of findings, particularly if several respondents have the same opinion. However, this leads to the criticism that including only fragments of the qualitative data to support a particular argument can be seen as reducing research to little more than journalism (Bryman 1988). Simply counting the number of respondents who made similar responses is an option, but doing so could be seen as forcing a positivistic approach to interpretive analysis (Johnson 1999). The epistemological and methodological basis for the current study was to utilise a mixed methods approach, thus maximising the advantages for the combination of methods used. In this context, the counting of similar responses was considered acceptable (indeed helpful) as it demonstrated the transferability of the observations being made (Silverman 2001). Furthermore, the inclusion of a critical, reflexive account as part of the discussion identifying constraints and highlighting how these were overcome as part of the presentation of findings strengthens confidence in the overall contribution to knowledge made by the current study.

Chapter 10

Conclusions, contributions to knowledge and practice, recommendations for further research.

10.1 Conclusions

The current study, by exploring the perceptions of those with RA, has demonstrated that foot complaints are an almost universal part of RA, often impacting on every facet of the daily lives for those with the disease. Symptoms in the feet in RA such as pain, stiffness and swelling are common, severe and often unremitting. Symptoms were reported to be more severe by those who were older or female. Taken together therefore, female gender, advancing age and stiffness, swelling or numbness presenting with increasing foot pain suggest worsening foot health in RA. It should be noted however, that further prognostic studies are needed in order to determine whether these factors can be considered as early markers for a poorer prognosis in respect of foot health in RA. In terms of the anatomical location of symptoms the involvement of the ankle and metatarsophalangeal joints was consistently the most frequent and troublesome. This finding has important implications, as these joints are vital for normal propulsive gait, disruption of these may lead to reduced mobility and loss of independence.

Yet, in spite of the almost universal acknowledgement of symptoms in the feet, the experience of foot complaints and their treatment for those with rheumatoid arthritis can overall be one of disjointedness, an incoherence that is multi-factorial in its origin. Therefore those people with RA who have a need for foot care (and sometimes those responsible for their care) become frustrated with long waiting lists while foot health deteriorates with deleterious effects on mobility, social inclusion and psychosocial health. This lack of coherence is further compounded by a tendency for clinical services to concentrate on managing other aspects of the overall complaint of RA, thus under-reporting foot complaints and in so doing exacerbating the perceptions that on occasions clinicians seem disinterested in foot problems. It is clear that prompt referral for foot care and potentially investment in a mechanism for annual review for foot complaints and impact on patients lives would be beneficial for those with RA, and may also provide greater job satisfaction for clinicians.

The current study has formulated more valid explanations of the phenomenon of foot complaints than previously identified by combining quantitative survey methods with qualitative investigations. A key finding of the present study is that practitioners must attach greater importance to patients' reports and theories, and should introduce a range of data capture methods that permit foot complaints to be included. This is in direct contrast to current practice where some of the predominantly quantitative indices, such as the DAS 28, that expressly exclude the feet, and are also weighted towards constructs (such as tender

joints) that may be affected by a number of inter-related psychological factors (such as anxiety or depression) that are rarely formally assessed.

The meanings people with RA attach to their foot complaints are characteristically socially constructed, in contrast to clinicians who operate from a more medically driven model. For example, it is not simply the level of pain or stiffness in the feet (though this is undoubtedly an important factor) that is key; it is the impact such symptoms have on individuals' ability to participate meaningfully in interpersonal relationships and society in general that has such a devastating affect. In particular, the loss of valued life activities due to the range and severity of foot complaints can rapidly have a marked and lasting negative impact on psychological and sociological health, which consequently can affect overall physical well-being. Typically, the methods of assessing and measuring outcome used by those who most commonly manage foot complaints in RA do not appear to take full account of the domains of importance to those with the disease. The limitations in assessment and management highlighted by the current study point to the need for a more patient-centred approach, where a biopsychosocial approach to foot complaints that includes quality of life, limitation on social interaction, the impact of social isolation and the need for social support could then be used to develop a more extensive range of interventions to complement current therapeutic strategies.

10.2 Contribution of the current study to knowledge

Based on the literature searches carried out in the course of the current study, this work appears to be the largest survey of foot complaints in RA from both patients' and clinicians' perspective undertaken in the UK, and the second largest worldwide. In an era where the understanding of RA has been dramatically enhanced, the current study is the first to quantify and explain the extent, nature and anatomical location of foot complaints. The data analysis produced an array of new information that pertained to both people with RA and clinicians and has potential for impact on practice. In particular, the current study has demonstrated foot pain is almost universally prevalent among those with RA, the extent of which is striking particularly in the light of modern disease modifying medication and the development of new biologic therapies. Other self-reported symptoms in the feet such as swelling, stiffness and numbness were also more prevalent than has previously been noted. More importantly however, those with RA are more concerned about the nature of the symptoms they experience and the impact this has on activities of importance to them than the presence of foot deformities *per se*. These findings are in contrast to clinicians, who in previous research identified in section 3.2, and the findings of the current study tend to concentrate on the physical signs of RA in the feet.

The nature of the experience of foot pain is a multi-faceted phenomenon for many with RA and the impact of foot complaints clearly extends far beyond the feet. People with RA find their mobility is considerably impaired because of their feet, in particular the predilection for symptoms to affect the ankle and forefoot, joints that are vital for normal propulsive gait, thereby marring their ability to undertake obligatory activities of daily living. However, and perhaps more importantly, discretionary activities (or valued life activities) are considerably impaired such that people with RA often find they are unable to participate in social activities that are important to them, resulting in disengagement and social isolation. This, coupled with the unremitting nature of foot complaints has for many a negative psychosocial impact with feelings such as anger, frustration and depression being expressed. This work is one of the first to elucidate the nature of physical symptoms in the feet resulting in negative emotionality and the interrelations between the two.

Regrettably the assessment of foot complaints by podiatrists and rheumatologists is all too often limited to measures of the intensity of pain experienced or the presence of foot deformity. In particular, outcome measures frequently used by rheumatologists that do not include the feet may discourage foot examination. Indeed for some with RA, their foot complaints appeared to be rarely considered as part of the overall management of the disease. In particular the formal consideration of the broader characteristics of the sensory aspects of foot pain and the maladaptive effects on social and occupational roles would seem to be warranted. The current study is one of the first to gather evidence to support the view that existing foot assessments may not entirely capture the inherent variability of symptoms in RA, or more importantly, the impact these symptoms have on the lives of people with the disease, highlighting the need for a more patient-centered approach to assessment and management. There is limited or no previous research into foot complaints in RA that addresses issues associated with valued life activities, yet Katz and colleagues (2004) have suggested the assessment of valued life activities may be simpler for clinicians than other standardised measures.

Finally, the current study has also demonstrated that the referral of people with foot complaints due to RA for specialist foot care is fraught with difficulty for both patients and clinicians and is a cause of considerable frustration for both parties. Rheumatologists and podiatrists need to work more closely together to develop a comprehensive foot care service to address the needs of people with RA.

10.3 Implications of findings of the current study for practice

The current study has produced an array of new information that pertained to both people with RA and clinicians, and a series of recommendations for practice can be derived. Firstly,

the current study has demonstrated that foot pain is almost universally prevalent among those with RA and the nature of this experience for many people with the disease is a multi-faceted phenomenon. However, assessment of foot complaints in RA is often limited to measures of the intensity of pain experienced. The current study highlights the need for formal consideration of the broader characteristics of the sensory aspects of foot pain and the maladaptive effects on social and occupational roles. In particular, rheumatologists should use outcome measures that include foot assessment. Podiatrists need to find ways of including assessments of quality of life and valued life activities, as these are currently under-represented in practice. A greater understanding of how patients are affected by RA might aid management by identifying how effective individual treatments are, improve current understanding of prognosis and enhance communication between patients and clinicians because a more patient-centred approach is implemented. For example, the use of outcomes determined to be important by those with RA highlighted in the current study would provide an enhanced understanding of patients' perspectives, and adapting interventions accordingly would improve the patient-centeredness of foot care services. This in turn could provide a further opportunity to supply evidence highlighting the positive impact of care delivered by Allied Health Professionals, such as podiatrists, in improving foot health as well as their contribution to aspects of overall health such as quality of life.

Key to implementing this broader assessment framework would be an enhanced understanding of clinicians' practice at the point of qualifying. It may be possible that newly qualified podiatry practitioners have a broader agenda owing to changes to the curriculum that highlight the value of engaging in reflective practice (Health Professions Council 2007). As noted previously, formal engagement in the process of reflection has not traditionally been part of podiatric practice therefore opportunities exist to further disseminate findings of the current study in the context of workshops on reflective practice as part of continuing professional development or seminars for podiatry educators. The researcher, being part of a Podiatry department within a Higher Education Institution is well placed to influence the curriculum for both under-graduate and post-graduate podiatry students in terms of broadening the approaches to assessment and monitoring of foot complaints in musculo-skeletal complaints. There are also opportunities to influence practice further by facilitating students to carry out further research. The researcher noted a number of advantages that the utilisation of a mixed methods approach in the current study provided. Previous research in podiatry is largely dominated by the quantitative paradigm therefore the researcher advocates the wider used of mixed methods approaches. It should also be noted that the lack of convergence between those with RA and clinicians reported in the present study could be transferable to other professions grounded in the medical model. Therefore the opportunities for dissemination are applicable to the multidisciplinary context. This is

particularly important in light of the number of professionals to whom rheumatologists report that they refer people with RA for management of foot complaints.

In respect of the management of foot complaints, the findings of the current study identified that footwear and orthoses are commonly prescribed interventions that involve considerable cost, yet for a variety of reasons are not being fully utilised. Advice to practitioners prescribing devices dealing with the importance of functional aspects of the foot in RA (such as sagittal plane motion), and in the consideration of acceptable cosmesis, is key to improving uptake of these devices. Furthermore, greater education for patients is also required regarding follow-up appointments and where to seek advice should problems arise.

Finally, the sharing of information relating to assessment findings and management interventions between different professions and agencies remains an issue. Opportunities to enhance information sharing should be sought; as has been the case in other specialities such as diabetes and child health, where patient-held records are considered the norm. In rheumatology, even simple information such as recent measures of inflammation (for example, ESR or CRP) or scores for joint swelling and tenderness would be relatively easy to record in a patient-held format, which would begin to enhance cross-disciplinary communication. The current study argues for a more patient-centred approach and patient held records would fit within this model. Moreover, once this process starts, people with RA could have diary-based sections to record outcomes of importance over the period of time between visits to clinicians. As noted previously it may be possible, either now or in the future, to make such entries electronically with the developments in hand held palm-top technology.

10.4 Dissemination of information and recommendations for further research

The most urgent undertaking following completion of this Doctorate is to disseminate the findings of the current study. To some extent this has been an on-going theme throughout the duration of the PhD with opportunities to present findings at professional meetings. Work focussing on both the methodological aspects together with the novel findings of the current study have either been published or are in preparation (appendix 12.1). Additionally, to date, a number of presentations have been accepted for national and international conferences (appendix 12.2). Presentations for the purpose of continuing professional development based on the findings of the current study have also been provided for rheumatologists at the local University Hospital Trust and podiatrists from the local Primary Care Trust, with other similar opportunities planned.

The current study considered the nature and extent of foot complaints in RA from the perspective of those with the disease and contrasted this with the opinion of podiatrists and rheumatologists. Current Government policy suggests that increasingly those with rheumatic complaints such as RA will receive most of their care in the Primary Care setting (Dept of Health 2005, 2006a). In particular an extended role for nurse practitioners has been highlighted (Mounce et al. 2001, Sigsworth 2004) especially in respect of monitoring on-going DMARD and biologic therapy. However, guidance documents for biologic therapies for nurses (Oliver 2003) do not mention the importance of screening for foot complaints (although leg ulceration is noted). As described in section 2.6, the need for biologic therapy is predicated on a high DAS 28 score, yet as discussed at length in section 9.6 this approach precludes the feet. It is possible therefore that foot complaints are overlooked in this context and presently collaboration with colleagues at the University of Leeds has led to an on-going project, proposed to British Society of Rheumatology biologics register, where the prevalence of foot lesions in people taking biologic drugs can be reported on a national basis to determine whether a trend truly does exist and to implement suitable recommendations for practice.

The design of the current study was novel in that the opinions of both people with RA and clinicians were included when exploring the nature and extent of foot complaints. Indeed Jacobi and colleagues (2004) highlight the value of gathering the perspective of practitioners when undertaking research into the nature of the need for care. As described in section 5.3, to keep the project within manageable parameters only podiatrists and rheumatologists were included as it was felt these professionals were most likely to be involved with the management of foot complaints in RA. Equally, as reported in section 3.8, it is widely acknowledged that care of the person with RA requires a range of specialists ideally working within a co-ordinated multi-disciplinary team; although recent research suggests such practice does not occur with clear uniformity across the UK (NRAS 2006). However, the expanding remit of a number of professionals within the multi-disciplinary care team (such as rheumatology specialist nurses, extended scope practitioners, consultant therapists and general practitioners with special interest in rheumatology (Dept of Health 2000b, 2006a, Mounce et al. 2001)) means there are a number of opportunities to generate data from these groups. This would lead to a more complete picture of the phenomenon of foot complaints in RA, and how they are managed, than can be provided solely by the current study.

An additional novel and unexpected finding of the current study was the negative impact foot complaints appear to be having on the ability of those with RA to actively participate in social events, leading to social isolation. Further qualitative research into the maladaptive effects of foot complaints in RA on both social and occupational activities would be valuable, as the

findings of the current study do suggest the impact of foot complaints appears to be more wide-ranging than previously thought. A more in-depth understanding of the impact of social isolation and the need for social support because of foot complaints could provide insights into a more extensive range of interventions to complement current therapeutic strategies. Realistically such work would represent a major study and in all probability may be more appropriate as part of new Doctoral work, although smaller-scale examples of the type of therapeutic approaches that might be considered have been suggested by Kahn and colleagues (2005) and Church and colleagues (2008), who demonstrated reflexology to be of value in managing foot pain and fatigue in RA.

The findings of the present study highlighted the limited role that outcome measures appear to currently have in clinical practice. Yet a number of foot specific instruments (for example, the Leeds Foot Impact Scale) do exist, as well as more generic instruments that are specific to RA (for example, the RA QoL). Currently these do not appear to be widely used in clinical practice. Furthermore, findings of the current study indicated that podiatrists wished to make more use of „objective“ outcome measures. Putting the debate regarding the relevance of objective measures versus subjective enquiry aside, there appears to be a need to determine why existing measures are not currently used. Of course it is possible to speculate that issues such as time constraints might be one difficulty, but many existing instruments are self-administered, therefore could be completed prior to the consultation. Either existing instruments are not widely understood, in which case there are opportunities to influence undergraduate and postgraduate education, or such instruments are not perceived to be a valuable way of informing clinical practice. If the latter is true, this would be a rich area for future research into the understanding of foot complaints in RA and into the clinical reasoning processes involved in deriving management plans. To some extent this work has already been undertaken with regard to foot orthoses (Clarke et al. 2006, Magalhães et al. 2006, Bellamy 2007), but this is only one aspect of the overall management of foot complaints in RA. The findings of the current study, in respect of issues such as quality of life and limitations of social interaction, indicate that future research needs to be broader in its remit. Linked to outcome measures is the area of valued life activities (VLA). Identifying which VLAs are most affected by foot complaints could lead to a novel, more patient-centred, method of assessing the impact of foot complaints in RA, which encompasses broader considerations than the limitations of the biomedical model that determines much of the current education for Allied Health Professionals and Medical Practitioners alike.

Finally, the researcher has also been a member of the steering group that has developed Standards of Care for Musculoskeletal Foot Health Complaints with the support of the

Podiatric Rheumatic Care Association and the Arthritis Research Campaign. Previously Redmond and colleagues (2006) reported that the absence of nationally agreed standards for podiatric services together with limited awareness of local standards or referral guidelines for podiatric care may be detrimental for those with RA. These new standards (PRCA 2008) were developed in response to such criticism and were a collaborative venture with representatives from a series of stakeholders, findings of the current study were used to inform this project. The standards project will contribute to improved health for people with arthritis and musculoskeletal conditions through a coordinated national initiative to set clear standards of expectation for foot health services complementing rheumatology care, and providing a useful lobbying tool for service users, providers, and commissioners to establish locally agreed models of care and levels of expectation.

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Challenging current perceptions:
An exploration of the nature and extent of foot
complaints in rheumatoid arthritis

Simon James Otter

A thesis submitted in partial fulfilment of the requirements of
the University of Brighton for the degree of Doctor of
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Volume II - Appendices

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Appendix 1 The aetio-pathogenesis of Rheumatoid Arthritis (RA)

1.1 The aetiology of RA

The precise initiating cause of RA remains unknown (Maini 2003). It is thought that environmental triggers (possibly a viral infective agent), together with genetic susceptibility activate an auto immune reaction (Golding 1981, Le Gallez 1994, Taylor et al. 1995). Ollier et al. (2001) report the evidence for this process is based on:

- The infiltration of the synovial membrane with immunocompetent cells.
- Strong association with Human Leukocyte (HLA) alleles.
- The development of auto-antibodies in some patients.
- The destruction of joints.
- A beneficial response with immunosuppressive therapy.

There remain two opposing views in the exploration of the aetiology of RA. The first proposes that RA is a T-lymphocyte cell driven disease where a particular HLA molecule recognises a joint-derived self-antigen and activates pathological reactions; the second suggests RA is a chronic inflammatory condition driven by uncontrolled cytokine production and regulation (Ollier et al. 2001, Maini 2003).

In terms of possible environmental triggers, there has been a great deal of speculation regarding viral infections of joints as these can produce a self-limiting arthritis as sometimes seen in rubella or Epstein-Barr virus (Corrigall & Panayi 2002, Williams & Fye 2003). Although immunological evidence suggests an infectious trigger, this has not been supported by epidemiological data (Buckley 1997, Isaacs & Moreland 2002, MacGregor & Spector 2003). Furthermore, attempts to isolate viruses from chronically arthritic joints have been largely ineffective (Denman 1987). There are a number of other possible environmental aetiological candidates and these are thought to account for as much as 70% of the susceptibility to RA (Moots & Jones 2004). Cigarette smoking has consistently found to be a risk factor for developing inflammatory polyarthritis (Voigt et al. 1994, Symmons et al. 1997, Hutchinson et al. 2001, Klareskog et al. 2006a, Klareskog et al. 2006b) in addition to being a marker for more severe expression of the disease (Padadopoulos et al. 2005, Manfredsdottir et al. 2006). Dietary factors have also received attention, for example Pattison and colleagues (2004a) reported that a lower level of fruit intake (especially a lower level of vitamin C intake) was associated with at

least a three-fold increase in the risk of inflammatory polyarthritis. In addition, a high level of red meat consumption may also represent a risk factor (Pattison et al. 2004b). Interest also surrounds psychological stress. In a recent review Straub and colleagues (2004) concluded sustained major stress (e.g. caring for a dependent relative) might be a disease permissive factor, or an aggravating factor in established disease leading to an increase in disease activity and exacerbation of bony erosions. Maini (2003) also reported claims of increased risk have also been reported in people exposed to occupational environmental hazards including silica dust, organic solvents and mineral oils. Finally, RA appears to be more common in areas of socio-economic deprivation (Moots & Jones 2004), while a number of factors described so far (e.g. smoking, diet and possibly stress) may fit with this prediction, controlling for these factors leaves a proportion where the underlying reasons for this increase are not fully understood.

Considering RA is more common in women than men, and that exposure to the contraceptive pill appears to confer a level of protection from initiation of the disease, and that pregnancy is associated with suppression of RA (Vandenbroucke et al. 1982, Maini 2003), it has been suggested that androgenic hormones have an influence on pathogenesis (Isaacs & Moreland 2002). In a review by Yaron (1995) oestrogens were reported to possess both immunostimulatory (e.g. enhance B cell maturation & increase CD4+ T cells) and immunosuppressive properties (e.g. decrease T-cell and NK cell responses). Progesterone appears to suppress the immune system by down regulating T-cell proliferation and increasing the number of CD8+ T-cells. Models of how hormones relate to the aetiology and pathogenesis of RA as well as opportunities for therapy continue to be explored.

In addition to issues surrounding the significance of gender, RA does appear be familial in nature, suggesting a genetic susceptibility. According to Silman (2002) the size of a genetic effect is generally estimated from the familial risk of recurrence (defined as the increased risk of first-degree relatives of affected individuals compared with the general population). However, RA does not demonstrate a simple Mendelian-type inheritance pattern. Studies of identical twins have shown the disease occurs in both siblings in up to 30% of cases (Silman et al. 1993) and the overall genetic susceptibility is thought to be in the region of up to 60% (Macgregor et al. 2000, Symmons 2002). However, figures vary widely between reports implying not only a substantial environmental contribution,

but also highlighting the difficulties inherent in carrying out this type of research with sufficient power to yield meaningful results (MacGregor et al. 2002). Some of the detail relating to how genetic susceptibility is conferred has been elucidated by Nepom and colleagues (1989) who reported some people with RA express either HLA-DR4 or HLA-DR1 products of the class II major histocompatibility (MHC) gene complex coded for on chromosome six. Detailed studies of the structure of the class II MHC structure revealed similarities in molecular structure leading to the hypothesis of a ‘shared epitope’ (Gregersen et al. 1987). This shared genetic sequence has subsequently been detected in up to 90% of people with RA in Western Europe and lends support to the T-cell model of pathogenesis (Maini 2003). Evidence for the links between HLA and the T-cell hypothesis is illustrated in more depth in table A1.1. Nepom and Nepom (2004) stress that these genetic contributions are insufficient to cause disease expression by themselves, although it is now thought that HLA genes may confer up to 50% of the genetic component of the disease (Maini 2003). Current thinking suggests alleles for the shared RA epitope are more likely to be markers for more severe and/or persistent disease (Nepom and Nepom 2004). The identification of genes responsible for susceptibility as opposed to those that may code for disease persistence or severity remains a rich area for research (Isaacs & Moreland 2002, Symmons 2002).

Table A1.1 – The potential role of HLA DR in rheumatoid arthritis

Adapted from Firestein (2003), Ollier (2003)

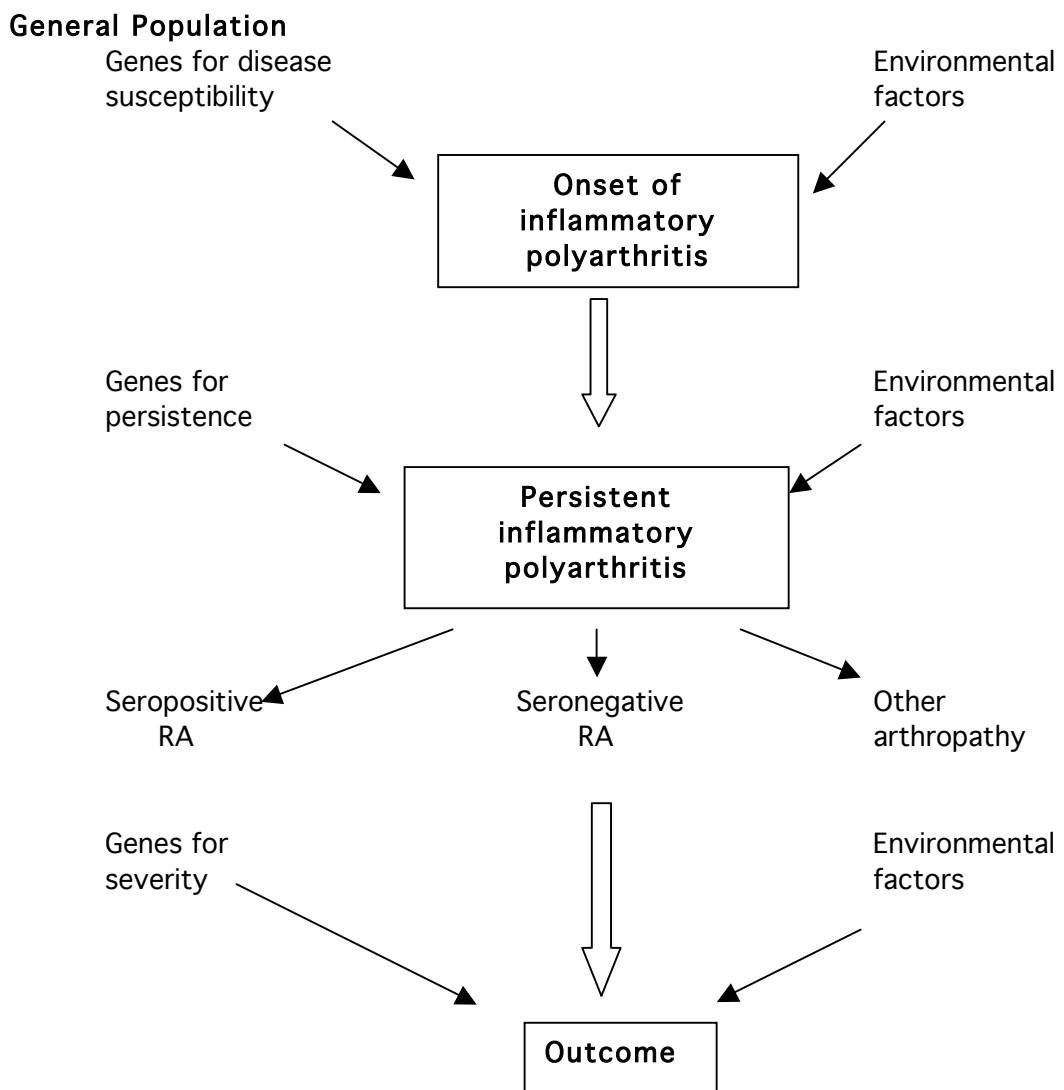
Influences and models the T-cell repertoire for individuals
Binds arthritogenic peptides and presents them to CD4 (helper) T-cells
Leads to enhanced T-cell activity owing to links between T-cell receptors and MHC genes
Disease associated HLA alleles may antigenically cross-react with pathogens leading to a breakdown in self tolerance
HLA molecules act as immune response genes for specific autoantigens

The interplay between genetic and environmental factors provides for a complex model of the evolution of RA (figure A1.1) and indicates that there are probably numerous genetic

and environmental factors at work. These factors are responsible not only for disease initiation and perpetuation, but also for disease type and severity.

Figure A1.1 - Stages in the evolution of inflammatory arthritis

Adapted from Huizinga and colleagues (2002) and Dixon and Symmons (2004)



1.2 The Immunopathogenesis of RA

In the normal non-pathological joint (illustrated in figure A1.2), the healthy synovium (the intima) consists of a film one or two cell layers thick of synoviocytes comprising type A (bone marrow derived) and type B (mesenchyme derived) cells lying on a bed of loose connective tissue (the sub intima) comprising connective tissue and blood vessels (Maini

2003, Goronzy & Weyand 2001). Based on attempts to fuse the two main aetiological models of RA identified previously, Ollier and colleagues (2001) have proposed that the pathogenesis of RA has three main phases:

- An early initiation where there is infiltration of the synovium with dendritic cells, macrophages T, B and NK cells.
- An amplification phase in which HLA genotypes have an important role in driving disease progression.
- A phase of chronic inflammation where unregulated cytokine production provokes pannus formation and the release of tissue destroying enzymes.

The effects of these pathological processes in terms of joint destruction are also illustrated in figure A1.2.

Figure A1.2 – Schematic diagram of the pathological changes seen in RA

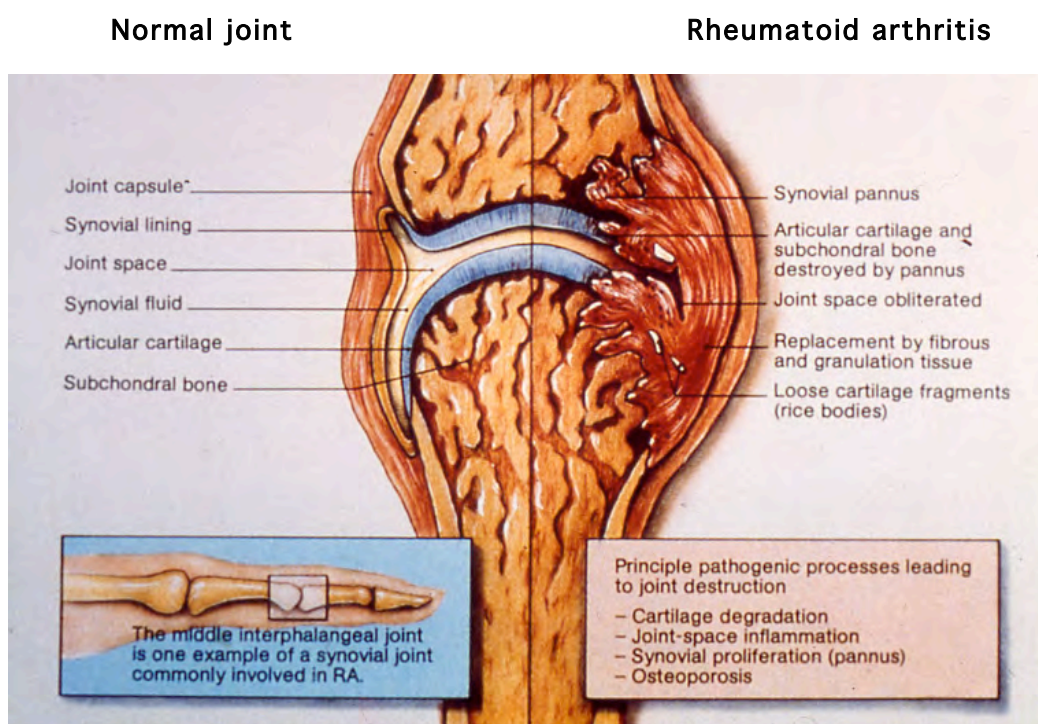


Image courtesy of Novartis Pharmaceuticals (1995)

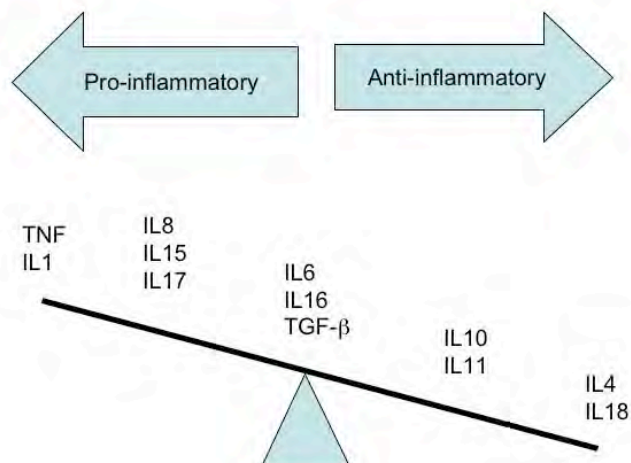
The start of the pathological process appears to commence with hyperplasia of the synovium and cellular infiltration with macrophages and lymphocytes (Maini 2003, Goronzy & Weyand 2001, Porth 2004). The sub intima also undergoes a process of

hyperplasia, lymphocyte infiltration and angiogenesis (Maini 2003 Goronzy & Weyand 2001). The cellular infiltrate bathing the thickened synovium is rich in CD4+ and CD8+ T-lymphocytes as well as macrophages and polymorphonuclear cells (Maini 2003).

Once in the joint, large populations of T-lymphocytes in conjunction with antigen presenting cells (such as macrophages) become sensitised and the secretion of cytokine molecules (notably tumour necrosis factor alpha ($TNF\alpha$), interleukin one (IL1) and Interleukin 17 (IL17)) begins (Coico et al. 2003 van den Berg 2008). This acute inflammatory phase is perpetuated by further cytokine release from synovial lining cells. Cytokines are protein messenger molecules that stimulate (or inhibit) the differentiation, proliferation or function of immune cells via specific receptors on the cell surface (Roitt 1994, Coico et al. 2003). Pro and anti-inflammatory cytokines are normally held in equilibrium, however in RA there is a preponderance of pro-inflammatory molecules. In many ways $TNF\alpha$ can be seen at the top of a hierarchy of pro-inflammatory cytokine molecules acting in a cascade manner as illustrated in figure A1.3.

Figure A1.3 - Hierarchy of cytokine molecules

(adapted from Goronzy & Weyand 2001)



The importance of cytokine molecules has been emphasised by the success of new anti $TNF\alpha$ therapies (Panayi et al. 2001, McInnes & Liew 2005), discussed in the next section. Cytokine molecules such as $TNF\alpha$ have a variety of functions in the pathogenesis of RA as

illustrated in figure A1.4. These functions include the chemotactic attraction of neutrophils and macrophages and continuing proliferation of B and T-lymphocytes, in addition synovial proliferation and capillary angiogenesis continues (Buckley 1997, Arend 2001).

Figure A1.4 - The role of $TNF\alpha$ in RA

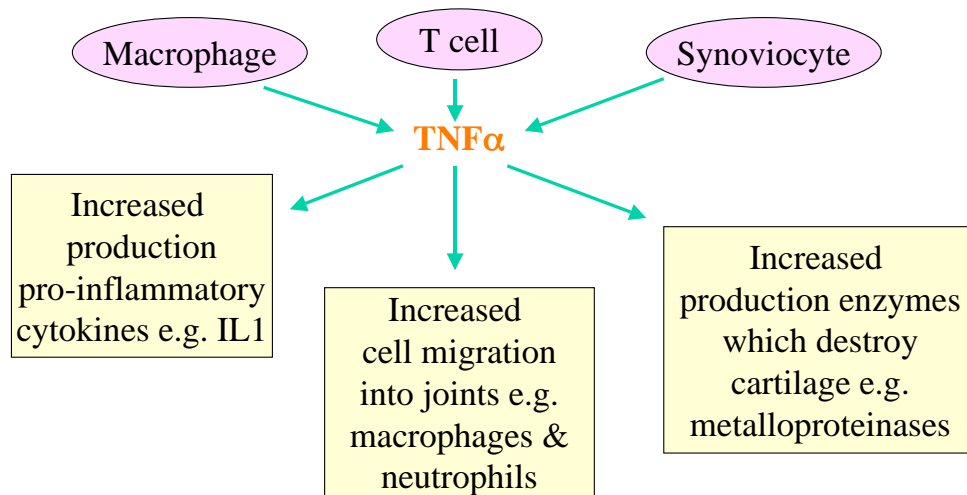


Diagram courtesy Weyth Pharmaceuticals

Scavenger cells (e.g. macrophages) engulf cellular remnants in an attempt to repair the tissue damage and as part of this process these cells secrete cytokine molecules further stimulating T-lymphocytes and other cells within the immune system such as fibroblasts (Arend 2001, Wong & Lord 2002). There is evidence to suggest that in this phase of the disease the role of T-cells is to orchestrate inflammatory pathways and subsequent tissue damage (Panayi et al. 2001, van den Berg 2008). The chronic inflammatory environment in which T-cells operate is thought to influence their function (Panayi et al. 2001). The continued unraveling of these complex interactions may yet offer further therapeutic opportunities (McInnes 2003).

The hypertrophic vascular synovial membrane (termed 'pannus') grows across the articular surface (Revell 1992, Maini 2003). Destruction of articular cartilage is primarily the result of the action of connective tissue proteinases released by synovial tissues, chondrocytes and pannus (Gravallese 2002). The mechanisms by which tissue destruction occurs in RA is summarised in table A1.2.

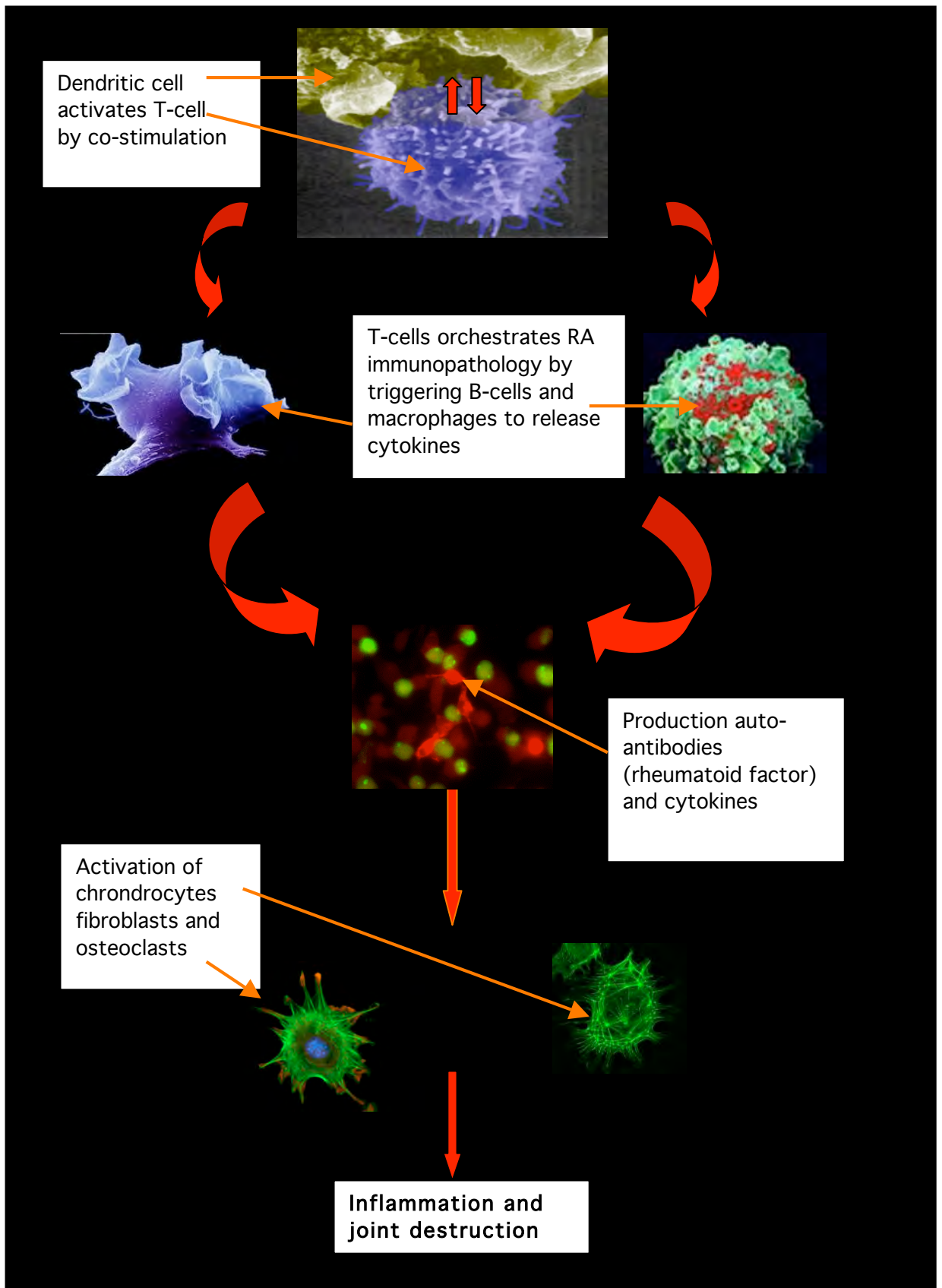
Table A1.2 - Mechanisms of joint destruction in RA.

(Goronzy & Weyand 2001, Murphy & Lee 2005, Murphy & Nagase 2008)

Mechanism	Effector molecules	Cellular origin
Differentiation of synovial macrophages into osteoclasts	Osteoclast differentiating factor	T-cells, synovial fibroblasts
Osteoclast differentiation and activation	IL-1, TNF- α , IL-6, IL-11, IL-17	T-cells, synovial macrophages
Decreased proteoglycan production by chondrocytes	IL-1, TNF- α	synovial macrophages
Degradation of collagen, proteoglycans, laminin, fibronectin and elastin	Matrix metalloproteinases (MMPs)	synovial macrophages and fibroblasts, chondrocytes
Degradation of collagen & proteoglycans	Disintegrin metalloproteinase	synovial macrophages and fibroblasts
Degradation of collagen, proteoglycans, fibronectin and elastin	Cathepsins L and B	synovial macrophages and fibroblasts
Degradation of type II collagen	Cathepsin K, tartrate-resistant acid phosphatase	Osteoclasts

In addition to the role of T-cells in driving the inflammatory processes in RA, there is renewed interest in the function of B-lymphocytes. B-cells have a role in antigen presentation and co-stimulatory signals for T-cells and so are critical for T-cell activation (Panayi 2005). The pro-inflammatory secretions of these activated T-cells (interferon gamma (INF γ) in particular) enable B-cells to undergo a process of growth and differentiation (Edwards 2002, Panayi 2005). Differentiated B-cells (known as plasma cells) secrete auto-antibodies (e.g. IgM). Immune complexes formed by IgG and IgM molecules are phagocytosed by neutrophils, which secrete more proteolytic enzymes further destroying articular cartilage (Roitt 1994, Maini 2003). This subsequent loss of cartilage leads to a narrowing of the joint space (Revel 1992). A summary of the pathological processes responsible for joint destruction in RA can be seen in figure A1.5 overleaf.

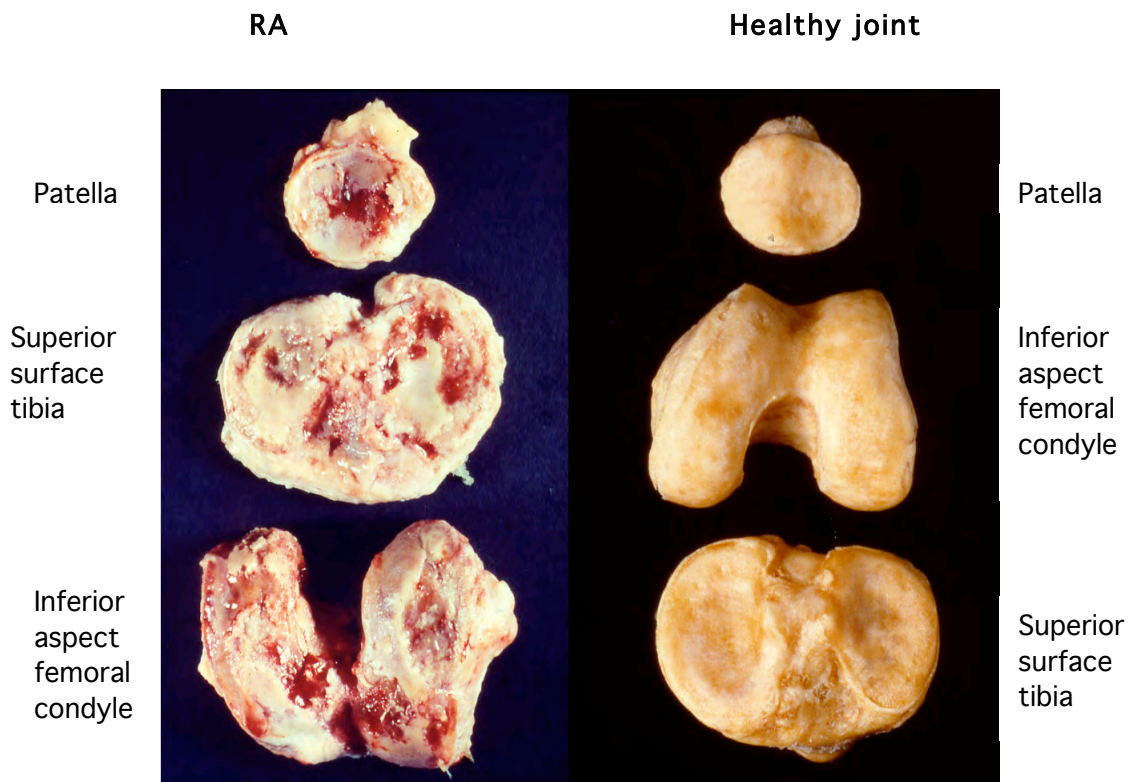
Figure A1.5 - T-cell driven pathogenesis leading to joint destruction in RA



Images courtesy of www.lbl.gov; www.visualunlimited.com; www.avalon.net; www.cip.ed.ac.uk; www.life.umd.edu; www.biomaterials.bme.northwestern.edu all accessed on 23/3/06

Following loss of articular cartilage, subsequent bone destruction seen in RA appears to occur due to osteoclast activation by cytokine molecules as outlined in table A1.2 (Goronzy & Weyland 2001, Gravallesse 2002, Murphy & Nagase 2008). These processes degrade the joint margins and give rise to peri-articular erosions (Revell 1992). Finally, in the late stages of the disease fibrous granulation tissue replaces the cartilage and bone, forming adhesions and fused articular surfaces (Goronzy & Weyland 2001). Figure A1.6 compares 'normal' articular surfaces of the knee with that of a patient with advanced RA following knee joint replacement.

Figure A1.6 - Comparison of joint surfaces seen in advanced RA with 'normal' articular surfaces. (Bullough & Vigorita 1984)

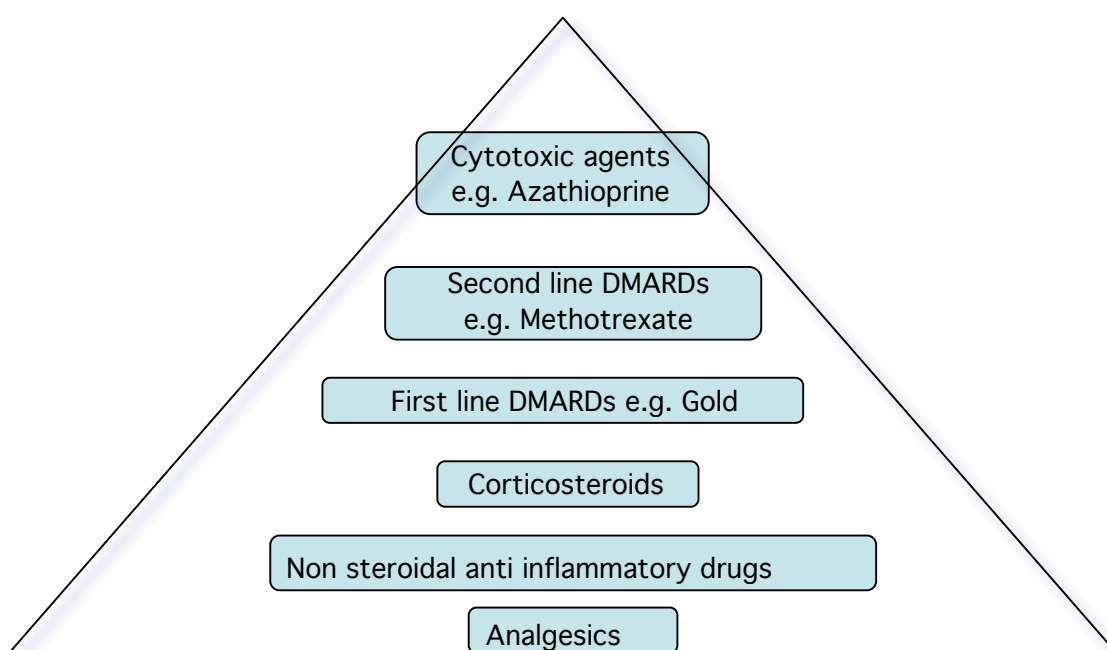


Appendix 2 The medical management of rheumatoid arthritis – historical and contemporary perspectives

2.1 The management of RA – a brief historical review

Historically, the management of RA was predominantly based on the medical model of controlling pain and inflammation through conservative treatment with non-steroidal anti-inflammatory drugs (Breedveld & Kalden 2004, Simon 2004). Disease-modifying anti-rheumatic drugs (DMARDs) were often withheld until there was clear evidence of joint damage (Breedveld & Kalden 2004). The traditional pattern of drug use in RA advocated the use of single agents in a slow sequential pattern, starting with symptom modifying agents before moving to potentially more toxic DMARDs as illustrated in figure A2.1 (Wilske 1993, Breedveld & Kalden 2004). The primary aim of such an approach was to control inflammation and minimise joint damage while avoiding drug toxicity (Hughes 1997). Concern about the toxicity of DMARDs (particularly in combination or high doses) often delayed their use in treating RA (Breedveld & Kalden 2004, O'Dell 2004). This approach yielded few long-term remissions and generally unsatisfactory outcomes as the long-term morbidity and mortality seen in RA was not substantially altered (Wilske 1993, Wilske & Healy 1993, Breedveld & Kalden 2004).

Figure A2.1 - The 'therapeutic pyramid' of drug use in RA



2.2 Contemporary approach to the medical management of RA

Despite the use of the traditional therapies described, RA tended to progress over time leading to increasing morbidity and decreased quality of life due to pain, fatigue and depression, as well as functional work disability and consequent loss of productivity and ultimately premature mortality (Wolfe et al. 1994, Wolfe & Hawley 1998, Young et al. 2002). There has been increasing evidence to suggest that the rate of joint damage due to persistent synovitis is greatest in the first two years of the disease (Brook & Corbett 1977, McCarty 1990, Wilske & Healy 1993); supporting the use of DMARD therapy early in the disease process to control synovitis and reduce joint damage (van der Heide 1996). The aim of current medical management of RA (which is still evolving) is not only to control pain and reduce inflammation, but also to limit disease progression, preserve joint function and allow the patient to maintain an improved quality of life (Griffith & Dacre 1994, Akil & Amos 1995a Simon 2004). The availability of new treatments and the increasing expectation of patient outcomes led to a dramatic change in the treatment paradigm for RA (Breedveld & Kalden 2004). There are a number of approaches to using combination DMARD therapy; with the principle of combining drugs with different mechanisms of action while limiting the potential side effects – similar to the combination cytotoxic treatments used in oncology (Suresh & Lambert 2005). Three main approaches to combination therapy have been described in the literature:

- A continuous approach where two or more DMARDs are prescribed simultaneously with the intention of continuing all the DMARDs involved (Breedveld & Kalden 2004).
- A step-up approach where aggressive therapy is prescribed for a subset of patients who do not respond to a single drug (Simon 2004, Suresh & Lambert 2005).
- A step-down approach where the most aggressive treatment is offered at an early stage (Simon 2004, Suresh & Lambert 2005).

There is clear evidence from randomised controlled trials that early use of combination therapy with DMARD's (+/- corticosteroids) improves physical function and decreases the rate of progression of joint damage (Boers 1997, van Gestel 1997). For example the Combinatietherapie Bij Reumatoide Arthritis (COBRA) trial (Landewe et al. 2002) reported

that patients undergoing a step-down combination with three DMARDs showed less radiographic progression over six months than those receiving monotherapy. However, the Dutch Behandel Strategieën (BeSt) trial (Geekoop-Ruiterman et al. 2005), found evidence to support the conclusion that a better clinical response and radiological outcome was achieved using a step-up combination other than monotherapy or a step-down approach. Unfortunately effective symptom control is only achieved in a proportion of patients, with others unable to tolerate such a regime (Maini 1999). DMARDs used in RA such as Methotrexate and Sulphasalazine have a number of serious side effects that commonly include gastrointestinal irritation, skin rashes, haematological abnormalities and liver toxicity (O'Dell 2004). Consequently constant monitoring is required usually in the form of regular full blood counts and liver function tests (Kwoh et al. 1996, Scott 2002). Breedveld & Kalden (2004) reported that DMARD therapy, while more efficacious than analgesia alone, has a number of limitations including:

- Slow onset of action (1-6 months).
- Difficult & complex dosing regimes.
- Need for close monitoring (monthly liver function and blood tests).
- Limited long term sustainability.
- Limited effectiveness in terms of disease progression and health related quality of life.

The need to deal with these limitations, together with recent advances in the understanding of the pathophysiology of RA have provided an opportunity to develop new, more effective therapeutic agents. In particular, the recognition that the pro-inflammatory cytokines, (tumour necrosis factor alpha ($TNF\alpha$) and Interleukin 1 (IL1)) mediate many of the pathogenic features of RA has enabled researchers to develop agents to specifically target these molecules, thus blocking an important part of the disease process (Maini 2001). Presently there are three main types of biologic agents:

- Monoclonal antibodies, (Infliximab and Adalimumab) - block $TNF\alpha$ receptor sites.
- $TNF\alpha$ Fc fusion proteins, (Etanercept) - prevents pro-inflammatory TNF molecules binding to cell surface receptors.
- Human receptor antagonists to IL1 (Anakinra) - bind to free IL1 neutralising it.

Placebo-controlled trials have demonstrated the rapid, sustained efficacy of TNF α blockers in dramatically reducing the severity of clinical, radiological and laboratory markers of RA (Weinblatt et al. 1999, Maini 1999, Lipskey et al. 2000, Weinblatt et al. 2003, Maini et al. 2004). In particular combining these drugs with methotrexate appears to be more efficacious than anti-TNF medication alone (Bathon et al. 2000, Breedveld et al. 2004, Klareskog et al. 2004). However, these new drugs are more expensive than DMARDs; - (TNF α blockade costing approximately £8000-10,000 a year/patient (Emery & Buch 2002)). For these reasons in the UK the National Institute for Clinical Excellence (NICE) has recommended that these drugs should be considered as options for the treatment of adults who have progressive, clinically active RA (Disease Activity Score >5.1) that has not responded to at least two DMARDs, including methotrexate (NICE 2002). The side effect profile of these drugs is encouraging, however TNF α is a key regulator of innate immunity and as such the risk of severe infection in cases of tissue breakdown is a real possibility (Pisetsky 2000, Bongartz et al. 2005). While some authors report then need for a high level of suspicion for infections in patients under anti-TNF α therapy, encouragingly an increased incidence of serious infections has not been noted in clinical trials (Bongartz et al. 2005). That said given the range of potential side effects it is important that Allied Health Professionals are familiar with these drugs as part of their role in the multi-disciplinary management of individuals with rheumatic disorders (Otter et al. 2004).

At the time of writing a number of new biologic agents were either being developed or in phase III clinical trials, these include:

Rituximab – a chimeric human/mouse monoclonal antibody directed at B cells.

Abatacept – a recombinant fusion protein, which interferes with T-cell activation.

Tocilizumab – a humanised anti-interleukin receptor.

(Singh et al. 2005, Smolen et al. 2007)

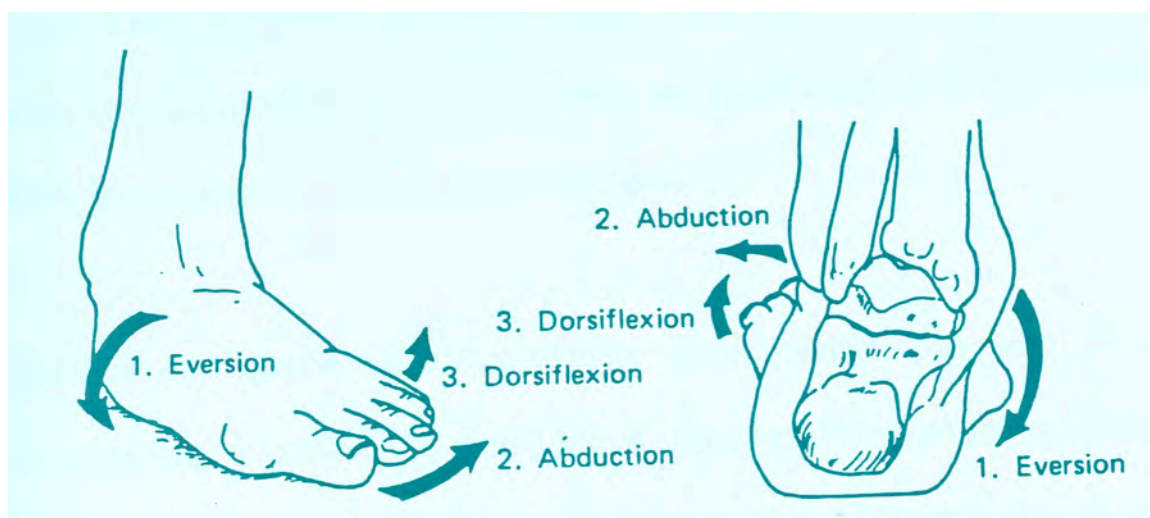
It is beyond the scope of this review to discuss these agents in details, but the principles of management already in use with existing biologic agents are likely to still apply.

Appendix 3 The pathomechanics of the foot in RA

3.1 Hindfoot Pathomechanics

The pathomechanics responsible for changes described above such as the valgus deformity of the hindfoot remain poorly understood, although several theories have been put forward. A common clinical feature associated with hindfoot symptoms is pronation at the subtalar joint (Vainio 1956, Gerber & Hunt 1985, Smidt 1987). Pronation is a composite term to describe abduction, eversion and dorsiflexion occurring at the subtalar joint and is illustrated in figure A3.1.

Figure A3.1 - Diagrammatic representation of Sub-talar joint pronation (Smidt 1987)



The reported aetiology of this feature in RA remains debatable with several factors being implicated. These include inflammatory synovitis, loss of articular cartilage and subsequent erosions of the talo-navicular and talo-calcaneo joints (Smidt 1987, Cracchiolo 1997, O`Brian et al. 1997) as well as weakness of the anterior and posterior tibial muscles (McGurie & Kumar 1987). Also implicated is weakness of the calf muscles causing delayed heel rise and loss of the varus force on the hindfoot normally seen during this stage of gait (Keenan et al. 1991).

The loss of articular cartilage and erosions at the talo-navicular and talo-calcaneo joints has received considerable attention recently, as technology such as 3-D MRI has become

more widely possible (Woodburn et al. 2002c). As the disease process progresses the pathological features of cartilage loss and bone erosion coupled with mechanical stress are thought to force the calcaneum to acquire a progressive valgus deformity (Keenan et al. 1991, Budiman-Mak et al. 1995). Foot pressure studies have indicated that this process causes a redistribution of load to the medial side of the foot (Stockley et al. 1990, Woodburn & Helliwell 1996). If the hindfoot valgus is greater than 10°, it has been reported that significantly higher pressures at the forefoot can occur (Chen 1996).

Weakness or rupture of the posterior tibialis tendon has also been discussed as a cause of the valgus foot in rheumatoid disease (Downey et al. 1988). Michelson and colleagues (1995) reported rupture of this tendon occurred in 11% of 99 patients using a physical examination criterion. Valmassy and Marozsan (1996) have reported that failure of this tendon may place excess stress on the plantar ligamentous structures, causing a plantarflexion of the talar head and eversion of the foot caused by the unopposed peroneal muscles contributing to the plano-valgus appearance with forefoot abduction, flexor substitution and propulsive gait. However, there remains some controversy over this Michelson's estimate, as neither Kirkham & Gibson (1989) nor Keenan and colleagues (1991) who separately studied 50 subjects with RA reported no instances of posterior tibial tendon rupture.

Finally, Keenan and colleagues (1991) reported a delayed heel rise due to weakness of the calf muscles seen during electromyographic studies. This finding was thought to reduce pressure over painful metatarsal heads possibly leading to a smoothing out of foot pressure values as the patient tends to place the foot on the ground rather than exhibiting a normal heel-toe gait pattern. In addition, (Jahss 1982) suggested the valgus deformity of the calcaneum may decrease intra-articular pressure (and therefore pain) at the sub-talar joint. This calls into question the Rootian theory (Root et al. 1975) that the posterior aspect of the calcaneum should ideally be perpendicular to the supporting surface. Such findings have important implications as it suggests assessment of hindfoot position may not be the only important anthropometric foot measurement to consider in clinical practice.

3.2 - Forefoot Pathomechanics

Inflammation of the small joints of the forefoot is a hallmark feature of RA and may through disruption of the joint capsule cause widening of adjacent toes (Chand 1973, Stainsby 1997). This feature is often referred to as the 'daylight sign' (Dixon 1981) and is seen as a precursor of other forefoot deformities. As suggested previously, the signs and symptoms that result from foot involvement in RA are most commonly reported to be pain, stiffness and deformity (Speigal & Speigal 1982, Keenan et al. 1991, Costa et al. 2004). However these features need to be interpreted against a background in which foot pathologies are not uncommon in the general population (Helliwell et al. 2007), with Garrow and colleagues (2004) reporting the prevalence of disabling foot pain to be up to 24% in a UK based population survey.

Hallux abducto valgus (HAV) is one of the commonest forefoot deformities seen in RA and this deformity is thought to worsen with the duration of the disease (Haas et al. 1999). The aetiology of hallux valgus in RA has been a long running debate owing to the commonality of this disorder in the general population and the influence of other variables such as anatomical variations seen in the feet, as well as differences in gait and footwear (Kilmartin & Wallace 1993, Rush 1998, Wiener-Ogilive 1999). Previously, Root and colleagues (1977) developing the work of Jordan and Brodsky (1951) argued that in the non-pathological or normal foot the primary aetiological factor in HAV was excess pronation occurring at the sub-talar joint. Excess pronation rendered the foot hypermobile, preventing locking at the mid-tarsal joint as the foot transferred from a mobile adaptor to a rigid lever for the propulsion phase of gait. However, the fundamental principles that underpin podiatric biomechanics such as Root et al's assertions have been questioned by Kidd (1991) and Kilmartin and Wallace (1993) owing to the lack of empirical evidence to link sub-talar joint pronation with HAV. Moreover, much of the work in podiatric biomechanics (including Root et al. 1977) only refers to the non-pathological foot and as such does not take account of the inflammatory synovitis seen in RA. This synovitis is reported to cause disruption of the ligamentous support around the first metatarsophalangeal joint (Mann 1997, Wiener-Ogilive 1999, Helliwell et al. 2007). Kirkup and colleagues (1977) and Rush (1998) suggested that medial divergence of the first metatarsal (metatarsus primus varus) has an association with HAV in both rheumatoid and non-rheumatoid subjects. Diamonte and Light (1982) reported that the subsequent

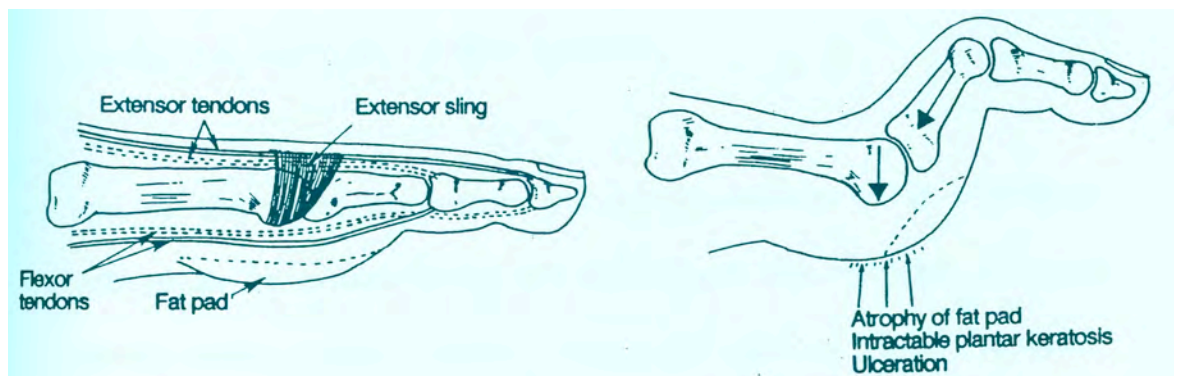
lateral deviation of the axes of the long flexor and extensor muscles seen in the medial deviation of the first metatarsal are altered such that they act like a bowstring forcing the hallux to adopt a more valgus orientation. Both McGuire and Kumar (1987) and Smidt (1987) argued that the consequent ground reaction forces on the great toe cause medial rotation and further valgus positioning. However, others have postulated that the significance of other factors such as inappropriate footwear, and the position shape and length of the first metatarsal should not be overlooked (Kilmartin et al. 1991, Kilmartin & Wallace 1993, Rush 1998). However, little work has been undertaken on the relative importance of these factors in RA.

An alternative aetiological series for forefoot pathomechanics based on the disease process of RA have also been proposed. Coughlin (1984) and Mann (1997) both suggest that the disease progression seen in RA, particularly the latter stages of the disease when articular cartilage destruction and subchondral bone reabsorption contribute to the development of a hallux valgus deformity. Yamamoto and colleagues (1996) using subjects with HAV reported higher plantar pressures over the second/third metatarsal head region. These pathological changes reportedly cause the weight-bearing function of the first ray to decrease, leading to a transfer of weight to the lesser rays and subsequent increased callus formation over the lesser metatarsal heads. However, Resnick (2002) reported the first metatarsal was the least commonly affected metatarsophalangeal joint in RA, pointing to the need for further epidemiological work in this area.

Subluxation of the lesser metatarsophalangeal joints and digital deformities are also common in RA. Again several aetiological theories have been discussed. Chand (1973), Spiegel and Spiegel (1982) and Cracchiolo (1993) have reported that synovitis and subsequent intra-articular degeneration of the metatarsophalangeal joints lead to a weakening of the joint capsule and its associated ligaments. In addition D`Amico (1976) reported that secondary to this metatarsophalangeal joint synovitis and capsular distention there is a lateral displacement of the extensor tendons (extensor digitorum longus and brevis) due to the chronic synovial inflammation. The resultant mechanical dysfunction is thought to cause the toes to become clawed and displaced laterally (Dixon 1981). Eventually the interphalangeal joints may dislocate dorsally into a valgus deformity (Kerschbaumer et al. 1996). Jahss (1991) has argued that synovitis and subsequent

capsular distension alters the axes of the intrinsic muscles to such an extent that they act as extensors, further aggravating the deformities. However, Diamonte and Light (1982) and Dixon (1987a) were of the opinion that the altered lines of pull of flexor tendons due to capsular distension further exacerbates digital deformity by increasing the hyperextension of the MTPJ and flexion of the interphalangeal joints, as illustrated in figure A3.2. Saltzman and Johnson (1993) consider that the ground reaction forces affecting the toes at heel-off may further exacerbate this process by causing the proximal phalanges to progressively dorsiflex and eventually dislocate at the MTPJ. The plantar fat pad migrates forwards and upwards because of these deformities, thus reducing protection for the metatarsal heads. It is probable that a number of intrinsic and extrinsic factors are responsible for the pathologies seen in the rheumatoid foot. These deformities lead to difficulty with shoe fitting, increasing pain, issues of cosmesis and secondary hyperkeratotic lesions such as callosities, which if too thick, limit skin elasticity and increase the risk of tissue viability problems due to ulceration (Dixon 1981, Diamonte & Light 1982, Dixon 1987a, Helliwell et al. 2007).

Figure A3.2 - Pathophysiology of digital deformities in RA
(Diamonte & Light 1982)



3.3 Extra-articular features seen in the feet

As discussed in chapter two of the main document, RA is a system disorder with a number of extra-articular features, many of which that can affect the feet and lower limbs. Extra-articular features in the feet may increase the impact of foot complaints on factors such as quality of life considerably.

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Appendix 4 - Overview of outcome measures for the foot in RA

Introduction

To enable a better understanding of the perspective current outcome measures can provide for clinicians, each of the foot specific outcome measures was reviewed in more detail. To facilitate this review, a literature search for outcome measures was undertaken as part of the overall literature search strategy. To narrow down the search the MeSH terms *outcome measure*, *critical appraisal*, *evaluation* were used and this approach revealed 14 articles on outcome measurement. To enable a critical review of these works, an appraisal method for the analysis of outcome measures based on a framework proposed by Greenhalgh and colleagues (1998) was used. Other centres expert in evidence-based medicine (e.g. NHS public health resource unit, Cochrane, York), provide guidance on the critical review of methodologies such as randomised controlled trials and so on, but not outcome measures, which are essentially the results of methodological investigation. The framework designed by Greenhalgh and colleagues (1998) was also considered appropriate for a number of other reasons:

- Designed to appraise instruments that measure outcomes.
- Highly applicable to the area under investigation (i.e. outcome measures in chronic disease).
- Designed for use in the primary care setting where most podiatric consultations take place.

The following tables (A4.1 – A4.14) review each of the foot-specific outcome measures identified from the literature using the review strategy.

Table A4.1 - Review of the Joint Alignment and Motion (JAM) scale (Spiegel et al. 1982)

<i>Aim</i>	The JAM scale was developed as an estimate of joint deformity in RA
<i>Content & scoring</i>	The JAM scores deformity or range of motion from 6 upper extremity and 5 lower extremity joints on a 5 point scale
<i>User-centeredness</i>	Development of the JAM scale is unclear but appears to be based on the perspective of clinicians with no input for those with RA
<i>Psychometrics</i>	Good inter-observer reliability ($r=0.72$) and appears stable overtime. Correlates well with functional measures and radiological measures of disease severity
<i>Clinical Utility</i>	The JAM appears to be a useful estimate of joint motion correlating with functional class and disease severity, but has only been tested with relatively small sample ($n<100$)
<i>Feasibility</i>	The JAM scale is quick to complete (takes 5-10 minutes), is simple and inexpensive
<i>Other comments</i>	
<i>Sources</i>	Spiegel et al. 1982, Parker et al. 1988

Table A4.2 Review of Index of Structural Deformity (Platto et al. 1991)

<i>Aim</i>	The Index of Structural Deformity was designed to measure foot deformity in RA
<i>Content & scoring</i>	The Index of Structural Deformity consists of 4 measures of deformity from the forefoot and 3 from the hindfoot. Each deformity is scored based on assessment of severity in degrees
<i>User-centeredness</i>	Development of the item is unclear, but appears to be based on the authors opinion without input from those with RA
<i>Psychometrics</i>	No independent studies of validity or reliability could be found. No values for test-retest reliability and internal consistency are reported. Inter-observer error is likely to be reduced as scores are allocated based on a category of deformity; i.e. mild calcaneal deformity is between 0-5°, but this has to be formerly confirmed
<i>Clinical Utility</i>	The Index of Structural Deformity was designed for RA, could be used for other complaints where deformity is prevalent
<i>Feasibility</i>	The index is administered by a clinician and takes between 5-10 minutes to complete
<i>Other comments</i>	Further work is needed to establish the psychometric properties of the measure
<i>Sources</i>	Platto et al. 1991

Table A4.3 Review of the American Orthopaedic Foot & Ankle Society (AOFAS) clinical rating scales (Kitaoka et al. 1994)

<i>Aim</i>	The AOFAS clinical rating scales were developed to provide a standard method of reporting clinical status of the ankle and foot
<i>Content & scoring</i>	The rating scales consist of 4 scales (ankle-hindfoot, midfoot, hallux, lesser toes) each with a total points score of 100 divided between function, pain and alignment (as measured with a goniometer). Each of the scales has different proportions of scores allocated to function, pain and alignment.
<i>User-centeredness</i>	Items were developed from consensus of orthopaedic surgeons with no patient involvement
<i>Psychometrics</i>	Scales have inherently limited precision due to the small number of response intervals available. Minor changes in response can make dramatic differences to total scores. Low levels of correlation with other measures suggest poor construct validity. Test re-test suggests adequate reliability over 1 week. However intra and inter observer reliability is poor
<i>Clinical Utility</i>	The AOFAS clinical rating scales are not disease specific although theoretically scales could be utilised for any chronic foot complaint. Content is limited to the feet and does not take account of the impact of foot complaints on social activities
<i>Feasibility</i>	The AOFAS clinical rating scales have to be administered by a clinician and each takes between 10-20 minutes to complete
<i>Other comments</i>	Authors suggest scores from AOFAS clinical rating scales should be treated with genuine suspicion and items need revision
<i>Sources</i>	Kitaoka et al. 1994, Pearce 1999, Guyton 2001, SooHoo et al. 2003, Baumhauer et al. 2006

Table A4.4 - Review of the Foot Function Index (FFI) (Budiman-Mak et al. 1991)

<i>Aim</i>	The FFI was designed to measure the impact of pathology in RA on function
<i>Content & scoring</i>	The FFI has 3 domains measuring pain (9 items), disability (9 items) and activity limitation (5 items). Each item is scored on a 100mm visual analogue scale. Items scores for each sub-scale are totalled and divided by the maximum possible score for all the possible sub-scale items the respondent indicated were applicable. Calculating the average of the 3 sub-scale scores derives the total foot function score.
<i>User-centeredness</i>	Items were selected & grouped by a panel including a rheumatologist, physical therapist and 2 podiatrists. Lay views were not systematically canvassed when developing the original pool of items.
<i>Psychometrics</i>	The instrument was validated using a population of patients with RA. Most were male and predominantly elderly with stage I or II radiological damage for RA. Nevertheless the FFI has a good test-retest reliability, (ICC 0.69 – 0.8), a high degree of internal consistency (Cronbach’s 0.73 – 0.93). The side-to-side reliability of pain has also been tested and yields an ICC of 0.79 – 0.89.
<i>Clinical Utility</i>	Although originally developed to assess the effects of foot orthoses in RA, the FFI has been used to assess general foot pathology unrelated to RA. However, authors of these papers altered the FFI without comment on the effect on validity or reliability.
<i>Feasibility</i>	The FFI is self-administered and takes 5-10 minutes to complete. However, respondents find the small font & VAS type scoring confusing at first. The FFI is manually scored, which is time consuming.
<i>Other comments</i>	Concern has been raised regarding the reliability of the activity limitation domain for respondents with high or very low activity limitation, leading to the risk of floor or ceiling effects. The overall

	<p>score can be skewed either by a single very high (or very low) score in any of the three domains. If a subject does not have orthoses they cannot respond to a number of the questions. Does not correlate well with measures traditionally used by rheumatologists, reflecting the complexity of foot complaints.</p>
<i>Sources</i>	<p>Budiman-Mak et al. 1991 Saag et al. 1996, Caselli et al. 1997, Pfeffer et al. 1999, Landorf & Keenan 2002, Hussain et al, 2003, Agel et al. 2005</p>

Table A4.5 Review of the Foot Health Status Questionnaire (FHSQ) (Bennett et al. 1998)

<i>Aim</i>	To measure the foot health status of people's feet
<i>Content & scoring</i>	The FHSQ has 3 parts; section 1 has 13 key questions spanning 4 domains, measuring foot pain (4 items) foot function (4 items) footwear (3 items) general foot health (2 items). Each item is scored using a 5 point Likert-type scale and for each sub-scale scores are transformed, summed and converted into a 0-100 score (100 indicating optimum foot health). Section 2 has 20 questions capturing generic measures of health, analogous to the SF36. Section 3 collects standard demographic data.
<i>User-centeredness</i>	Items were initially developed from focus groups with Podiatric surgeons in Australia. Subsequently, an expert panel of podiatrists, measurement experts and potential respondents refined the questionnaire. Lay views were not systematically canvassed when developing the original item pool. Podiatry patients were subsequently involved in the validation process, but not all of these patients were being considered for surgery.
<i>Psychometrics</i>	The psychometric properties of the FHSQ have been tested. The FHSQ is respondent to change compared with the Foot Function Index. High test-retest reliability, (ICC 0.74-0.92) and a high degree of internal consistency (Cronbach's α 0.89-0.95) are reported. The goodness of fit index of 0.90 and a comparative fit index of 0.96 are also noted.
<i>Clinical Utility</i>	The FHSQ is not disease specific and was originally designed with surgical outcomes in mind. It has been validated in terms of content, criterion and construct validity across a range of foot pathologies, including skin, nail and musculo-skeletal disorders.
<i>Feasibility</i>	The FHSQ is self-administered and takes 3-5 minutes to complete. Manual scoring takes longer, but there is a computerised version.
<i>Other comments</i>	Lack of discrimination in the general foot health domain means respondents tend to cluster on certain values. The need for the

	generic section in light of other well-validated instruments is questionable.
<i>Sources</i>	Bennett et al. 1988, Bennett & Patterson 1998, Landorf & Keenan 2002

Table A4.6 Review of the Ankle Osteoarthritis Scale (AOS) (Domsic & Saltzman 1998)

<i>Aim</i>	The AOS was developed as a clinical measure of ankle osteoarthritis
<i>Content & scoring</i>	The AOS was based on the FFI. Authors eliminated the activity limitation subscale as they had concerns over its internal consistency. How to score this measure is unclear from the report
<i>User-centeredness</i>	Physicians without systematic lay input developed this scale. Validity testing was undertaken with patients with ankle osteoarthritis (OA) from the authors' database.
<i>Psychometrics</i>	As the data is non-parametric log transformations were used in order to undertake parametric testing. Test-retest reliability is reported as being excellent (ICC 0.97). Construct validity is reported as being $r=0.88$. Criterion validity is more difficult to assess as only the criteria from the AOS that matched those from the WOMAC and SF36 were tested
<i>Clinical Utility</i>	This instrument is both disease specific and specific for an anatomical location
<i>Feasibility</i>	The instrument relies on visual analogue scales, these are time consuming to score and difficult to complete
<i>Other comments</i>	There is concern about the premise upon which this scale is based. To assume factors that affect patients with RA are the same as those for patients with OA, without including patient opinion could be flawed. In addition this measure does not contain items that have been shown by other to be important to patients including body image and psychological impact.
<i>Sources</i>	Bennett et al. 1998, Domsic & Saltzman 1998, Garrow et al. 2000, Rowan 2001

Table A4.7 Review of the Manchester foot pain disability questionnaire (MFPDQ)

(Garrow et al. 2000)

<i>Aim</i>	The MFPDQ is a self administered instrument designed to assess foot pain and disability
<i>Content & scoring</i>	The MFPDQ is a 19-item questionnaire with 3 domains, functional limitation (12 items) pain intensity (4 items) and personal appearance (3 items). Scoring is via a 3 point Likert-type scale.
<i>User-centeredness</i>	A total of 1028 patients' opinions were surveyed in the development and validation of this instrument. Subjects involved had both long-term conditions that cause foot disability such as RA and osteoarthritis as well as local foot problems; all had consulted their GP about their foot problem.
<i>Psychometrics</i>	The Internal consistency was tested via Cronbach's Alpha and scored 0.99. Item-total correlation varied between 0.25 and 0.62
<i>Clinical Utility</i>	The MFPDQ is not disease specific and can be used in any condition where foot pain or disability may be an issue. It has been used in a variety of studies including the use of foot orthoses and the effect of reflexology.
<i>Feasibility</i>	This instrument is quick (<5 mins) and simple to both complete and score
<i>Other comments</i>	There is concerns about the potential for floor or ceiling effects owing to the limitations of scoring
<i>Sources</i>	Garrow et al. 2000, Khan et al. 2005 Helliwell et al. 2005, Springett et al. 2005

Table A4.8 Review of the Foot and Ankle Outcome Score (FAOS)

(Roos et al. 2001)

<i>Aim</i>	The FAOS is intended to evaluate symptoms and functional limitations related to the foot and ankle
<i>Content & scoring</i>	The FAOS is developed from the knee injury and osteoarthritis outcome score (KOOS); it is not clear how the KOOS were adapted. The FAOS contains 42 items related to; pain (9 items), other symptoms (7 items), activity of daily living (17 items), sport and recreational activity (5 items) and foot and ankle related quality of life (4 items). Each instrument is scored using a 5-point Likert-type scale. The 5 sub-scale scores are calculated as a sum of the items included and raw scores are transforms into a 0-100 scale. It is not clear how to undertake this transformation
<i>User-centeredness</i>	There is no data presented on lay or user involvement in developing the FAOS. Validity testing was undertaken via questionnaire with patients who has undergone ankle ligament repair
<i>Psychometrics</i>	Internal consistency was tested via Cronbach's Alpha and scored between 0.88 and 0.97. The test-retest results suing Spearman's rank were $r = 0.85-0.96$ and ICC varied between 0.70-0.92
<i>Clinical Utility</i>	This instrument could be considered reliable & valid, but only for the purpose of ankle ligament reconstruction
<i>Feasibility</i>	The questionnaire is self-administered and takes between 7-10 minutes to complete
<i>Other comments</i>	There is concern about the validity of adapting a different outcome measure without reference to lay input at the development stage. There is no reference to footwear or psychological symptoms associated with foot/ankle problems with or without ankle ligament involvement
<i>Sources</i>	(Roos et al. 2001)

Table A4.9 Review of the Rowan foot pain assessment questionnaire (ROFPAQ)

(Rowan 2001)

<i>Aim</i>	The ROFPAQ was develop as a multi-dimensional measure of chronic foot pain
<i>Content & scoring</i>	The ROFPAQ has 3 dimensions measuring aspects of chronic pain; a sensory sub-scale (16 items), affective and cognitive sub-scales (10 items each). Items are scored using a 5 pt Likert-type scale and sub-scale scores obtained by summing individual items and dividing by the number of items within that scale
<i>User-centeredness</i>	Items were developed from focus groups and semi-structured interviews with people with chronic foot pain
<i>Psychometrics</i>	No independent studies of validity or reliability could be found. The author reports acceptable values for test-retest reliability and internal consistency (Cronbach's $\alpha > 0.7$)
<i>Clinical Utility</i>	The ROFPAQ is not disease specific and no studies that use this measure have been found, although theoretically the ROFPAQ could be utilised for any condition causing chronic foot pain
<i>Feasibility</i>	The ROFPAQ is self-administered and takes between 2-20 minutes to complete
<i>Other comments</i>	Further work is needed to establish the scale responsiveness to clinical change (sensitivity)
<i>Sources</i>	Rowan 2001

Table A4.10 Review of the Foot function index with verbal rating scales (FFI-5pt)
(Kuyvenhoven et al. 2002)

<i>Aim</i>	Development of a Dutch version of the FFI using verbal rating scales rather than visual analogue scales
<i>Content & scoring</i>	Lay and professional people translated the original FFI using a forward and backward procedure. Items in the instrument remained the same, but scoring is via health rating scales ((5 pt Likert-type scale)
<i>User-centeredness</i>	Health professionals deemed visual rating scales more appropriate than visual analogue scales. Lay views were used to validate the new FFI-5pt with the original FFI
<i>Psychometrics</i>	The new FFI-5pt instrument was validated using a population of patients with general foot problems – not RA as originally intended. The FFI-5pt has an improved test-retest reliability, (ICC 0.70-0.81) and slightly better internal consistency (Cronbach's α 0.88-0.93)
<i>Clinical Utility</i>	This new instrument was validated with a wider population range than the original. The lack of lay views in its development gives cause for concern as to the applicability of all the items
<i>Feasibility</i>	The FFI-5pt is self-administered and is quicker to complete and score than the original FFI
<i>Other comments</i>	There is concern regarding how responsive to change this new instrument is
<i>Sources</i>	Kuyenhoven et al. 2002

Table A4.11 - Review of the Podiatry Health Questionnaire (PHQ)

(Macran et al. 2003)

<i>Aim</i>	The PHQ was developed to assess foot related health
<i>Content & scoring</i>	PHQ consists of 6 domains (walking, hygiene, nail care, foot pain, worry, quality of life) and a 10cm visual analogue scale. Each domain is scored via 3 point Likert type scale. Additionally a clinician scored podiatry clinical score is used alongside the patient completed component
<i>User-centeredness</i>	The PHQ was developed to be used alongside other instruments e.g. EQ-5D and as such shares some properties. Development of the PHQ based on consensus from podiatry managers, no patient input was included in item development
<i>Psychometrics</i>	No independent tests would be located and the authors report further testing of psychometric properties is required. The instrument does appear to have good face validity.
<i>Clinical Utility</i>	The PHQ is a useful tool, although not disease specific but the lack of patient input means issues of importance to patients may not be included. However this is one of the few measures to include worry and quality of life among the items.
<i>Feasibility</i>	The PHQ is self administered, but requires clinician scoring & is designed to be used alongside other measures (EQ-5D), which increases the time required to administer & score
<i>Other comments</i>	
<i>Sources</i>	Macran et al. 2003

Table A4.12 - Review of the American Academy of Orthopaedic surgeons (AAOS) Foot and Ankle Instrument

(Johanson et al. 2004)

<i>Aim</i>	The AAOS Foot and Ankle Instrument was developed for the efficient collection of outcomes data for disorders of the lower limbs
<i>Content & scoring</i>	The AAOS Foot and Ankle Instrument forms part of a range of lower limb instruments, the Foot and Ankle Instrument consists of 20 items for pain, swelling, stiffness, function and 'giving' way'. Scoring is yes/no or using a variety of Likert-type scales to generate a single score as scoring function is provided
<i>User-centeredness</i>	Development of the AAOS Foot and Ankle Instrument is based on expert consensus, no patient input was included in item development or subsequent instrument testing
<i>Psychometrics</i>	No independent tests could be located, however the authors report good internal reliability ($\alpha = 0.83-0.91$), good test re-test reliability ($r=0.7-0.99$) and good internal reliability ($r=0.72$) and appears stable overtime.
<i>Clinical Utility</i>	The AAOS Foot and Ankle Instrument is a useful tool, although not disease specific. Only validated with relatively small sample ($n=71$), the lack of patient input means issues of importance to patients may not be included
<i>Feasibility</i>	The AAOS Foot and Ankle Instrument is self administered, but requires computerised scoring
<i>Other comments</i>	Potential floor and ceiling effects have not been tested
<i>Sources</i>	Johanson et al. 2004

Table A4.13 - Review of the Leeds Foot Impact Scale (LFIS)

(Helliwell et al. 2005)

<i>Aim</i>	The Foot Impact Scale is designed to assess foot status in RA
<i>Content & scoring</i>	The instrument is a 51-item questionnaire covering 2 domains of impairments/shoes (21 items) and activities/participation (30 items). Each item is scored with a dichotomous (true/false) scale.
<i>User-centeredness</i>	Items were developed from semi-structured interviews with people with RA, with validation via Rasch analysis and postal surveys
<i>Psychometrics</i>	This scale is new and has not been tested independently. The authors report good psychometric properties for the scale, test-retest analysis of the impairments/shoes domain, (ICC 0.84) and test-retest analysis of the activities/participation (ICC 0.96).
<i>Clinical Utility</i>	The Foot Impact Scale is relatively new has not yet been widely reported in clinical usage
<i>Feasibility</i>	This instrument would appear to be a reliable disease-specific scale to measure the outcomes of intervention studies in this field
<i>Other comments</i>	A large number of patients (30 interviewees & 192 questionnaires) with RA of varying disease duration were involved in the development of this instrument. The 2 scales have been validated independently of each other
<i>Sources</i>	Helliwell et al. 2005

Table A4.14 - Review of the Bristol Foot Score (BFS)

(Barnett et al. 2005)

<i>Aim</i>	A patient-centred foot health assessment tool
<i>Content & Scoring</i>	The questionnaire contains 15 items covering 5 domains, mobility (4 items), pain (2 items), footwear (3 items), foot health & disability (3 items) and perception of self as a result of foot problems (3 items). The instrument is scored using Likert-type scales ranging between 3 and 6 points.
<i>User-centeredness</i>	Semi-structured interviews, focus groups and questionnaires were used to develop and validate this instrument
<i>Psychometrics</i>	The authors report a good internal consistency (Cronbachs α 0.904) and a test-retest score of -0.83 (using the Bland Altman technique)
<i>Clinical Utility</i>	The authors suggest the measure is sensitive to change for toenail surgery, but no independent reports are yet available. The instrument is brief (1 side A4) and can be completed & scored relatively quickly
<i>Feasibility</i>	This instrument is not disease specific and theoretically could be used with a wide range of foot problems, whether the severity of problems experienced by patients with systemic disease will be adequately reflected requires further testing
<i>Other comments</i>	
<i>Sources</i>	Barnett et al. 2005

Table A 4.14 Review of the Manchester-Oxford Foot Questionnaire (MOXFQ)

(Dawson et al. 2006)

<i>Aim</i>	The MOXFQ was developed to assess the outcomes of hallux valgus surgery
<i>Content & scoring</i>	MOXFQ consists of 16 items in 3 domains (walking, pain, social interaction) each question is scored on a 5 point Likert-type scale
<i>User-centeredness</i>	The MOXFQ was developed from existing instruments (MFPDQ, SF36, AOFAS hallux clinical scale) in conjunction with interviews with patients
<i>Psychometrics</i>	This instrument was tested for underlying factor structure, dimensionality, internal reliability and construct validity in relation to the SF36 and AOFAS Hallux scale Internal reliability (Cronbachs Alpha coefficients) was 0.92 for walking, 0.86 for pain and 0.7 for social interaction. Convergent and divergent validity were all $r > 0.5$ In Rasch models for dimensionality no single item significantly above the 5% level
<i>Clinical Utility</i>	The PHQ is specific for hallux valgus surgery but may be able to be adapted for other situations. It is one of the few measures to include a social-interaction domain.
<i>Feasibility</i>	This short questionnaire is quick and simple to complete and score
<i>Other comments</i>	
<i>Sources</i>	Dawson et al. 2006

Appendix 5 Ethical Approval for each stage of the study


5.1 Ethical approval from University of Brighton research ethics committee for generating data from people with RA who are members of NRAS

260.6 Epidemiology of foot problems in rheumatoid arthritis Simon Otter, PhD, School of Health Professions (REC05-59)

The information sheet states that the participant would be asked to sign a consent form, yet under ethical issues the proposal says that consent forms would not be used, as returned questionnaires would be taken as consent to participate. This needs to be clarified. The reference to the Brighton and Sussex Medical 'Scholl' needed to be corrected.

With this observation, the proposal was approved.

5.2 Ethical approval from Brighton and Hove research ethics committee to generate data from people with RA who are BSUH patients



Brighton and Mid Sussex Research Ethics Committee
 Brighton & Hove City Teaching PCT
 1st Floor, Prestamex House
 171-173 Preston Road
 Brighton
 East Sussex
 BN1 6AG

Telephone: 01273 545373
 Facsimile: 01273 545372

28 April 2006

Mr Simon Otter
 Senior Lecturer
 University Of Brighton
 Leaf Hospital
 St Annes Rd
 EASTBOURNE, BN21 2HW

Dear Mr Otter

Full title of study: **Epidemiology of foot problems in rheumatoid arthritis**
REC reference number: **06/Q1907/12**

Thank you for your letter of 24 April 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application Parts A and B only		08 February 2006
Investigator CV		08 February 2006
Protocol	1	08 February 2006
Covering Letter		11 January 2006
Letter from Sponsor		13 January 2006
Questionnaire	3	24 April 2006
Letter of invitation to participant - From Consultant	3	24 April 2006
GP/Consultant Information Sheets	2	04 April 2006
Participant Information Sheet	3	24 April 2006
Response to Request for Further Information		23 March 2006

An advisory committee to Surrey and Sussex Strategic Health Authority

Response to Request for Further Information		24 April 2006
Consent form to inform GP	3	24 April 2006
Letter from Funder		17 November 2005
Letter from Funder		07 November 2005
Honorary contract with Brighton and Sussex University Hospitals		12 January 2006
Letter from University Research Committee		25 July 2005
Supervisor's CV	1	01 December 2005
CV of Dr Kate Springill	1	01 December 2005
Flow Chart	1	08 February 2006

Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

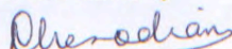
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q1907/12

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Dr Paul Seddon
Chair

Email: nischinth.cherodian@bhcpct.nhs.uk

Enclosures: *Standard approval conditions*

Copy to: Anne Moore
Clinical Research Centre
University of Brighton
Mithras House
Lewes Road
Brighton

R&D Department for Royal Sussex County Hospital

5.3 Ethical Approval from University of Brighton research ethics committee to generate data from rheumatologists

**259.3 A questionnaire based study to identify & explore the approaches and methods rheumatologists use to assess, evaluate and manage foot and lower limb problems in early rheumatoid arthritis
Simon Otter, PhD, School of Health Professions (REC05-53)**

There were no ethical concerns raised by the proposed amendment to the route through which participants would be accessed.

The proposal was approved.

5.4 Ethical approval from University of Brighton research ethics committee for generating data from podiatrists

245.7

A questionnaire based study to identify and explore the approaches and methods podiatrists use to assess, evaluate and manage the foot and lower limb in early rheumatoid arthritis (two proposals). Simon Otter, PhD, School of Health Professions (REC05-17)

The committee noted the use of the past tense in the proposal, and queried whether the study had already begun, or whether this referred to the fact the study built on existing research or practice. The researcher is asked to respond on this point to the Secretary. The committee also noted that if the statistical analysis had not already been designed, further advice could be sought from the Statistics Unit, if desired.

The proposal was approved.

Appendix 6 Draft questionnaires

6.1 Draft questionnaire for people with RA

1 a Does your arthritis affect your feet? (please tick 1 box)

Yes

No

1 b If yes, how are your feet affected? (please tick as many boxes as apply)

Pain

Stiffness

Swelling

numbness/tingling

Other (please specify) _____

2 On average, how painful are your feet? (please circle the number which most closely applies to you)

0

1

2

3

4

5

Not at all
painful

Extremely
painful

3 In general, how stiff are your feet? (please circle the number which most closely applies to you)

0

1

2

3

4

5

Not at all
stiff

Extremely
stiff

4 On average, how swollen are your feet? (please circle the number which most closely applies to you)

0

1

2

3

4

5

Not at all
swollen

Extremely
swollen

5 In general, how much numbness/tingling do you get in your feet? (please circle the number which most closely applies to you)

0

1

2

3

4

5

No numbness
or tingling

Extremely
numb

6 How often do you get symptoms in your feet, which you associate with your arthritis?

(please circle only one of the following)

Never	Once a week or less	2-3 times a week	Almost every day	All the time
-------	------------------------	---------------------	---------------------	-----------------

7a Do you feel your life in general is affected by the arthritis in your feet? (please tick 1 box)

Yes	No
-----	----

7b If yes, which aspects of your life are affected by the arthritis in your feet? (please tick as many boxes as apply)

<input type="checkbox"/> standing	<input type="checkbox"/> walking
<input type="checkbox"/> climbing stairs	<input type="checkbox"/> wearing different shoes
Other (please specify) _____	

8 In general, how much difficulty do you have in standing? (please circle the number which most closely applies to you)

0	1	2	3	4	5
No difficulty in standing					Extreme difficulty in standing

9 On average, how much does the arthritis in your feet affect your walking? (please circle the number which most closely applies to you)

0	1	2	3	4	5
No difficulty in walking					Unable to walk at all

10 On average, how much does the arthritis in your feet affect your ability to climb up and down stairs? (please circle the number which most closely applies to you)

0	1	2	3	4	5
No difficulty in climbing stairs					Unable to climb stairs

Other (please specify) _____

21 What treatments have you received for the arthritis in your feet? (please tick as many boxes as apply)

None

Insoles/Special shoes

Tablets

Physiotherapy

Other, please specify _____

22 Have you been seen by any practitioner (other than those you have mentioned in question 20) because of your arthritis?

Please list what type of practitioner you have seen (e.g. reflexologist)

Thank you for completing this questionnaire.

6.2 Draft questionnaire for rheumatologists

Imagine you are undertaking your first consultation with a patient who has an undifferentiated inflammatory arthropathy, do you:

1) *Systematically take a history of any foot problems the patient has been experiencing?*

Yes No

If yes, what do you ask?

2) *Examine the feet?*

Yes No

If yes, what do you examine?

3) *Undertake any specific investigations (e.g. X-rays)?*

Yes No

If yes, which investigations?

4) *Routinely use any validated outcome measure (e.g. DAS 28)?*

Yes No

If yes, what do you use?

5) *Routinely use any foot-specific outcome measure (e.g. the foot function index)?*

Yes No

If yes, what do you use?

What is the main clinical environment in which you work?

Teaching hospital DGH Private practice Other

What grade are you?

Consultant Specialist registrar Other

How many years experience do you have in your speciality?

Now consider that you are undertaking a consultation with a patient who has been diagnosed with rheumatoid arthritis within the last 6 months do you:

6) *Systematically take a history of any foot problems the patient has been experiencing?*

Yes No

If yes, what do you ask?

7) *Routinely examine the feet?*

Yes No

If yes, what do you examine?

8) *Undertake any specific investigations (e.g. X-rays)?*

Yes No

If yes, which investigations?

9) *Routinely use any validated outcome measure (e.g. DAS 28)?*

Yes No

If yes, what do you use?

10) *Routinely use any foot-specific outcome measure (e.g. the foot function index)?*

Yes No

If yes, what do you use?

Thank you for your participation, Simon Otter

Please return to S. Otter, Leaf Hospital, St Annes Rd, Eastbourne, BN21 2HW

Tel 01323 645555, Fax 01323 411605, email so54@bton.ac.uk

6.3 Draft questionnaire for podiatrists

Imagine that you are undertaking a consultation with a patient who has been diagnosed with rheumatoid arthritis within the last 3 years. Please answer the following questions with such a patient in mind.

1 Would you examine the joints of the foot for pain?

Please circle one; Yes No

1a If yes, please list which joints you assess

1b, Would you assess pain in these joints?

Please circle one; Yes No

1c, If yes, please outline how you assess pain

2 Would you examine joints in the foot for range of motion?

Please circle one; Yes No

2a If yes, please list which joints you examine

2b, Would you measure the range of motion in these joints?

Please circle Yes No

2c, If yes, please outline how you measure range of motion

3 Do you routinely record any deformities present in the feet?

Please circle one; Yes No

3a If yes, how do you record this information?

3 Do you look at patients when they are standing still?

Please circle one; Yes No

3a If yes, please indicate what you are looking for

4 Do you routinely examine the arterial supply & venous drainage to the feet?

Please circle one; Yes No

5 Do you routinely examine the neurological status of the patients' feet?

Please circle one; Yes No

6 Do you examine patients' shoes for wear patterns?

Please circle one; Yes No

7 Please describe what patients have said to you in the course of their treatment about how their feet affect their mobility? For example, *'its hard to get going in the morning'*

8 Please describe what patients have said to you in the course of their treatment about what symptoms they experience in their feet. For example *'its like standing on pebbles'*

9 Please describe what patients typically say about how their feet affect carrying out everyday activities, such as standing at the sink or walking to the shops

10 If your patients have ever reported that their feet reduce their quality of life, for example that they are unable to go out; please describe what they have said

11 Do you routinely use standard outcome measures to assess patients' feet, such as the Foot Function Index?

Please circle one; Yes No

11a If yes, which outcome measure(s) do you routinely use?

12 Some measures use a 100mm visual analogue scale (VAS) on which to record findings such as the level of pain being experienced. Do you find such scales helpful?

Please circle one; Yes No Don't use a VAS scale

13 Please list any aspects of foot assessment that you would like to record, but are unable to do so

13a Which factor(s) prevent, or deter you from recording such information?

14 What, in your opinion, would most enhance podiatric care for patients with early rheumatoid arthritis within your locality?

Thank you for taking the time to complete this questionnaire

Please place your responses in the envelope provided and hand it in to Simon Otter, or if you prefer to complete it later & return it by post.



University of Brighton

**Survey of foot
complaints
among people
with Rheumatoid
arthritis**

About you

Firstly, we are seeking some general information about you

1. How old are you? Years
2. Are you male or female? Male Female
3. Are you currently working?
YES, I have a paid job Full-time Part-time

IF YES, what do you do? _____

OR I do unpaid work Full-time Part-time

IF YES, what do you do? _____

OR I am on sick leave
I am retired

IF YES, what did you do? _____

OR NO, I do not work

4. Are you currently a cigarette smoker?
No, never No, I gave up Yes

5. Approximately how tall are you?
 feet inches **OR** cm

6. Approximately how much do you weigh?
 stones lbs **OR** kg
-

About your rheumatoid arthritis

Next, we need some information about your rheumatoid arthritis

7. How long ago did your symptoms of rheumatoid arthritis actually start?

Symptoms started Months / Years ago
(delete as appropriate)

8. How long ago were you first told you had rheumatoid arthritis?

I was told Months / Years ago
(delete as appropriate)

9. At the start of your condition, which joints were affected by your rheumatoid arthritis.

Please indicate which were involved first by putting number 1, second by 2, third by 3 and so on... If a joint has NEVER been involved, please leave that box blank or put 0.

Finger/hand joints	<input type="checkbox"/>	Back	<input type="checkbox"/>
Wrist joints	<input type="checkbox"/>	Hip joints	<input type="checkbox"/>
Elbow joints	<input type="checkbox"/>	Knee joints	<input type="checkbox"/>
Shoulder joints	<input type="checkbox"/>	Ankle joints	<input type="checkbox"/>
Neck	<input type="checkbox"/>	Toe/foot joints	<input type="checkbox"/>

10. Are you currently under the care of a hospital Rheumatologist?

Yes

No

11. Are you taking any medication prescribed by your doctor for your arthritis at the current time?

Yes

No

12. **IF YOU ARE TAKING ANY MEDICATION**, please look at the list of treatments below and tick any that you are currently taking:

- | | | | |
|-------------------------|--------------------------|-----------------------|--------------------------|
| Prednisolone (steroids) | <input type="checkbox"/> | Azathioprine | <input type="checkbox"/> |
| Deflazacort | <input type="checkbox"/> | Leflunomide | <input type="checkbox"/> |
| Methotrexate tablets | <input type="checkbox"/> | Cyclosporin-A | <input type="checkbox"/> |
| Methotrexate injections | <input type="checkbox"/> | Hydroxychloroquine | <input type="checkbox"/> |
| Sulphasalazine | <input type="checkbox"/> | Infliximab injections | <input type="checkbox"/> |
| Gold tablets | <input type="checkbox"/> | Adalimumab injections | <input type="checkbox"/> |
| Gold injections | <input type="checkbox"/> | Etanercept injections | <input type="checkbox"/> |
| Penicillamine | <input type="checkbox"/> | Cyclophosphamide | <input type="checkbox"/> |

13. When you get out of bed in the mornings, do some or all of your joints currently feel stiff?

Yes

No

IF YES, how long does the stiffness generally last for?

Stiffness lasts for Minutes / Hours each day
(delete as appropriate)

About your feet

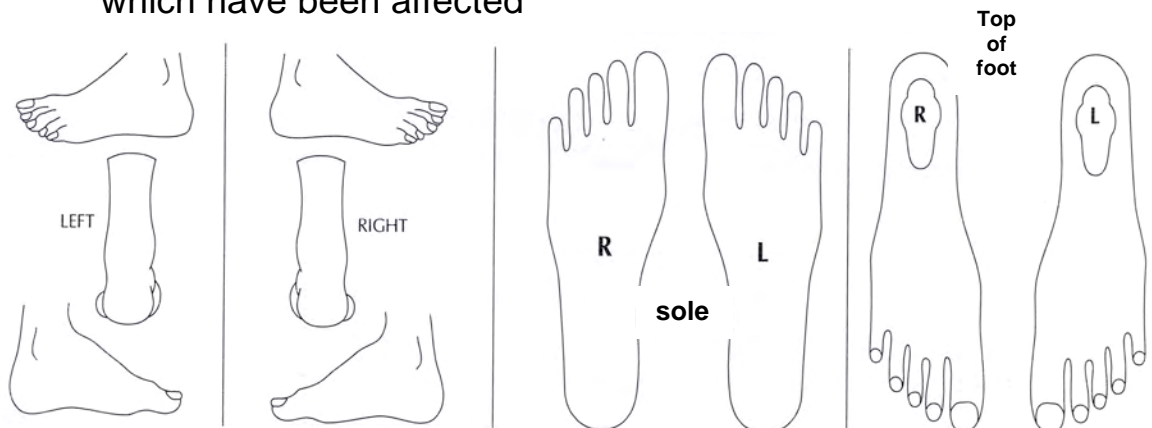
We are particularly interested in how your arthritis affects your feet

14. Have you **ever** had pain in your feet which you think is because of the rheumatoid arthritis which lasted one day or longer?

Yes

No

IF YES, please circle on the diagrams below ALL the places which have been affected

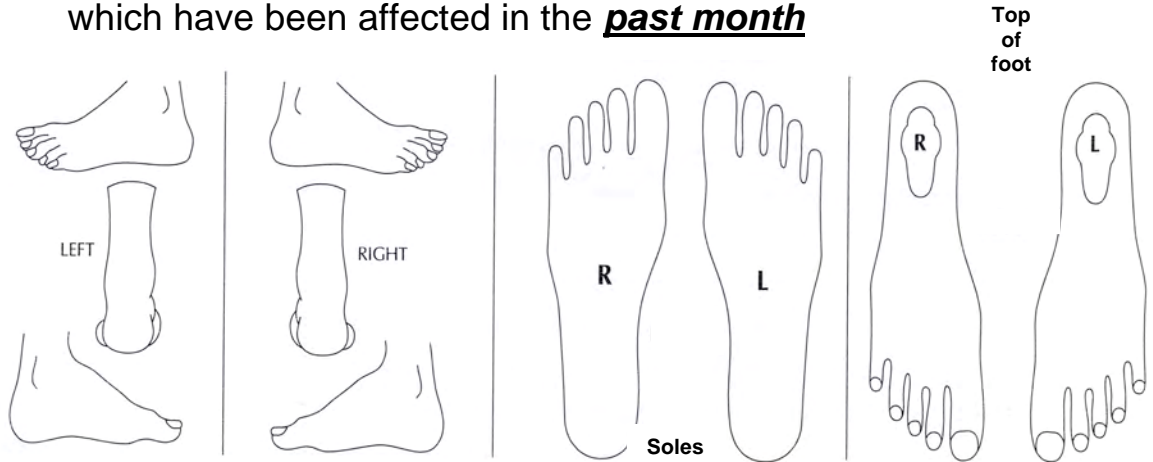


15. In the **past month**, have you had pain in your feet because of the rheumatoid arthritis which lasted a day or longer?

Yes

No

IF YES, please mark on the diagrams below ALL the places which have been affected in the **past month**

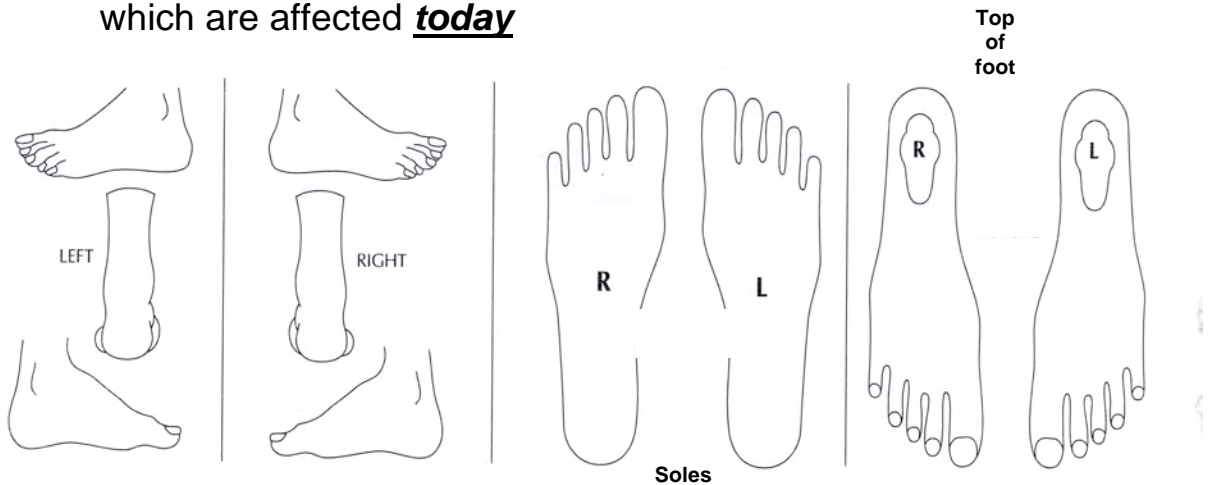


16. **Today**, do you have pain in your feet which you think might be because of the rheumatoid arthritis?

Yes

No

IF YES, please mark on the diagrams below ALL the places which are affected **today**



AND IF YES, please estimate how severe it is **today**

No **0**
pain



10

Worst
pain
ever

17. Apart from pain, do you have any of these other symptoms in your feet? (please tick ALL that apply)

	No NEVER	Yes, SOMETIMES	Yes, ALL THE TIME
Stiffness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Swelling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Numbness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. Have you discussed your foot symptoms with your GP at any time?

Yes No

19. Have you discussed your foot symptoms with your hospital Rheumatologist at any time?

Yes No N/A

20. Approximately how long ago did a doctor or specialist rheumatology nurse last examine your feet?

Approximately | Months / Years ago
(Delete as appropriate)

21. Approximately how long ago did a doctor or specialist rheumatology nurse last examine your hands?

Approximately | Months / Years ago
(Delete as appropriate)

22. Do you have difficulty cutting your toe nails because of your rheumatoid arthritis?

Yes No

23. Have you ever seen a chiropodist/podiatrist about your feet?

Yes No

24. Have you ever seen a foot surgeon about your feet?

Yes No

25. Have you ever had an operation on your feet?

Yes

No

26. Please list any problems that you have had with your feet e.g. corns, ulcers, callus, bunions, flat feet etc.

27. Have you been prescribed insoles for your shoes?

Yes

No

IF YES, for which foot?

Right

Left

Both

AND IF YES, do you still wear them?

Yes

No

IF YOU DO NOT WEAR THEM, why not?

They were not helpful

They wore out

They caused more pain

My symptoms got better

I had surgery

I had special shoes made instead

Did not fit in my shoes

28. Have you ever been prescribed hospital shoes?

Yes

No

AND IF YES, do you still wear them?

Yes

No

IF YOU DO NOT WEAR THEM, why not?

They were not helpful

They wore out

They caused more pain

My symptoms got better

They look unattractive
I had surgery
Do not fit

29. To what extent has your arthritis in your feet interfered with your normal social activities with your family and/or friends?
(Please tick one box)

Never Once or twice Sometimes Often All the time

30. How has your arthritis in your feet affected your normal social activities with your family and/or friends?

(a) *I have to cut down the amount of time I spend participating in social activities*

Never Once or twice Sometimes Often All the time

(b) *I am limited in the kind of social activities I can undertake*

Never Once or twice Sometimes Often All the time

(c) *I have difficulty performing the social activities I wish to participate in*

Never Once or twice Sometimes Often All the time

31. Is there any additional information that you would like to provide?

**THANK YOU FOR TAKING THE TIME TO
COMPLETE THIS QUESTIONNAIRE**

Please return completed questionnaire to:
Mr Simon Otter, Leaf Hospital, St Anne's Road, Eastbourne, BN21 2HW
In the stamped, addressed envelope provided

7.2 Final questionnaire for rheumatologists

Rheumatoid arthritis and the foot																									
1	During any stage of their disease, what proportion of patients with rheumatoid arthritis would you estimate experience foot problems?																								
2	Early in the course of their rheumatoid arthritis (within <i>the first 12 months</i>), what proportion of patients with rheumatoid arthritis would you estimate experience foot problems?																								
3	In your experience, what proportion of patients with rheumatoid arthritis have foot problems but do not report them to you?																								
4	Please indicate what foot problems are <i>most commonly</i> reported by patients with RA? (please order your responses by placing 1 in the box which is most common, 2 in the next most common, 3 in the third etc.)																								
	<table border="1" style="width: 100%; border-collapse: collapse;"> <tbody> <tr> <td style="width: 50%; padding: 5px;">Metatarsal pain</td> <td style="width: 5%; text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> <td style="width: 50%; padding: 5px;">Pain in the mid foot/arch</td> <td style="width: 5%; text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> </tr> <tr> <td style="padding: 5px;">Heel pain</td> <td style="text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> <td style="padding: 5px;">Ankle pain</td> <td style="text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> </tr> <tr> <td style="padding: 5px;">Difficulty walking</td> <td style="text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> <td style="padding: 5px;">Difficulty obtaining shoes</td> <td style="text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> </tr> <tr> <td style="padding: 5px;">Foot deformity</td> <td style="text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> <td style="padding: 5px;">Ulceration</td> <td style="text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> </tr> <tr> <td style="padding: 5px;">Cold feet</td> <td style="text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> <td style="padding: 5px;">Corns/Callus</td> <td style="text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> </tr> <tr> <td style="padding: 5px;">Swelling of the feet</td> <td style="text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> <td style="padding: 5px;">Numbness in feet</td> <td style="text-align: center; padding: 5px;"><input style="width: 20px; height: 20px;" type="text"/></td> </tr> </tbody> </table>	Metatarsal pain	<input style="width: 20px; height: 20px;" type="text"/>	Pain in the mid foot/arch	<input style="width: 20px; height: 20px;" type="text"/>	Heel pain	<input style="width: 20px; height: 20px;" type="text"/>	Ankle pain	<input style="width: 20px; height: 20px;" type="text"/>	Difficulty walking	<input style="width: 20px; height: 20px;" type="text"/>	Difficulty obtaining shoes	<input style="width: 20px; height: 20px;" type="text"/>	Foot deformity	<input style="width: 20px; height: 20px;" type="text"/>	Ulceration	<input style="width: 20px; height: 20px;" type="text"/>	Cold feet	<input style="width: 20px; height: 20px;" type="text"/>	Corns/Callus	<input style="width: 20px; height: 20px;" type="text"/>	Swelling of the feet	<input style="width: 20px; height: 20px;" type="text"/>	Numbness in feet	<input style="width: 20px; height: 20px;" type="text"/>
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Swelling of the feet	<input style="width: 20px; height: 20px;" type="text"/>	Numbness in feet	<input style="width: 20px; height: 20px;" type="text"/>																						
	Other (please describe)																								

Examination & Assessment

5 For **each** of the following scenarios, please indicate what proportion of RA patients' feet you would examine?

A patient with newly diagnosed RA

An established RA patient being considered for anti TNF treatment

A well controlled patient who has had RA for 8 years and no reported foot problems

6 Which of the following would usually cause you to examine RA patients' feet? (please tick **all** that apply)

High inflammatory markers	<input type="checkbox"/>	When patients report foot pain	<input type="checkbox"/>
Signs of inflammation elsewhere e.g. in the hands	<input type="checkbox"/>	When patients report difficulty walking	<input type="checkbox"/>
Previous examination findings	<input type="checkbox"/>	Routine practice	<input type="checkbox"/>
Instinct	<input type="checkbox"/>	When changing medication	<input type="checkbox"/>

7 How frequently do you usually examine RA patients' **feet**? (please select the **one** which most closely represents your practice)

Every consultation	<input type="checkbox"/>	Every other consultation	<input type="checkbox"/>
Annually	<input type="checkbox"/>	Every 2 years	<input type="checkbox"/>
No regular practice	<input type="checkbox"/>	Never examine feet	<input type="checkbox"/>

8 How frequently do you usually examine RA patients' **hands**? (please select the one which most closely represents your practice)

Every consultation	<input type="checkbox"/>	Every other consultation	<input type="checkbox"/>
--------------------	--------------------------	--------------------------	--------------------------

	Annually	<input type="checkbox"/>	Every 2 years	<input type="checkbox"/>
	No regular practice	<input type="checkbox"/>	Never examine hands	<input type="checkbox"/>
9	How frequently do you usually assess RA patients' gait? (please select the one which most closely represents your practice)			
	Every consultation	<input type="checkbox"/>	Only if walking difficulty reported	<input type="checkbox"/>
	No regular practice	<input type="checkbox"/>	Never assess gait	<input type="checkbox"/>
10	How frequently would you usually request an X-ray of the feet for RA patients'? (please select the one which most closely represents your practice)			
	Every consultation	<input type="checkbox"/>	Every other consultation	<input type="checkbox"/>
	Annually	<input type="checkbox"/>	Every 2 years	<input type="checkbox"/>
	No regular practice	<input type="checkbox"/>	Never request foot X-rays	<input type="checkbox"/>
	Only if foot problems reported	<input type="checkbox"/>	Only if surgery contemplated	<input type="checkbox"/>
11	How frequently would you usually request an X-ray of the hands for RA patients'? (please select the one which most closely represents your practice)			
	Every consultation	<input type="checkbox"/>	Every other consultation	<input type="checkbox"/>
	Annually	<input type="checkbox"/>	Only if hand problems reported	<input type="checkbox"/>
	No regular practice	<input type="checkbox"/>	Never request hand X-rays	<input type="checkbox"/>
	Every 2 years	<input type="checkbox"/>	Only if surgery contemplated	<input type="checkbox"/>
12	Would you order a MRI for RA patients' whom report foot problems?			
	Yes	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
			No, never	<input type="checkbox"/>
13	Would you order ultrasound imaging for RA patients' whom report foot problems?			
	Yes	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
			No, never	<input type="checkbox"/>
14	Would you order additional blood tests for RA patients' whom report foot problems?			
	Yes	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
			No, never	<input type="checkbox"/>
(a)	If yes, which blood tests would you order			
Referral practice				

15	Would you routinely refer RA patients with foot complaints to other healthcare professionals?						
	Yes <input type="checkbox"/>		No <input type="checkbox"/>				
(a)	If yes, to whom do you refer?						
	Occupational Therapist	Always	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Never	<input type="checkbox"/>
	Orthotist	Always	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Never	<input type="checkbox"/>
	Physiotherapist	Always	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Never	<input type="checkbox"/>
	Podiatrist/Chiropodist	Always	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Never	<input type="checkbox"/>
	Specialist Nurse	Always	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Never	<input type="checkbox"/>
About Local foot Services							
16	Are the following services available locally? (please tick one for each)						
		Yes, easily	Yes, but long waiting list	No	Don't Know		
	Podiatry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	Foot Surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	Chiropody	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
17	What influences your decision on making a referral to each of these groups (please tick all that apply)						
		Podiatry		Foot Surgery		Chiropody	
		Yes	No	Yes	No	Yes	No
	Ease of availability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Presence of severe foot symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Severity of RA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Type of drug therapy (e.g. Anti TNF)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Lack of skin Integrity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Severity of foot deformity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Age of patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Mobility of patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Co-existing disease (e.g. diabetes)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Inability to care for feet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18	Does anything hinder effective referral to local foot care services?			
	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
(a)	If yes, do any of the following apply? (please tick all that apply)			
		Podiatry	Chiropody	Foot Surgery
	Don't know how to refer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Don't know who to refer to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Unaware of referral criteria	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Service is unavailable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Other:			
Outcome measurement				
19	Do you routinely use validated disease activity measures (e.g. DAS 28) in your clinical practice?			
	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
(a)	If yes, which ones do you use? (please tick all that apply)			
	DAS 28	<input type="checkbox"/>	HAQ	<input type="checkbox"/>
	Other:			
20	Do you routinely use foot specific outcome measures (e.g. Foot Function Index) in your clinical practice?			
	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
(a)	If yes, which ones do you use? (please tick all that apply)			
	Foot Function Index	<input type="checkbox"/>	Foot pain disability score	<input type="checkbox"/>
	Leeds Foot Impact Scale	<input type="checkbox"/>	Foot Health Status Questionnaire	<input type="checkbox"/>
	Bristol Foot Score	<input type="checkbox"/>	Joint Alignment & motion scale	<input type="checkbox"/>
	Other:			
About You				
20	What is the main environment in which you work?			
	DGH	<input type="checkbox"/>	Teaching Hospital	<input type="checkbox"/>
	Private Practice	<input type="checkbox"/>	Primary Care	<input type="checkbox"/>

21	How long have you been working in Rheumatology?				
	<input type="text"/>	<input type="text"/>	Years		
22	How would you best describe yourself?				
	Consultant	<input type="checkbox"/>	Trainee / SpR	<input type="checkbox"/>	GpwSI / Clinical assistant
23	Are you?				
	Male		<input type="checkbox"/>	Female	

Thank you for completing this questionnaire.

Please return it in the SAE provided to:

Simon Otter
School of Health Professions
Leaf Hospital
St Annes Rd
Eastbourne
BN21 2HW

7.3 Final questionnaire for podiatrists

Imagine that you are undertaking a consultation with a patient who has been diagnosed with rheumatoid arthritis within the last 3 years. Please answer the following questions with such a patient in mind.

1a Do you routinely examine the joints of the feet to see if they are painful? *Please tick one;*

Yes [] Sometimes [] No []

1b If you do examine foot joints for pain, which ones do you examine? *Please tick all that apply?*

Ankle [] Sub-talar [] Mid-tarsal [] Metatarsophalangeal []

Interphalangeal [] Other – please specify _____

1c Please describe what factors determine whether you examine joints for pain?

2a Do you assess the level of pain in the joints of the foot? *Please tick one*

Yes [] Sometimes [] No []

2b If you do assess the level of pain in joints of the feet, what measure (if any) do you use to record this?

3a Do you examine the joints of the feet for range of motion? *Please tick one*

Yes [] Sometimes [] No []

3b If you do examine foot joints for range of motion, which ones do you examine? *Please tick all that apply?*

Ankle [] Sub-talar [] Mid-tarsal [] Metatarsophalangeal []

Interphalangeal [] Other – please specify _____

3c Would you measure the range of motion in these joints? *Please tick one*

Yes [] Sometimes [] No []

3d If you do examine the joints of the feet, for range of motion, how do you record this?

4a Do you routinely record any deformities present in the feet?

Yes [] Sometimes [] No []

4b If you do record foot deformities, how do you record this information?

5a Do you observe patients when they are standing still?

Yes [] Sometimes [] No []

5b If you observe patients when they are standing still, please indicate what you are looking for

6a Do you assess patients gait? *Please tick one*

Yes [] Sometimes [] No []

6b If you do assess patients gait, please describe what you are looking for

7 Do you routinely examine the arterial supply & venous drainage to the feet? *Please tick one*

Yes [] Sometimes [] No []

8 Do you routinely examine the neurological status of the patients' feet? *Please tick one*

Yes [] Sometimes [] No []

9 Do you examine patients' shoes to see how well they fit? *Please tick one*

Yes [] Sometimes [] No []

10 Do you examine patients' shoes for wear patterns? *Please tick one*

Yes [] Sometimes [] No []

11 Please describe what patients have said to you in the course of their treatment about what symptoms they experience in their feet. For example *'its like standing on pebbles'*

12 Please describe what patients have said to you in the course of their treatment about how their feet affect their mobility? For example, *'its hard to get going in the morning'*

13 Please describe what patients typically say about how their feet affect carrying out everyday activities, such as standing at the sink or walking to the shops

14 If your patients have ever reported that their feet reduce their quality of life, for example that they are unable to go out, please describe what they have said

15a Do you routinely use standard outcome measures to assess patients' feet, such as the Foot Function Index? *Please tick one*

Yes [] Sometimes [] No []

15b If you routinely use standard outcome measures, which outcome measure(s) do you use?

16 Some outcome measures use a 100mm visual analogue scale (VAS) on which to record findings (such as the level of pain being experienced). Do you find such scales helpful?

Please tick one

Yes [] Sometimes [] No []

17a Please list any aspects of foot assessment that you would like to record, but are unable to do so

17b What are the factor(s) that prevent, or deter you from recording such information?

18 What, in your opinion, would most enhance podiatric care for patients with early rheumatoid arthritis within your locality?

Thank you for taking the time to complete this questionnaire

Please return completed questionnaire to:

Mr Simon Otter, Leaf Hospital, St Anne's Road, Eastbourne, BN21 2HW

In the stamped, addressed envelope provided

Appendix 8

Raw data from all groups of respondents

N.B. Data available on CD located on inside back cover

Appendix 9
Demographic details of respondents who provided qualitative comments

Subject number	Age	Sex	Duration of RA (yrs)		Subject number	Age	Sex	Duration of RA (yrs)
1	71	F	49		85	73	F	4
8	32	F	20		86	31	F	16
9	39	F	16		87	74	F	9
11	72	F	29		88	52	M	6
12	64	F	4		90	69	F	4.6
20	77	F	25		91	66	F	7
21	56	F	24		93	56	F	8
22	50	F	6		97	62	F	8
23	47	F	8		98	56	F	24
24	52	F	18		99	67	F	8
25	58	M	1		100	71	F	10
26	80	F	32		102	53	M	2.6
33	61	F	20		103	61	F	0.5
37	56	F	1		104	54	M	22
38	29	F	5.6		105	55	F	2.6
39	54	F	5.6		108	64	F	20
40	49	F	33		109	67	F	7
41	63	F	20		110	63	F	4
42	42	F	9		111	61	F	1.2
44	61	F	27		112	42	F	0.2
47	40	F	17		113	54	F	23
48	36	F	0.1		116	64	M	2.5
49	68	F	35		118	28	F	8
52	59	F	3		120	55	F	10
55	59	M	5		122	59	F	17
56	64	F	NO DATA		123	79	F	20
57	58	F	2		124	66	F	8
58	57	F	3		125	74	M	4
63	60	F	9		126	63	F	8
64	71	F	34		127	50	F	4.5
65	62	F	11		129	56	F	1.5
68	55	M	3.5		130	51	F	2
70	76	F	NO DATA		134	46	F	18
71	46	F	5		135	45	F	0.8
72	41	F	3.6		139	60	M	16
73	51	F	7		143	70	M	7
74	68	F	17		145	47	F	14
78	54	F	24		146	57	F	3
79	50	F	8		148	63	F	1.4
80	59	M	11		149	68	F	13
84	62	F	19		150	53	F	1.8

Subject number	Age	Sex	Duration of RA (yrs)		Subject number	Age	Sex	Duration of RA (yrs)
152	61	F	25		226	50	F	3.5
154	56	M	1.4		228	63	F	11
156	58	F	5.9		230	73	F	20
158	62	F	35		231	48	F	18
159	34	F	2.5		233	52	F	9
160	62	M	15		235	54	F	6
161	53	F	2		239	79	F	43
166	54	F	5		241	65	M	17
168	45	F	8		244	32	F	3
169	60	M	20		245	61	M	4
170	70	F	36		249	40	F	3
171	56	F	0.5		250	81	F	26
172	45	F	5		251	67	F	3.3
177	43	F	1.8		254	60	F	4.5
179	29	F	8		260	58	F	0.8
181	76	F	4		261	41	F	2
182	70	M	11		262	30	F	27
183	55	F	3.5		264	62	F	4
184	61	F	3		265	56	F	7
185	61	F	21		268	65	F	20
187	41	M	5		269	59	F	1.2
188	46	F	11		275	54	F	6
192	63	F	2.5		278	61	M	2.2
194	46	F	0.3		281	49	F	12
196	50	F	4		284	81	M	5.5
199	68	F	6		286	66	F	13
202	58	F	19		288	71	F	6
203	47	F	14		289	50	M	0.3
204	58	F	19		290	72	F	2
205	44	F	2		292	58	F	13
207	56	F	14		294	32	F	1.9
208	63	F	38		295	56	2	16
211	60	F	2.1		296	48	F	2
212	47	F	0.5		297	82	F	17
213	53	F	25		301	60	F	10
215	63	M	7		302	62	F	20
216	50	F	2		303	65	F	17
217	59	F	21		304	50	F	0.8
218	58	F	6		306	47	F	5
221	57	F	12		308	26	F	1
222	77	F	77		311	71	F	20

Subject number	Age	Sex	Duration of RA (yrs)
313	45	F	1
314	57	F	4
316	54	F	20
319	68	F	10
323	50	F	5
326	75	F	53
327	76	F	1
328	58	F	3
329	70	F	9
330	42	F	5
334	57	M	7
336	74	M	3
340	67	F	18
341	59	M	0.1
342	43	F	24
343	39	F	10
344	43	F	25
347	39	F	4
349	60	F	5
350	73	F	3
351	54	F	7
352	62	F	6.5
354	60	F	3
355	59	F	2.5
358	58	F	25
360	72	F	3.3
366	49	M	NO DATA
368	75	F	8
369	59	F	5
370	46	F	1.5
371	57	F	37
373	69	F	36
375	72	F	2
376	37	F	4
380	39	F	18
382	57	F	25
383	56	F	40
384	28	F	2
385	63	F	10
386	45	F	2.3
388	62	F	9

Subject number	Age	Sex	Duration of RA (yrs mnths)		Subject number	Age	Sex	Duration of RA (yrs mnths)
1001	54	F	35		1083	57	F	4
1002	77	F	20		1085	57	F	NO DATA
1004	75	M	30		1088	58	F	22
1005	41	F	12		1089	31	F	4
1008	47	F	2		1094	67	F	55
1009	73	M	12		1099	58	M	8
1013	67	F	11		1100	65	F	25
1014	45	F	3		1103	55	F	7
1015	62	F	4		1104	68	F	24
1017	65	F	15		1105	52	M	22
1018	58	F	30		1106	87	F	2
1019	53	F	8		1109	50	F	2
1020	67	M	9		1110	75	F	25
1025	58	M	1.5		1111	95	M	13
1026	79	F	NO DATA		1113	75	F	40
1027	56	M	12		1115	59	F	32
1030	69	M	5		1116		F	14.5
1032	75	F	5		1119	59	F	8
1034	80	M	55		1121	58	F	25
1036	65	F	7		1122	71	M	10
1037	55	M	4		1123	85	F	63
1038	60	F	10		1124	68	F	12
1039	55	F	20		1125	60	F	40
1041	73	F	23		1126	76	F	NO DATA
1042	74	F	8.3		1128	54	F	15
1047	62	F	20		1129	51	F	9.5
1050	86	F	4		1131	56	F	6
1051	71	M	3.5		1134	77	F	NO DATA
1057	66	F	25		1135	55	F	6
1058	62	F	32		1141	79	M	NO DATA
1059	66	F	25		1142	75	F	36
1060	80	M	4		1143	44	F	2.3
1062	83	F	NO DATA		1146	68	F	4
1063	28	F	1.5		1148	57	F	4
1064	74	M	20		1149	63	F	2
1067	63	F	21.5		1152	55	F	18
1070	58	M	20		1153	51	F	44
1076	60	M	10		1155	82	M	6
1077	49	F	31		1157	59	F	22
1081	42	F	9		1158	67	F	22
1082	59	F	1.5		1159	63	F	25

Subject number	Age	Sex	Duration of RA (yrs mnths)
1160	60	F	30
1162	67	F	19
1168	62	F	8
1170	70	M	15
1181	59	F	3
1182	51	F	8
1184	64	F	22
1185	55	F	21
1186	54	F	14
1187	53	F	3
1188	49	F	0.1

Appendix 10

Themes generated from analysis of qualitative data

Following the thematic analysis (described in section 5.8.2) of qualitative comments from those with RA, five emergent themes were represented. These were:

- The overwhelming severity of symptoms experienced in the feet.
- Reduced mobility due to the severity of foot complaints.
- An inability to find shoes that were comfortable and cosmetically acceptable.
- The culmination of symptoms in the feet, reduced mobility and unsuitable footwear had a profoundly negative impact on quality of life and ability to undertake valued life activities.
- A perceived lack of interest by clinicians in foot complaints.

The most obvious theme was one of overwhelming severity of symptoms in the feet suffered by those with RA. A number of subjects commented on the intensity of the pain they frequently experienced, often these symptoms were more severe and/or frequent than symptoms elsewhere. For example,

“Its even very painful to stand barefoot on thick carpet. Have sharp stabbing pain whilst standing or seated (even when feet elevated or in bed)” (subject 145)

“Feet are in constant pain – cannot walk more than 200 yards without orthotics and trainers with support under ball of foot... Pain level increases the more I walk” (subject 231)

“I have localised areas of severe pain on the soles of my feet and a generalised lower level of pain in the whole of the soles of my feet. The pain is there all the time even when in bed” (subject 269)

“My feet still cause me the most pain and I have great difficulty in buying comfortable shoes that I can wear all day at work. I had corrective foot surgery in both feet in 2004” (subject 296)

“Foot problems cause everyday living to be very painful” (subject 371)

“My feet are constantly sore whereas pain in my other joints varies – sometimes little pain, sometimes very painful” (subject 1037)

“I have more pain in left foot and ankle, but have pain in both feet all the time. I find stairs very difficult. Sometimes I walk with a stick on bad days” (subject 1103)

The on-going pain and discomfort in the feet experienced by those with RA consequently reduced subjects mobility, with some commenting that they were slower at getting around and required more rest or the use of walking aids, which sometimes included the use of wheelchairs. For example,

“I have found the problems with my feet very frustrating. I’m unable to walk any distance and I have to resort to a wheelchair, which I hate” (subject 172)

“I cannot wear attractive footwear. I cannot walk. I am in constant pain.” (subject 221)

“Walking of being on feet for extended periods exacerbates foot arthritis – just requires well judge rest periods” (subject 1015)

The overwhelming severity of foot complaints closely associated with the consequent negative impact on mobility gave rise to a third theme that a number of respondents clearly felt very strongly about, that of not being able to find shoes that were comfortable enough to walk in and/or were acceptable from a cosmetic perspective. Examples of the difficulties with finding shoes reported by those with RA included,

“Buying shoes and boots are a nightmare. I have lots of shoes as what I can wear one day I cannot wear the next day. My toes feel hot and I need to keep exercising them and my feet become very swollen. I suffer from the cold and once my feet become cold it is difficult to get them warm again” (subject 103)

“I’ve had 3 ops on right foot, 1 on left and waiting for another and I’ll probably need a fusion on the left one in a couple of years. Right one already done. My shoe/boot/trainer size has gone from size 7 to as low as a size 4. I hate my feet! I couldn’t wear shoes/boots for 4½ years” (subject 168)

“I find it almost impossible to buy shoes which are comfortable. Most shops are useless in providing advice. Mail order is not satisfactory either” (subject 108)

“Arthritic feet make life very difficult. Walking is limited and painful and worst of all fashionable shoes are a no no. Trainers are best” (subject 217)

“My feet problems are probably the most difficult to live with. Finding shoes which fit is an absolute nightmare. Vanity stops me wearing my “hospital” shoes. Every step I take feels like I’m walking on marbles” (subject 1182)

The loss of mobility and/or the need to rely on others because of foot complaints coupled with the inability to find comfortable shoes in which were cosmetically acceptable to respondents and enabled them to ambulate satisfactorily had a profound effect on their quality of life and ability to undertake social and occupational activities that were important to them.

“It is very difficult to find shoes on the High Street, other than lace-ups, which will accommodate orthotics. Not being able to wear a “stylish” shoe makes a person feel disabled and lowers self-esteem and mood” (subject 105)

“I feel upset that I cannot wear shoes, sandals or boots if I wish to walk (for last 10 years)” (subject 231)

“Pain in my feet/ankles and other joints caused me to give up my career in nursing and take a more sedentary job working for a bank. It has impacted greatly on my life” (subject 306)

“My symptoms are much improved because I am on Etanercept injections. Previously I had severe problems with my feet (unable to wear normal shoes) causing bad posture, pain and unable to walk any distance. This all impacted on my way of life, work and sleep. I was never offered any chiropody help only wax treatment via physiotherapy or insoles” (subject 275)

“RA has dictated my lifestyle for the last 30+ years. After the initial period of being very unwell and in a lot of pain until it was correctly diagnosed and treated. I had long periods in remission when I was younger, though my life was restricted by the damage to feet, hands and wrists in the early stages” (subject 1058)

“I used to be a long distance runner thirteen years ago. I also loved long walks across hills and dales, mountain climbing, dancing. All finished now. If I do any of these things now I can barely walk next day” (subject 1085)

As the previous four themes illustrate, foot complaints in RA caused those with the disease a number of difficulties, these included having to cope with severe symptoms and the impact these have on mobility as well as difficulties obtaining suitable shoes, which coupled with symptoms adversely affected quality of life. The final theme reported by those with the disease was a perceived disinterest by clinicians in their foot complaints. Often those with RA highlighted that their feet were not routinely examined, in spite of the severity of symptoms experienced, and this was a further cause of frustration for many. For example,

“My feet have generally not been of particular interest in my rheumatology care. For me the difficulties I’ve had with both my feet have been the most difficult to cope with. Thank you for your questionnaire.” (subject 33)

“I am glad you are carrying out this research, because I feel it is a neglected area in the treatment of RA. My feet are my biggest problem. It is getting increasingly difficult to find any sort of footwear that fit my deformed feet. I resort to wearing

old shoes and trainers which depresses me greatly. Generally, not much interest has been shown by medical professions in problems with my feet.” (subject 44)

“Pain and stiffness in feet improving since commencing Embrel 26th June 2005. I cannot understand why feet and toes are not part of the assessment for Embrel. Hands and feet are routinely x-rayed for” (subject 90)

“Have had feet x-rayed several times, but when I tell nurse or doctor at hospital about problems and pain with feet, they say there are too many bones in the feet to look into it! So they only x-ray them to see any deterioration” (subject 93)

“Rheumatologist dismisses foot pain/swelling, etc as “part of the illness – nothing we can do” – NEVER examines feet” (subject 129)

“I don’t think rheumatologists pay enough attention to the feet when checking for joint progress/deterioration. As they carry you about all day the pain can be excruciating. I only wear trainers from Ecco with my insoles to protect the balls of my feet and my feet hurt after about 10 minutes of being upright” (subject 343)

“Apart from providing surgical shoes with insoles the feet seem to be disregarded when assessing RA. When I have the Infiximab infusion, the feet are disregarded when adding the scores. All other joints are scored regarding amount of pain. My feet are never free of pain” (subject 1159)

In summary, the qualitative information provided by those with RA gave a unique insight into the nature and extent of foot complaints seen in RA. In addition these data afforded an opportunity to determine how foot complaints affect everyday living for people with RA and highlight how foot complaints are a central part of the pattern of symptoms experienced by those with the disease. Perhaps more importantly these data bestows a perception of the consequences of foot complaints that would not normally be available to those who have not experienced RA.

Appendix 11

Details of Statistical analysis