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# 'My feet – visible, but ignored ...' A qualitative study of foot care for people with rheumatoid arthritis

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Anita E Williams<sup>1,2</sup> and Andrea S Graham<sup>1</sup>

## Abstract

**Objective:** To explore patients' experiences of foot problems associated with rheumatoid arthritis, from onset of symptoms to being provided with foot health interventions.

**Design:** A qualitative design was used with an interpretive phenomenological approach to the data collection and analysis.

**Setting:** University of Salford, School of Health Science.

**Subjects:** Sixteen female and six male adults with rheumatoid arthritis-related foot problems and experience of receiving foot health interventions.

**Method:** Data were collected through digital recordings of three focus groups which were conducted by an experienced researcher. An observer made field notes. Transcribed data were analysed using a thematic framework. Data were verified with randomly selected participants and agreement achieved with the participants, researcher and observer.

**Results:** The results were organized into five themes: the significance of foot symptoms in relation to diagnosis of rheumatoid arthritis; knowledge of and explanation about foot symptoms; accessing foot health interventions; the effectiveness of foot health interventions; and improvements to foot health interventions. Despite foot problems being of concern to the participants, they were often ignored by practitioners from before diagnosis through to foot management.

**Conclusions:** This study has highlighted a polarity between what these participants need in relation to their foot symptoms and the management of them. That foot problems are often ignored is of concern at multiple levels. These range from the implications of ignoring foot symptoms that may aid diagnosis of rheumatoid arthritis, to ignoring the need for effective foot health interventions.

## Keywords

Foot and ankle, healthcare, qualitative study, rheumatoid arthritis

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<sup>1</sup>Directorate of Prosthetics, Orthotics and Podiatry, School of Health Science University of Salford, UK

<sup>2</sup>Centre for Health, Sport and Rehabilitation Sciences Research, University of Salford, UK

## Corresponding author:

Anita E Williams, Brian Blatchford Building, University of Salford, Frederick Road, Salford M6 6PU, UK  
Email: a.e.williams1@salford.ac.uk

## Introduction

A number of studies have described the common structural and functional changes in the foot affected by rheumatoid arthritis,<sup>1-6</sup> with up to 89% of people with rheumatoid arthritis having some form of foot pathology.<sup>7</sup> These foot problems have the potential to impact negatively on physical function, social participation and quality of life,<sup>8-10</sup> with pain affecting the majority on a daily basis even when the disease is in remission.<sup>11</sup> Further, the multidimensional implications of living with feet affected by rheumatoid arthritis include restrictions in the choice of footwear and clothing.<sup>12-14</sup>

The aims of managing feet affected by rheumatoid arthritis are to relieve pain and preserve foot function, thereby improving the individual's mobility and activity. The therapeutic components that are central to achieving these aims are foot health management,<sup>15</sup> foot orthoses and specialist therapeutic footwear.<sup>16,17</sup> Foot health management includes the appropriate care of skin callosities, which contribute to foot symptoms and foot ulceration.<sup>18</sup>

In support of the need for foot health management, it is recommended<sup>19-21</sup> that people with rheumatoid arthritis have access to foot health services and a specialist podiatrist. Despite this, there is evidence of patchy service provision<sup>22,23</sup> with some indication of the impact of this on individuals. However, what is not known is the patient's perspective of their whole experience of foot problems. Therefore, the aim of this study was to explore patients' personal experiences of rheumatoid arthritis-related foot problems from the initial onset of foot symptoms through to their management.

## Method

### Study design

A qualitative methodology was used with an interpretive phenomenological approach<sup>24</sup> being adopted for both the data collection and analysis. This approach considers the experiences of the participants and acknowledges the researcher's previous experiences of the subject.<sup>25</sup> This results in a 'fusion of horizons'<sup>26</sup>

and an agreed level of understanding. Focus groups were chosen as the method of data collection. The group dynamics, social interaction and group synergy are distinct features of this method, creating a richness of data.<sup>27</sup> It is suggested that three or four groups of six to eight participants will achieve sufficient data for the aim of the study to be achieved.<sup>28</sup>

### Participants

Following ethical approval from the University of Salford Ethics Committee, participants were purposively recruited. The inclusion criteria were adults (>18 years) who could read speak and understand the English language, a positive diagnosis of rheumatoid arthritis<sup>29</sup> and experience of foot problems, foot orthoses, foot surgery and/or specialist therapeutic footwear. The exclusion criteria were those with an unconfirmed diagnosis of rheumatoid arthritis, no experience of foot problems or foot health interventions, those who could not speak and understand the English language and those who declined to be involved. The participants were recruited from the National Rheumatoid Arthritis Society branches in the north west of England. Twenty-five people who met the inclusion criteria were provided with written information about the study. Three people declined due to reasons of hospital appointments or holidays.

### Data collection

Twenty-two participants agreed to proceed to one of three focus groups which were carried out at the University of Salford. The focus groups comprised one with eight participants and two with seven in each and were a mix of males and females. Formal informed consent was obtained and the participants were assured that they could withdraw from the study at any time.

All the focus groups were conducted by an experienced researcher with an independent observer taking field notes. Both had 10 years of clinical experience of working as podiatrists within a rheumatology service. The dialogue was recorded on a digital voice recorder. The researcher (AW) asked an initial question: 'Tell me about your experiences

of foot problems and how they have been managed.’ Further ad hoc prompts were used if the participants wandered off the subject of feet for too long. All were encouraged to contribute when a specific issue was raised to ensure that the experiences revealed were not just those of one or two participants.

### Data analysis

The dialogue was transcribed verbatim immediately after the focus groups by the researcher (AW) and confidentiality achieved by replacing participants’ names with pseudonyms. Analysis was carried out using a thematic approach<sup>30</sup> with the framework agreed by the researcher and the observer. To enhance credibility of the analysis, we reviewed and coded the data, discussed the themes, further coded the data and then the agreed codes were then organized into themes. Exemplars from the transcripts were identified in order to illuminate the true ‘authentic’ nature of the participants’ experiences and to support the trustworthiness of the findings. Four of the participants from each group were randomly selected to read and verify that the transcripts and results reflected the experiences of the groups.

### Results

Sixteen females – mean (SD) age was 58 (11.9) years and mean (SD) disease duration was 15 (5.2) years. Six males – mean (SD) age was 59 (6.0) years and mean (SD) disease duration was 13 (5.0) years.

All participants reported experience of foot pain. One participant had been recently diagnosed with diabetes but had no known complications associated with it. None of the participants were house bound and only one female used a walking aid.

All participants had accessed some form of professional foot care for their nails and skin with all but two participants having experience of foot orthoses. Four females and one male had experience of being provided with specialist therapeutic footwear but only one female wore the footwear on a regular basis. Three had experience of foot surgery.

The results indicate that despite foot problems being of concern to them, their foot problems and their

needs are often ignored by practitioners from before the diagnosis of rheumatoid arthritis through to the management of their foot problems. This global theme is supported by the following five themes. These five themes were evident in all three focus groups.

#### *Theme 1 – The significance of foot symptoms in relation to the diagnosis of rheumatoid arthritis*

Many of the participants reported that they had experienced problems with their feet before a diagnosis of rheumatoid arthritis was made. Most reported that their feet were ignored by their general practitioners (GPs) even if they mentioned foot symptoms during a consultation. Foot symptoms were of great concern to the participants and one of the most worrying aspects of their disease. They also perceived that their GPs did not understand the significance of foot symptoms in relation to the possibility of rheumatoid arthritis:

‘It wasn’t picked up even though I kept saying that it was rheumatoid . . . felt I wasn’t listened to by my doctor . . . even when I complained about my feet I was told that it was my shoes.’ [F 54]

Some of the participants reported a delay in being referred to a rheumatologist and had to be proactive in achieving this:

‘It took months to get a diagnosis . . . mine was four years and I had joint pain and particularly foot pain . . . all that time . . . I had to change to another practice and then I was listened to.’ [M 60]

They felt anxious and this was compounded by the thought that they might be perceived as being a nuisance. Some recognized that delays in referral for diagnosis and then delayed intervention had a detrimental effect on their feet:

‘No one asked about it until it seemed too late and my feet had deformed. . . . I am so angry about that . . . something might have been done if . . . well its no use now is it?’ [F 59]

The fact that their feet were ignored by their GPs resulted in an overall lack of confidence in them and anger that their foot symptoms had been ignored.

### *Theme 2 – Knowledge of and explanation about foot symptoms*

The participants reported that they had patchy knowledge of what causes the foot problems associated with rheumatoid arthritis. Some had been referred to podiatry services where they had received the information that they needed:

‘Didn’t associate pain in foot with rheumatoid arthritis . . . stupid really . . . and then they started changing shape . . . I was referred to the podiatrist and was so relieved when I was told what was going on.’ [F 55]

However, a small number suggested that too much information could be detrimental. All agreed that it would be more appropriate for the patient to take the lead as to when information should be given;

‘I don’t think I would have liked too much info in the beginning as you don’t take it in but it would have been good to have the opportunity to be able to ask when needs arise.’ [F 57]

Further, some thought that written information can be frightening if it is not supported with verbal explanation:

‘The information leaflet on feet left me quite traumatized. . . . There was no reassurance (in leaflet) that things could be done to prevent it – he (the podiatrist) didn’t discuss it.’ [F 52]

The majority expressed relief once they had acquired knowledge about their foot symptoms. However, the lack of timely ‘information giving’ by many practitioners resulted in them being left to work out what their foot problems were. Many were never asked what they needed to know or when they needed it.

### *Theme 3 – Accessing foot health interventions*

When they had been diagnosed with rheumatoid arthritis by a rheumatologist, some reported that they had difficulty getting foot care, with delays in both being referred and then getting an appointment with a podiatrist:

‘When I eventually got referred to the consultant he asked all about my feet . . . but it then took ages to get to see a podiatrist.’ [M 68]

For some, the lack of attention given to feet during their consultation with a rheumatologist resulted in delayed referral for podiatry. Some reported that their feet were ignored until, almost by accident, they were seen in a context other than the usual or expected referral route:

‘I was visiting my mother in hospital and she had a lady to look after her feet . . . I asked her how I could get it . . . now I go . . . and feel good when I have been.’ [F 59]

Having their feet ignored invoked feelings of anger and desperation:

‘They don’t ask about the feet . . . Heather Mills can walk and she has a false leg. I wondered if it would be better to have a below-knee amputation and get on with it . . . it took me to get angry and say to my consultant “you have to do something!”’ [F 64]

These same feelings were expressed in relation to accessing foot surgery:

‘I had to bang doors down to get it and get very angry with my consultant . . . they are my feet and I know what will help . . . it should be my choice . . . now I have less pain . . . I knew it would get rid of it.’ [F 59]

There appeared to be a reluctance to refer people for foot surgery:

‘I didn’t get referred for a surgical opinion until my podiatrist discussed it with me as an option . . . I could

have cried . . . just to think that I could have all these toes straight sooner so I could have worn more decent shoes for my son's wedding.' [F 62]

The overall impression was that their rheumatologists had to be more focused on the medical management and other areas of the body but it was identified that: 'if they did take the shoe off then perhaps they wouldn't ignore them' [M 62].

#### *Theme 4 – The effectiveness of foot health interventions*

Frequently, it was reported that the potential effectiveness of foot orthoses was limited by the footwear styles that the participants liked to wear. They thought that this problem is often ignored:

'I got insoles but they were not comfortable at all, particularly in certain shoes. . . . She said keep trying but I could only wear them in my boots . . . you will get used to them she said.' [F 61]

Abnormal wear of their footwear caused by the orthoses stopped some participants using them or they had to purchase new footwear:

'You get a line in the shoes where the end of the insole finishes and that means the shoes wear out quicker . . . and then they crack and break. . . . Need more shoes . . . so that's another problem.' [M 48]

However, when foot orthoses fitted into a variety of footwear styles, engagement was much better and hence foot symptoms improved:

'I had these supplied by the specialist podiatrist . . . she really listened to me and then made suggestions for shoes . . . I got them and then she checked them over . . . then made the insoles to fit in with my feet . . . they are really comfy and I can't walk without them.' [F 58]

Some had experience of wearing specialist therapeutic footwear but all reported a loss in choice of clothes and associated loss of femininity. They thought that the practitioners providing this footwear did not understand this:

'I hate these shoes but they are the only things I can wear . . . the man at the hospital was really nice but 'erm . . . I don't think he understands what it is like to be a woman wearing men's shoes.' [F 65]

However, despite these feelings most acknowledged some benefits:

'I look and feel like an old lady with these on but they are comfy . . . at least.' [F 60]

Most had accessed general foot care for nails, corns and callus. They valued this in respect of improvements in comfort:

'Having feet looked after is one of the things I don't have to worry about.' [F 63]

They understood the difference between generalist and specialist podiatrists and valued the links that the specialists had with the wider multidisciplinary team:

'I have a good podiatrist . . . she is very clever and understands my problems . . . she specializes in this . . . I only have to ask her and she sees me . . . my feet are so much better with the insoles and treatment . . . she knows all about the drugs too unlike the one I went to before.' [M 55]

'This one can get me into the consultant and the nurse when I need it . . . and that's really good it's like being in a big family.' [F 59]

It was also acknowledged that the option for open access to podiatry was reassuring in that they could get immediate help when new problems arose.

#### *Theme 5 – Improvements to foot health interventions*

The majority expressed the opinion that GPs should have knowledge about rheumatoid arthritis and the significance of foot problems in its diagnosis. Once a diagnosis has been made then referral to podiatry services was considered to be essential for those with foot pain.

There was overarching agreement that podiatry services should be valued more with a perception that lack of finances and managerial support being an obstacle:

‘I would like more importance to be given to foot care and orthotics so it’s not bottom of the pile . . . perhaps it needs more investment so there are no waiting lists for foot care . . . do you think the managers know how important it is to us?’ [F 64]

In relation to finding footwear in which to accommodate both their feet and their foot orthoses was an issue for the majority. It was suggested that in an age of technological advances therapeutic footwear should be designed and manufactured in contemporary styles with improvements in fit:

‘I know a lady who went to France and they put her feet in a scanner . . . her shoes fitted perfectly . . . it is so hit and miss with the dressmaker’s tape measure . . . no wonder it goes wrong.’ [F 55]

The need for a variety of therapeutic shoes for different functions was expressed:

‘Someone should invent a sandal that will take the insole and support your foot. . . . You put up with your feet being roasted in the summer.’ [F 56]

Informed decision-making was considered to be vital to regaining control over their foot problems:

‘Just because you have arthritis it doesn’t mean that you have to live with feet like this . . . if surgery will help then it should be available.’ [F 54]

## Discussion

This qualitative study has revealed much about the participants’ experiences of their foot problems from the point of disease onset, through to diagnosis and management. Foot problems continue to be common and disabling<sup>7,11</sup> despite the progress in new treatments<sup>11</sup> and therefore should not be ignored. The potential for the effective management

of feet<sup>15–17</sup> has been clearly evidenced. However, this study has highlighted a polarity between what people with rheumatoid arthritis perceive their needs to be and what is provided. The result of this is that for the participants of this study there is a gap between what the outcomes of foot health interventions could be and what they actually are. This study is not without its limitations. This was a relatively small number of participants and they were all from the north west of England and therefore the study is not a fully representative cross-section of the wider population of people with rheumatoid arthritis-related foot problems. The results may also have cultural specificity and generalizability may be limited to healthcare systems such as those in the north west of England. Bias could also have occurred in that the people volunteering to take part in the study may have done so because they have had negative experiences. In that respect we cannot claim that the results of this study reflect the experiences of the wider population of people with rheumatoid arthritis-related foot problems.

Although there are these limitations, it is clear that the participants of this study have revealed much about their experiences from which we can learn. That foot problems are ignored is of concern at multiple levels, ranging from the implications of ignoring foot symptoms that may aid diagnosis, to ignoring the need for foot health interventions. As rheumatoid arthritis often presents in the early stages in the small joints of the feet,<sup>2,6</sup> ignoring this at initial presentation may delay diagnosis and the commencement of appropriate medical management. Most of the participants in this study thought that feet were ignored even when a diagnosis was made when compared with the attention given to hands. The focus on hands places feet in a relegated position and therefore it is of no surprise to find that the participants consider that their feet are ignored. Also, ignoring feet at the point of diagnosis means that the ‘window of opportunity’ is being missed for the provision of foot orthoses which have the potential to contribute to the maintenance of good foot structure.<sup>31</sup>

Given the evidence for the clinical benefits of foot health management<sup>15–17</sup> it is of concern that for these participants, referral is patchy and often

delayed. However, even when they were referred, some participants reported negative experiences, particularly in relation to therapeutic footwear and foot orthoses. This may reflect the difficulty in achieving marriage between the function of these interventions and their aesthetic acceptability. However, there was little evidence of empathy being demonstrated by practitioners as highlighted in previous studies.<sup>12,13</sup>

Timely management of their foot health by empathic and knowledgeable practitioners with attention to the patient's needs were considered to be pivotal in ensuring that the known benefits of these interventions are realized.

Further work will be to survey a wider population of people with rheumatoid arthritis to ascertain a more comprehensive picture.

Despite being ignored in the clinical context, it is clear that people with rheumatoid arthritis wish to have a voice about their foot problems and the care that they need. Meeting their needs is important in relation to the potential for good foot health and as such, it is our duty to listen.

### Clinical messages

- Patients consider that foot symptoms are important in relation to the potential for a diagnosis of rheumatoid arthritis.
- Foot symptoms should instigate referral for foot health interventions, including surgery.
- Foot health interventions and patient education need to be provided with consideration for the patients needs.

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### Conflict of interest

The authors declare that there are no conflicts of interest in relation to this study.

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