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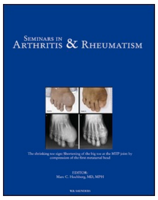

# Living with foot and ankle disorders in rheumatic and musculoskeletal diseases: A systematic review of qualitative studies to inform the work of the OMERACT Foot and Ankle Working Group

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## ABSTRACT

*Objectives:* This study aimed to determine outcome domains of importance to patients living with foot and ankle disorders in rheumatic and musculoskeletal diseases (RMDs), by exploring the symptoms and impact of these disorders reported in existing qualitative studies.

*Methods:* Six databases were searched from inception to March 2022. Studies were included if they used qualitative interview or focus group methods, were published in English, and involved participants living with RMDs (inflammatory arthritis, osteoarthritis, crystal arthropathies, connective tissue diseases, and musculoskeletal conditions in the absence of systemic disease) who had experienced foot and ankle problems. Quality was assessed using the Critical Appraisal Skills Programme qualitative tool and confidence in the findings was assessed using the Grading of Recommendations Assessment, Development and Evaluation Confidence in the Evidence from Reviews of Qualitative research (GRADE-CERQual) approach. All data from the results section of included studies were extracted, coded and synthesised to develop themes.

*Results:* Of 1,443 records screened, 34 studies were included, with a total of 503 participants. Studies included participants with rheumatoid arthritis ($n = 18$), osteoarthritis ($n = 5$), gout ($n = 3$), psoriatic arthritis ($n = 1$), lupus ($n = 1$), posterior tibial tendon dysfunction ($n = 1$), plantar heel pain ($n = 1$), Achilles tendonitis ($n = 1$), and a mixed population ($n = 3$), who live with foot and ankle disorders. Seven descriptive themes were generated from the thematic synthesis: pain, change in appearance, activity limitations, social isolation, work disruption, financial burden and emotional impact. Descriptive themes were inductively analysed further to construct analytical themes relating to potential outcome domains of importance to patients. Foot or ankle pain was the predominant symptom experienced by patients across all RMDs explored in this review. Based on grading of the evidence, we had moderate confidence that most of the review findings represented the experiences of patients with foot and ankle disorders in RMDs.

*Conclusions:* Findings indicate that foot and ankle disorders impact on multiple areas of patients' lives, and patients' experiences are similar regardless of the RMD. This study will inform the development of a core domain set for future foot and ankle research and are also useful for clinicians, helping to focus clinical appointments and measurement of outcomes within clinical practice.

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## Introduction

Foot and ankle disorders are common in rheumatic and musculoskeletal diseases (RMDs) and are associated with a reduction in quality of life [1–6]. However, despite widespread use of conservative, pharmacological and surgical interventions for these disorders in clinical practice, there is a lack of high-quality evidence for treatments [7]. Outcomes used to evaluate the effectiveness of treatments for people with foot and ankle disorders in RMDs are often measured inconsistently, limiting the ability to compare findings and synthesise data in meta-analyses [8,9]. Additionally, the current selection of outcomes in studies does not always reflect endpoints that are meaningful for patients with RMDs, whose priorities can differ substantially from those of clinicians and researchers [10,11].

These problems can be addressed through development of a core outcome set (COS); an agreed, standardised set of outcomes that are measured and reported, as a minimum, in all clinical trials in a specific area of health [12]. A COS reduces outcome heterogeneity and selective outcome reporting, and increases the relevance and transferability of study findings into clinical practice. The international Outcome Measures in Rheumatology (OMERACT) Initiative has successfully developed COSs for many RMDs [13]. An OMERACT Foot and Ankle Working Group, consisting of patient research partners, clinicians, and researchers was established in 2018 with the aim of developing an internationally agreed COS for foot and ankle disorders in RMDs. The first stage of this work is to develop a core set of outcome domains; a minimum set of *what* outcomes to measure, with a later stage focussing on *how* to measure these core domains [14].

Qualitative research is considered a necessary step as the gold-standard for developing a COS, leading to the identification of meaningful outcome domains that researchers may not have anticipated [15,16]. To our knowledge, no previous studies have synthesised the findings of existing qualitative studies exploring the lived experiences of people with foot and ankle disorders in RMDs.

We conducted a systematic review of qualitative studies to address the following research question: What are the perceptions and experiences (including symptoms reported and impact of symptoms) of people living with foot and ankle disorders in RMDs and how do these disorders impact upon their daily lives? Our aim was to determine which outcome domains are important to patients and should be considered for inclusion in a COS.

## Methods

Our systematic review was registered on PROSPERO (CRD42021299523). We followed the Enhancing Transparency of Reporting the Synthesis of Qualitative Research (ENTREQ) framework in reporting this review [17].

### *Inclusion criteria*

Studies in which the authors had used qualitative interviewing or focus group methods to explore the perceptions and experiences of adults (≥ 18 years) living with foot and ankle disorders in RMDs were eligible for inclusion. Eligible participants included adults with rheumatoid arthritis, osteoarthritis, spondyloarthropathies (SpA) (e.g. psoriatic arthritis), crystal arthropathies (e.g. gout) or connective tissue diseases (CTDs) (e.g. systemic lupus erythematous and systemic sclerosis) and a foot and/or ankle disorder, or with a musculoskeletal disorder affecting the foot and/or ankle (e.g. plantar heel pain, Achilles tendinopathy) independent of systemic disease.

We excluded studies with participants who had acute trauma to the foot and ankle, sports-related injuries, stress fractures, or foot and ankle disorders caused by diabetes or neurological conditions, including peripheral neuropathy.

We included full articles in the English language that were published in peer-reviewed journals. Conference abstracts were excluded, as were qualitative surveys, as it was our intention to conduct an in-depth analysis. Mixed-methods studies reporting quantitative and qualitative data were only eligible for inclusion if the qualitative interview/focus group data could be extracted separately. Studies including both eligible and ineligible participants (e.g. healthcare professionals or patients with diagnoses of other diseases) were included only if the data on eligible participants could be separated from the data on ineligible participants.

### *Search strategy*

A literature search was performed using Ovid MEDLINE, Ovid Embase, CINAHL, PROSPERO, Ovid PsycINFO, Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Trials (CENTRAL) from inception to March 2022. The search strategy was conducted with guidance from two health librarians (BT and JE); examples are included within the supplementary material. We screened references and related citations of included articles for potentially eligible articles that the database searches may have missed, and undertook forward citation tracking using Scopus. Additionally, we discussed the literature with experts within the wider international OMERACT Foot and Ankle Working Group, to minimise the likelihood of overlooking any additional relevant articles. Systematic reviews were also included in the initial database searches and screened for relevant articles.

### *Study selection and data extraction*

Screening was undertaken by two authors trained in qualitative methods (LSC and HJS), under the supervision of an experienced qualitative methodologist (CAF). Studies retrieved from the database searches were imported into EndNote (EndNote X9.3.3, Clarivate, 2021). After removing duplicates, we reviewed titles, excluded irrelevant literature, and then reviewed abstracts. Once further irrelevant literature was excluded, full texts of the studies identified as being potentially eligible for inclusion were assessed against the inclusion and exclusion criteria. Any disputes during title screening, abstract screening or full text review were settled through discussion or by a third reviewer (CAF) when necessary.

One author (LSC) extracted the following data from full texts eligible for inclusion using a standardised data collection form in Microsoft Excel (Microsoft Office Professional Plus 2016): study details (lead author, year of publication), design, country, RMD, sample size, participant demographics (age range, disease duration, ethnicity), intervention type (conservative, pharmacological, surgical), data collection method (e.g. focus group, semi-structured interview), data analysis method, and study findings (including themes, subthemes and verbatim participant quotes and authors' interpretations).

### *Quality assessment*

Two reviewers (LSC and HJS) independently assessed the quality of the included studies using the Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist [18]. The CASP checklist consists of 10 items, and each item includes multiple signalling questions to help users interpret the item (29 signalling questions in total). Any discrepancies were resolved through discussion or by a third reviewer (CAF). A summary table detailing the frequency of responses to each signalling question was constructed. The CASP checklist has no scoring matrix; therefore a narrative summary of the quality of the individual included studies is provided.

### *Data synthesis and analysis*

A thematic synthesis approach was undertaken to identify themes from the included articles [19]. All extracted data from the findings section of each study were considered in the synthesis. One reviewer (LSC) read each article multiple times to achieve immersion, then performed line-by-line coding of the data to search for concepts. Codes were independently verified by two other reviewers (HJS, CAF). Following comparisons of common convergent and divergent concepts within and across studies, codes were organised into related areas to construct descriptive themes and subthemes. This was achieved through an iterative process of translating concepts from one study to another by adding coded text to existing concepts and creating new concepts when deemed necessary. The preliminary coding framework was discussed with two other reviewers (HJS, CAF). Descriptive themes were then inductively analysed further to construct analytical themes, to 'go beyond' the findings reported in our included studies and generate additional understanding relating to our specific research question [19]. Outcomes of importance to patients identified from the analytical themes were categorised into OMERACT Filter 2.1 core areas of pathological manifestations, life impact, death and resource use, as part of the OMERACT domain selection process [20] and presented as a conceptual map. Each included article was subsequently re-read by one reviewer (LSC) to ensure themes were represented in the primary data, and illustrative verbatim quotations were incorporated. The proposed descriptive and analytical themes were subsequently presented, discussed and finalised with the entire review team.

Two reviewers (LSC, HJS) then independently assessed the confidence in the findings of the thematic synthesis using the Grading of Recommendations Assessment, Development and Evaluation Confidence in the Evidence from Reviews of Qualitative research (GRADE-CERQual) approach [21]. Four components were considered to formulate an overall assessment of confidence in the synthesised qualitative findings: methodological limitations (using CASP), coherence of data, adequacy of data and relevance of the studies. Full definitions of each GRADE-CERQual component and confidence ratings are presented in the supplementary material. Any disagreements in confidence ratings were resolved through discussion or by a third reviewer (CAF). Key review findings, confidence judgements for each finding, and an explanation of each judgement are presented in a Summary of Qualitative Findings table.

### *Patient involvement*

OMERACT patient research partners (PR, CH) were involved throughout our review, including during the design of the study and interpretation of the results, through attendance at study meetings and contributions to ongoing discussions about the findings. Our patient research partners recognised their own experiences in the review findings. Their input resulted in the identification and naming of themes, and changes to the presentation of the conceptual map; for example, they introduced the presentation of target domains within the broad domains of change of appearance and function, and highlighted how specific target domains linked to other broad domains within the map.

## Results

### *Study selection*

Our searches yielded 1443 records, of which 42 were retrieved for full-text screening. Thirty-four studies representing 32 data sets met our inclusion criteria. The full selection process is presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 flow diagram (Fig. 1) [22]. An overview of the characteristics of included studies is provided in Table 1. The sample included 503 participants with foot and ankle disorders in RMDs. Studies were conducted in seven different countries and included participants with rheumatoid arthritis (RA) [23–40], osteoarthritis (OA) [41–45], gout [46–48], psoriatic arthritis (PsA) [10], lupus [49], posterior tibial tendon dysfunction (PTTD) [50], plantar heel pain [51], Achilles tendonitis [52], and mixed conditions. Mixed condition studies included participants with hallux rigidus or hallux valgus [53,54], and RA or OA [55].

### *Quality appraisal*

The frequency of responses ('yes' or 'no') to each signalling question in the CASP checklist [18] is detailed in the supplementary material. Strengths observed in all studies included: clearly stated objectives, appropriate methodology and design, justification as to why the participants selected were the most appropriate to provide access to the type of knowledge sought by the study, clarity regarding how categories/themes were derived from the data, sufficient data presented to support the findings, explicit findings, adequate discussion of the evidence both for and against the researchers' arguments, findings discussed in relation to the original research question, discussion of contribution of the study to existing knowledge or understanding). Strengths observed in at least 31 studies included: explanation of how participants were selected, explicit and justified data collection methods, discussion of issues raised by the study and ethics approval, in-depth description of the analysis process, discussion of credibility of findings, identification of new areas where research is necessary, discussion of transferability of findings. The following limitations were identified in at least 20 studies: no discussions around recruitment, no justification of the setting for data collection, no critical examination of the researchers' own role, potential bias and influence during the formulation of the research question and data collection, insufficient details of how the research was explained to participants, lack of contradictory data taken into account, no critical examination of the researchers' own role, potential bias and influence during analysis and selection of data for presentation.

### *Synthesis of qualitative studies*

Our synthesis identified seven descriptive themes: pain, change in appearance, limited activities, social isolation, work disruption, financial burden and emotional distress. These were further organised into five analytical themes corresponding to potential outcome domains of importance, to specifically address our overall research aim: pain, change in foot/ankle appearance (deformity, swelling, skin/nail complaints), function (physical function, social function, occupational function), cost, footwear requirements, and emotional status. A conceptual map showing the proposed links between analytical themes is displayed in Fig. 2; outcome domains are presented as "broad domains" (an outcome domain of interest to be measured) and "target domains" (a structure or process within a broad domain), according to OMERACT definitions [15].

### *Descriptive theme 1: pain*

Participants in all studies described experiencing foot or ankle pain. Pain occurred on first step, in the morning, or in the evening, during or after activity, or at rest, with some participants describing spreading, burning or throbbing pain. Participants reported different severity levels of foot/ankle pain, with some describing it as unrelenting and unbearable:

> "The pain is horrific. It's just terrible, I wish someone could … you know what, I would have it cut off and a false one there if they could. It's horrendous pain, it's terrible. It's driving me round the bend. I'd go for anything to get rid of this pain, I'd try anything now." - participant with OA [44]

> "Foot pain was the most influential symptom experienced by study participants and was described as the worst aspect of the disease by the majority." – authors' interpretation (RA) [31]

Pain linked closely to most other themes; it affected daily activities, influenced social participation and occupational function, and caused emotional distress:

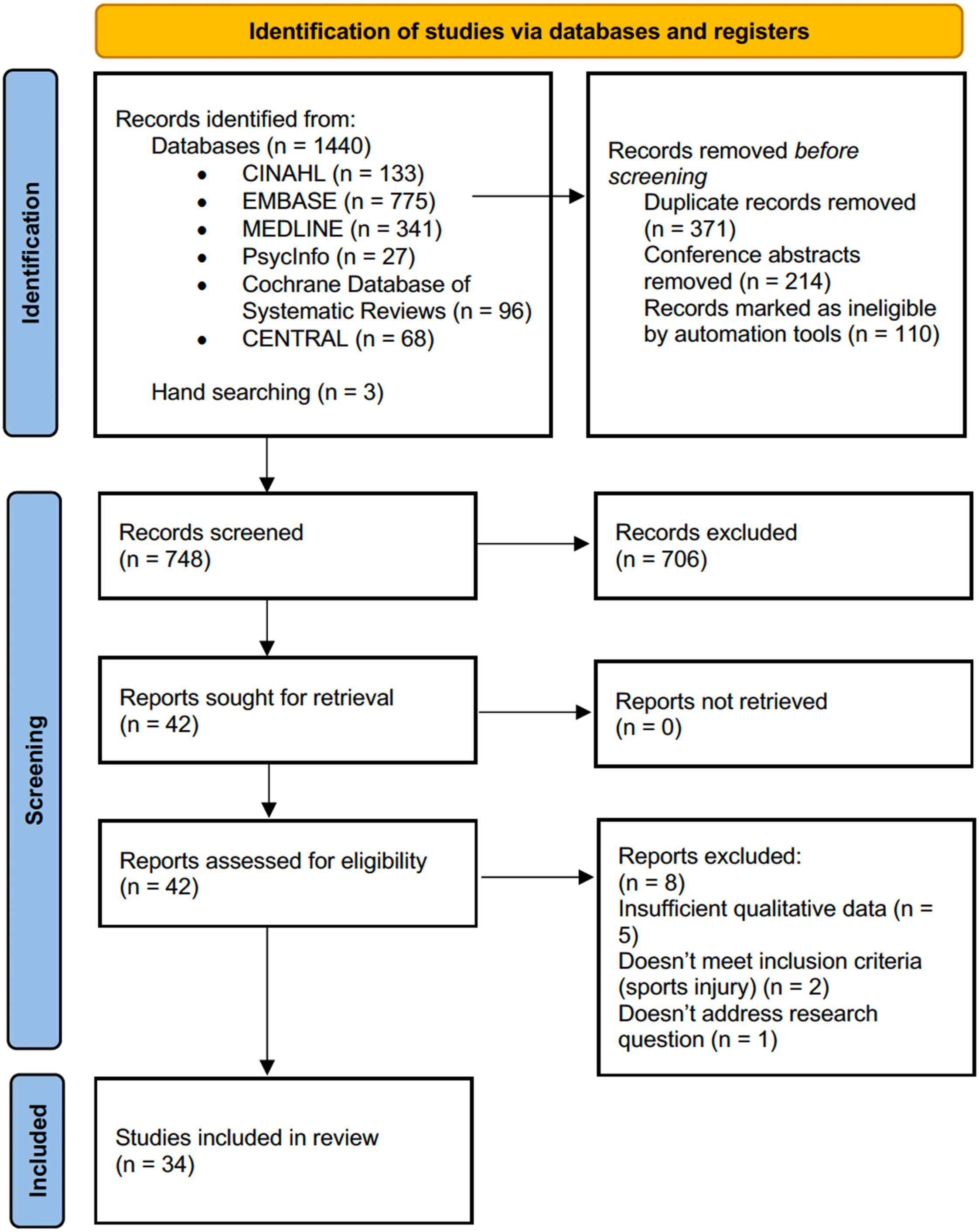

**Fig. 1.** PRISMA flow diagram.

> “If your feet don’t work or they are painful it impacts on the whole quality of your life from what you do recreationally, socially, work if you are still working. It impacts on everything.” – participant with RA/OA* [55]

Participants discussed how foot and ankle pain caused fatigue [24,30,31,34,54] and impaired sleep [10,27,46,53,54]. Foot and ankle pain also led to issues with footwear; it impacted on the ability to wear regular shoes, and was sometimes caused or made worse by footwear [10,26,27,33,34,36,37,44,46,50,51,53,54]:

> “You’ve got a formal or a fancy event to go to, you kind of, you just sacrifice as I’ve said earlier you deal with the consequence tomorrow because this looks right or this is more appropriate for that activity so you just basically suck it up and consequences come tomorrow.” – participant with gout [46]

> “Women expressed a desire to wear footwear which were feminine, however, in most instances were unable to wear these types of shoes due to their RA-related foot pain and deformity.” – authors’ interpretation (RA) [33]

### *Descriptive theme 2: change in appearance*

Many participants reported foot or ankle deformity [10,23–26,29–40,43,46,47,49,53–55]:

**Table 1**
Characteristics of included studies.

| Study ID (lead author, year) | Design | Setting (country) | RMD | Sample size | Participant demographics | Intervention type | Data collection method | Data analysis method |
|---|---|---|---|---|---|---|---|---|
| Backhouse 2016 | Phenomenological | UK | RA (post-surgery) | 10 | 8 women, 2 men; age range 33–81; disease duration range 6–30 years; 1–6 months post-operative; ethnicity not reported. | Surgical (post-surgery) | Semi-structured interviews | Inductive thematic analysis |
| Bjork 2018 | Critical incident technique | Sweden | RA | 59 | Age range 20–63 years; other demographics not reported. | N/A | Semi-structured interviews | Content analysis |
| Blake 2013 | Case study approach | UK | RA | 9 | 4 women, 5 men, age range 40–72 (mean 58), 1–30 years duration (mean 12.6); ethnicity not reported. | Conservative (podiatry) | Semi-structured interviews | Framework approach to content analysis |
| Campbell 2019 | IPA | UK | PTTD | 5 | 2 women, 3 men; age range 40–80; disease duration 7–20 months; ethnicity not reported. | Conservative | Semi-structured interviews | IPA |
| Carter 2018 | Qualitative interview | Australia, New Zealand | PsA | 21 | 13 women, 8 men, mean age 53 (SD 13), mean disease duration 11 (9) years; 18 Caucasian, 2 Fiji-Indian, 1 Indian. | N/A | Semi-structured interviews | Constant comparative analysis and thematic framework approach |
| Ceravolo 2020 | Grounded theory | Australia | Achilles tendinopathy | 11 | Demographics not reported. | N/A | Focus groups and semi-structured interviews | Grounded theory |
| Conlin 2021 | Qualitative descriptive approach | Canada | Ankle OA | 10 | 8 men, 2 women, age range 59–90; disease duration not reported; ethnicity not reported. | Surgical | Semi-structured interviews | Content analysis |
| Cotchett 2020 | Qualitative descriptive design | Australia | Plantar heel pain | 18 | 12 women, 6 men; mean (SD) age 58.2 (6.6) years; mean (SD) duration of heel pain 15.9 (16.3) months; ethnicity not reported. | N/A | Semi-structured interviews | Framework analysis |
| Dando 2020 | Qualitative | UK | RA/OA | 19 | 8 women, 11 men; other demographics not reported. | N/A | 4 focus groups | Thematic analysis |
| de Souza 2016 | Qualitative | UK | RA | 9 | 8 women, 1 man; age range 27–68 (mean 50) years; disease duration range 4–46 (mean 16.6) years; 7 White, 1 Black, 1 Mixed Race. | N/A | 2 focus groups | Inductive thematic analysis within a realist paradigm |
| Dismore 2021 | Interpretivist paradigm with a subjective ontology | UK | Hallux valgus/ hallux rigidus | 16 | 14 women, 2 men; age range 45–73 (mean (SD) 61 (7.23)) years; disease duration not reported; all White Caucasian. | Surgical (pre-surgery) | Semi-structured interviews | Inductive thematic analysis |
| Dismore 2022 | Qualitative | UK | Hallux valgus/ hallux rigidus | 15 | 14 women, 1 man; age range 45–73 years; disease duration not reported; all White Caucasian. | Surgical (post-surgery) | Semi-structured interviews | Thematic analysis |
| Firth 2011 | Qualitative interview | UK | RA | 23 | 6 men, 17 women; age range 45–88 years; disease duration range 5–64 years; ethnicity not reported. | N/A | Individual interviews | Framework analysis |
| Firth 2013 | Qualitative design | UK | RA | 23[*] | 6 men, 17 women; age range 45–88 (mean 69 (SD 10)) years; disease duration range 5–64 (mean 23 (SD 16)) years; ethnicity not reported. | N/A | Individual interviews | Framework analysis |
| Frecklington 2019 | Qualitative design | New Zealand | Gout | 11 | 9 men, 2 women; age range 40–83; disease duration range 2–25 years; 3 Māori, 4 NZ European, 3 Pacific Island, 1 South African. | Conservative | Individual interviews | Thematic analysis |

(continued on next page)

**Table 1** (*continued*)

| Study ID (lead author, year) | Design | Setting (country) | RMD | Sample size | Participant demographics | Intervention type | Data collection method | Data analysis method |
|---|---|---|---|---|---|---|---|---|
| Goodacre 2011 | Qualitative symbolic interactionist approach | UK | RA | 15 | All women; age range 38–75; disease duration range 1–47 years; ethnicity not reported. | Conservative | 2 individual interviews | Thematic network analysis |
| Hendry 2013 | IPA | Australia | RA | 12 | 12 women; age range 44–83; disease duration 3–34 years; ethnicity not reported. | Conservative | Semi-structured interviews | Thematic analysis |
| Hoque 2022 | IPA | UK | RA | 8 | 7 women, 1 man; age range 40–68; disease duration 3–56 years; ethnicity not reported. | N/A | Semi-structured interviews | Thematic using principles of IPA |
| Laitinen 2022 | Descriptive qualitative study | UK | RA | 20 | 18 women, 2 men; age range 24–83 (mean (SD) 64 (13); disease duration not reported; ethnicity not reported. | N/A | Semi-structured interviews | Inductive content analysis |
| Liddle 2015 | Qualitative design | UK | Gout | 43 | 29 men, 14 women; age and disease duration range/mean not reported; 40 White British, 3 Asian British. | N/A | Semi-structured interviews | Thematic analysis |
| Naidoo 2011 | Modified IPA | UK | RA | 8 | All women; age range 36–84; disease duration range 3–34 years; ethnicity not reported. | Conservative | Semi-structured interviews | IPA |
| Pinsker 2020 | Phenomenological | Canada | Ankle OA (post-surgery) | 25 | 12 women, 13 men; age range 25–82 years; disease duration not reported; duration since surgery range 1–10 (mean 3.2) years; ethnicity not reported. | Surgical (post-surgery) | Semi-structured interviews | Giorgi's method for analysing interview data |
| Ramos-Petersen 2021 | Qualitative approach with thematic framework | Spain | RA | 6 | All women; age range 32–75; disease duration range 1.5–45 years (mean 17.8 years); ethnicity not reported. | Conservative | Semi-structured interviews | Inductive thematic analysis |
| Richardson 2015 | Qualitative design | UK | Gout | 14** | 14 women; age and disease duration range/mean not reported; 13 White British, 1 Asian British. | N/A | Semi-structured interviews | Thematic analysis |
| Sanders 2017 | IPA | UK | RA | 5 | 4 women, 1 man; age range 35–78 years (mean 64); disease duration range 6–32 years (mean 20.2); ethnicity not reported. | Pharmacological | Semi-structured interviews | Thematic analysis within the IPA framework |
| Tehan 2019 | Qualitative approach | New Zealand | RA | 20 | All women; age range 27–75; disease duration range 3 months-45 years; 8 NZ European, 5 Pacific Island; 6 Asian; 1 Māori. | Conservative | Semi-structured interviews | Reflexive thematic analysis |
| Thomas 2013 | Qualitative interview | UK | Foot OA | 11 | 6 women, 5 men; age range 56–80 years; disease duration not reported; ethnicity not reported. | N/A | Semi-structured interviews | IPA |
| Williams 2007 | IPA | UK | RA | 13 | 10 women, 3 men; women age range 44–76 (mean 59) years, men age range 50–57 (mean 53) years; women disease duration range 5–26 (mean 14) years, men disease duration range 4–12 (mean 6) years; ethnicity not reported. | Conservative | Semi-structured interviews | Hermeneutic phenomenological analysis |
| Williams 2010 | IPA | UK, Spain, Netherlands | RA | 30 | All women; UK participants mean (SD) age 57 (10.68), Spain participants mean (SD) | Conservative | Semi-structured interviews | Thematic analysis |

(*continued on next page*)

**Table 1** (*continued*)

| Study ID (lead author, year) | Design | Setting (country) | RMD | Sample size | Participant demographics | Intervention type | Data collection method | Data analysis method |
|---|---|---|---|---|---|---|---|---|
| | | | | | age 57 (SD 6.01), Netherlands participants mean (SD) age 11.93; UK participants disease duration mean (SD) 15 (6.72) years, Spain participants disease duration mean (SD) 13 (4.96) years, Netherlands participants disease duration mean (SD) 15 (5.16) years); ethnicity not reported. | | | |
| Williams 2012 | IPA | UK | RA | 22 | 16 women, 6 men; women mean (SD) age 58 (11.9), men mean age (SD) 59 (6.0) years; women mean (SD) disease duration 15 (5.2) years, men mean (SD) disease duration 13 (5.0) years; ethnicity not reported | N/A | Focus groups | Thematic framework |
| Williams 2017 | IPA | UK | Lupus | 12 | All women; age range 42–72 years (SD 9.26); disease duration range 11–35 years (SD 8.07); all White Caucasian | N/A | Conversational interviews | Thematic framework approach |
| Wilson 2017 | Qualitative interview | UK | RA | 7 | All women; age range 29–72 (mean 56); disease duration range 2–27 years; ethnicity not reported. | N/A | Semi-structured interviews | Inductive thematic analysis |
| Yeowell 2021 | Exploratory qualitative research design, using Gadamerian hermeneutic phenomenology. | UK | Ankle OA | 9 | 8 men, 1 woman; age range 30–70 (mean 54); disease duration range 1–20 years (median 2 years); ethnicity not reported | Conservative | Semi-structured interviews | Reflexive and inductive thematic analysis |
| Zaidi 2013 | Qualitative, interview-based approach | UK | Ankle OA | 14 | 6 men, 8 women; age not reported; disease duration range 10–40 years; ethnicity not reported | Surgical (post-surgery) | Semi-structured interviews | Inductive thematic analysis |

[*] Same dataset as Firth 2011.

[**] Same dataset as Liddle 2015

IPA interpretive phenomenological analysis, OA osteoarthritis, PTTD posterior tibial tendon dysfunction, SD standard deviation, RA rheumatoid arthritis.

> "My feet have undergone several surgical procedures, my toes are crossed and I cannot spread them out, my big toe grows against the other toes. I don't like to look at them, or care for them." – participant with RA [32]

Some participants described swelling of their foot or ankle [10,24,26,29,30,32,40,44,47,54]. Swelling occurred at rest, or during or after activity:

> "If I want to play golf I just go out in a buggy [golf buggy to avoid walking], but you do a lot of twisting. And I can see it, even though I've got my socks on, I can see it is all swollen and it's throbbing." – participant with OA [44]

Prescence of callosities, dry skin, and nail pathologies were also reported [10,23,25,28,30,31,39,40,49]:

> "…they split and they can bleed because they get so dry." – participant with lupus [49]

Some participants [25,28,40] discussed different types of foot infections and the impact of foot wounds, including wound healing time and recurrence of wounds:

> "They take that long to heal. . ..they do heal but then within three or four weeks, if I just do a bit more walking than normal, they're back again.'' – participant with RA [27]

A minority of participants highlighted changes in circulation [49].

Change in appearance of the feet or ankles impacted on participants' choice of footwear [10,23–25,27,29,31–40,43,46,48–50,53–55] and subsequent clothing options [10,27,29,31–33,36,37,39,40,53,54]:

> "I think about them all the time, because when I'm going out, I think 'do my bunions stick out, do my shoes look alright.' I'd love to wear strappy sandals and your flip flops and all that sort of thing, but I never would." – participant with OA [43]

> "Another element of concern expressed about the effects of changed physical appearance was the focus on the accompanying special footwear often prescribed for patients with particular foot problems, such as deformity." – authors' interpretation (RA) [35]

### *Descriptive theme 3: activity limitations*

Many participants had difficulties walking [10,23,24,26,27,29–32,34–38,40–44,47–49,51,53–55]. Participants emphasised the importance of being able to walk, and the negative impact of reduced mobility

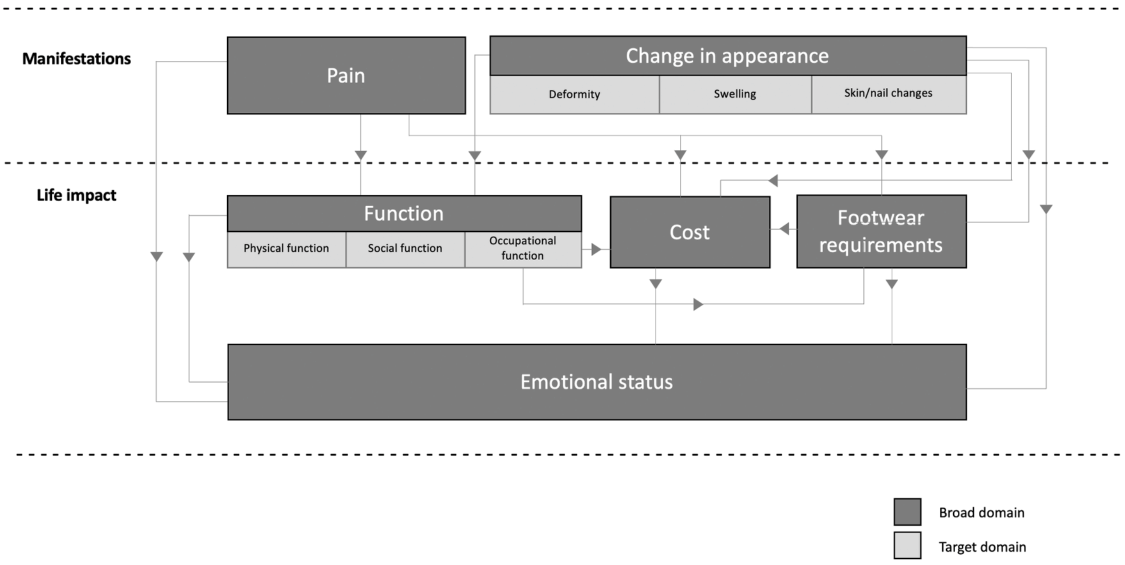

**Fig. 2.** Conceptual map of broad and target domains.

as a result of foot and ankle problems, particularly pain:

> “Some days I really can’t walk, the pain is so bad [referring to foot pain]. I’ve never broken a bone in my life. But if I had to imagine what a broken bone felt like, that’s what it feels like when I walk.” – participant with RA [40].

> “On some level, for all participants, mobility was restricted or affected by foot pain.” – authors’ interpretation (OA) [43].

In contrast, some participants identified that walking was affected even when pain had reduced following surgical intervention, leading to negative self-image:

> “…it’s [the surgery] taken..... the worse pain away..... I mean I still walk like a waddling duck.” – participant with RA [23].

Foot and ankle disorders reduced step length, walking speed and distance, and led to difficulty walking on different terrains, and up or down stairs and slopes:

> “I am very restricted, I can’t walk very far, I use a mobility scooter.” – participant with RA [30].

Participants also expressed how their foot and ankle disorders meant they couldn’t walk normally; they described shuffling, limping, or hobbling:

> “I’ll be limping around right and people will be asking me ‘what’s wrong with your feet?’… It doesn’t feel good.” – participant with PsA [10]

A minority of participants also discussed reduction in muscle strength as a symptom [32], which was perceived as a barrier to being able to walk:

> “I would love to walk, but I can’t because I have no muscle strength in my feet and my feet do not sustain my body weight.” – participant with RA [32]

Some participants identified a reduction in balance, feeling unstable and fear of tripping or falling when walking or using stairs [10,24,32,33,36,41]; in some cases this was a consequence of a surgical implant or of the footwear participants had to wear due to foot and ankle pain and deformity:

> “Every time I make a step, I look to where I’m stepping … I do that subconsciously … I watch where I step. I look for potholes in the road or wherever I go.” – participant with OA [41]

Many participants described modifying, limiting or ceasing specific physical and domestic activities as a result of their foot or ankle disorders [10,23,24,27,28,31,32,34,38,40–43,45,49–55]:

> “Squash, golf, I can’t do any of them now; the only activity I can do is swimming. I have put a lot of weight on as a result of not being able to do what I used to; I just hope to get back to doing something.” – participant with OA [45].

> “I do play bowls. I don’t play as much now, because I have to stand all of the time … it’s not so easy anymore.” – participant with PTTD [50].

> “The patients also described foot impairments during domestic activities such as assembling furniture while kneeling, climbing a ladder when painting the house, shovelling snow, and in gardening.” – authors’ interpretation (RA) [24].

Some participants needed to drive instead of walk [34], whereas others explained how their foot or ankle disorder made driving difficult [10,24].

Joint stiffness, and lack of movement in the foot or ankle joints, was also discussed by participants [10,24,30,32,34,40,41,43,44]. Stiffness was eased by activities in some cases, but occurred as a result of activity in others:

> “And when I get that [referring to a flare] I’m more conscious of my feet. When I’m not having a flare it’s only when I’ve walked too far or … stood for a long time. And then I become aware that my toes have become a bit stiff and my heels hurt.” – participant with RA [32]

Some participants identified the importance of joint movement for everyday activities:

> “That’s the biggest difference that I find. Just walking, any kind of movement, trying to run, or trying to catch a ball or trying to chase the [grand]kids. . . . It’s easier because I’ve got more movement in the left [replaced] ankle.” (Conlin)

### *Descriptive theme 4: social isolation*

Foot and ankle disorders impacted on many participants’ social lives [10,23,24,27,29–34,36–38,40,42–44,49–54]. Participants experienced changes in their family roles and friendships, describing social withdrawal and isolation as a result of not being able to do their usual activities because of their foot and ankle problems:

> "I'm sat in the house, I can't do nothing. I have no social life. My friends, they all say come and have a pint, but what's the good in going for a pint when I'm sat there, I can't move, I can't go to the bar, I can't get to the toilet." – participant with OA [44]

> "There are things that you can do, whereas I don't know about you guys, but when I had the Achilles, it was like being in gaol, that real restriction of your freedom for things that you enjoy doing." – participant with Achilles tendinopathy [52]

> "The experience of pain was also an obstacle to being socially active, with some participants expressing a feeling of social isolation." – authors' interpretation (plantar heel pain) [51]

In contrast, participants whose foot and ankle disorders had improved with treatment described positive changes in their social lives [34]:

> "Some reported an improvement in their social life as a result of a reduction in symptoms of RA in their feet, connecting physical comfort with their activity levels and associating perceived improvement in their physical activity and general wellness with improved quality of life." – authors' interpretation (RA) [34]

Limitations in footwear and clothing choices occurring as a result of foot and ankle disorders, also had a negative impact on social participation, particularly for women [10,12,24,27,29,31,33,36–38]:

> "...I panic when I do get an invite... I think oh gosh these boots....I was invited to a wedding and just sat at home and cried." – participant with RA [38]

> Yes, yeah, definitely. I did, I mean, and I noticed all the other women's footwear at the wedding and there was loads of really, really high shoes. I mean mainly young girls but there were some really classy shoes there and I thought, 'That's me goodbye forever.'" – participant with gout [48]

### *Descriptive theme 5: work disruption*

Foot and ankle disorders negatively affected participants' work lives [36,40,42,43,45,47,48]. Participants described difficulty in performing various job roles, restricting or changing their work activities and working hours, and taking time off work because of their foot and ankle problems:

> "Being self-employed, I was getting to the point where I was working and I couldn't work, so I was losing … my self-respect as far as not been doing enough work every day right? … I wasn't doing my work 100%." – participant with OA [43]

> "With my job, if we have to tie the ship up and I have to swing over the side to take the cables, I often think about how I'm going to be landing on the dock … Everything I'm doing, I've got to think." – participant with OA [42]

Other participants had to give up work entirely [10,30,53]:

> "I actually gave up work because I just couldn't. I was a trainer and I could only train standing up so I had to give up a job I loved and it was all wrapped around pain." – participant with hallux valgus/hallux rigidus* [53]

> "I quit my job...because it's mostly you have to stand... get on the ladder... physically get down on the floor... It's very physical." – participant with PsA [10]

Some participants worried they appeared lazy at work, or in unemployment, and perceived a lack of understanding amongst their work colleagues or within employment services because their foot or ankle disorders were hidden:

> "So that's the thing, you might come with a broken arm to work, in plaster, it's very easy to understand, but going there with small unrecognizable problems like hurting feet. . .that's tiresome and not so easy to understand." – participant with RA [24]

> "They expressed that their daily experience of living with foot pain was invisible, and something that could not possibly be understood by their peers, and this influenced their full participation in the workforce." – authors' interpretation (RA) [36]

The impact of foot or ankle pain and deformity on footwear and clothing choices also affected participants' work. Participants discussed the difficulties of being unable to wear certain types of footwear at work (e.g. safety boots or smart shoes) [10,24,29,36,40,46,53], and felt judged by their footwear choice:

> ""Footwear for work became a problem…I was conscious if I wore a dress or a suit for meetings or something like that of the shoes that I had to wear." – participant with hallux valgus/hallux rigidus* [53]

### *Descriptive theme 6: financial burden*

Participants also discussed the financial burden of living with foot and ankle disorders. In some cases, this related to having to pay for podiatric care to address foot/ankle pain, deformity, and skin and nail complaints [24,30,31,48]:

> "Many respondents were persevering with their disease-related foot problems because they couldn't afford foot care. Some participants conducted trade-offs between items that they normally included in their budget, in order to pay for foot care." – authors' interpretation (RA) [30].

A minority of participants also highlighted the financial implications of needing transport to attend an increased number of appointments because of their foot and ankle disorders [26].

Footwear restrictions also led to financial burden [26,28,30,33,35,39,45]; some participants highlighted the excess costs associated with buying multiple pairs of unsuitable shoes or needing to buy specialist shoes, whilst others were unable to afford new footwear:

> "….my boots, the ones that I've worn all the way through the winter, but they haven't been comfortable. But I couldn't afford to buy another pair so I just had to make do." – participant with RA [39]

> "Many women discussed financial pressures contributed to making bad choices in relation to footwear, and this led to anxiety about purchasing decisions." – authors' interpretation (RA) [35]

For some participants, the impact of foot and ankle disorders on their work resulted in loss of income [10,24,29,39,44,46]:

> "I went from being somebody that was quite dynamic and ran a business that employed 20 people, and I loved what I did …. I have had a massive drop in income and a massive drop in self-esteem." – participant with RA [30]

> "I'd worked with it for 3 weeks, walking on the side of my foot […] it's probably the worst pain I've had, in my life […] I was a piece worker so what I made I got paid for, if I didn't make it, I didn't get paid, so and, you know, we were, young family then, so… […] eventually I just had to give in and go to the doctors and get signed off for a week or two." – participant with gout [47]

> "The ability to work was a key factor that not only induced a perceived need for surgical intervention but also resulted in patients delaying the timing of surgery. In these cases, loss of earnings during the postoperative rest period was the reason for putting off surgery. This represents a 'worker's paradox' since surgery is required to continue in employment, but the temporary loss of earnings during the recovery period is seen as being prohibitive." – authors' interpretation (OA) [45]

### *Descriptive theme 7: emotional distress*

Foot and ankle disorders affected participants' emotions [10,23,24,27,28,30–34,36-40,42–44,48–55]. Participants described feeling anxious, angry, sad, hopeless, frustrated, ashamed, paranoid, self-conscious, embarrassed and depressed about their foot and ankle problems:

> "I'm just useless, just because of a daft ankle. It's unbelievable that isn't it. It makes me feel as if I'm good for nothing, I might as well just turn it in, you know, just go for a couple of tablets and I'll call it a day. Just a waste of time. I'm good for nothing at the minute. I feel like crying. It's horrible. Every day of my life; it gets a bit upsetting. You just wanna give in, in the end, you get sick of it." – participant with OA [44]

> "Anxiety about the anticipated duration of ulceration was common and for some participants this was linked to specific concerns that an open wound might delay surgery or treatment." – authors' interpretation (RA) [28]

Emotional distress occurred a direct result of pain and change in appearance of the feet or ankles, and of the subsequent reduction in physical, social and work activities:

> "I don't want to overstate the cranky and anger stuff, but there's definitely a general feeling of – it's almost depression, but not clinical depression, but you just don't feel good about yourself or the world." – participant with Achilles tendinopathy [52]

> "One of the best things about football was going for a drink with the boys afterwards [.....] So I stopped going. Not only could I not play anymore but the loss of the social side, not seeing my mates and all that made me feel really low." – participant with RA [40]

Change in appearance of the feet and ankles impacted on body image and self-identity [10,23,29,33,34,36,37,43,53,54]; participants identified stigma associated with disability, and described feeling visibly different to "normal" people. Participants with deformity felt embarrassed by the appearance of their feet, hated their feet, and did not want to look at their own feet, perceiving that other people did not want to look at their feet either:

> "You can see it in their faces, like I don't want to look at your feet … feet phobia." – participant with RA [34]

Participants expressed wanting to hide their foot and ankle problems from others. Similar experiences were expressed by those who reported having deformity prior to surgical intervention, whilst those without deformity discussed how they did not want deformity to occur:

> "Well just the looks of your feet really you know, just the looks of the feet, they were awful they really......they look a lot better than they did and you know I never liked to take my shoes off before or my socks of or anything which you know I don't mind now sort of thing." – participant with RA [23]

> "I'd deal with it if my toes went crooked. I'd just think, well that's just part of [RA] but I don't really want them to get that unsightly. Your toes aren't the nicest things." – participant with RA [25]

Emotions were similarly affected by limitations in footwear and clothing choices [10,27,29,33,35-40,48,50,53,55]:

> "I can go in a shoe shop and within 5 or 10 minutes I can be in tears trying on shoes because I just absolutely hate my feet because of the way they have gone with the arthritis. The thing that I absolutely hate shopping for is shoes." - participant with RA [29]

> "Powerful emotions of shame, sadness and frustration were clearly identified by these women when speaking about their feet, footwear and body image." – authors' interpretation (RA) [33]

> "The shoes....as soon as I see a person I can say oh yes she's got hospital shoes on..... I compare my boots with other people and they are more feminine and pretty and that makes me feel sad." – participant with RA [37]

In contrast, some participants who had undergone surgery for foot and ankle disorders reported feeling more optimistic, with improved psychological wellbeing, improved mood and quality of life [53,54].

### *Assessment of confidence in the review findings (GRADE-CERQual)*

We had moderate confidence in most of the review findings (Table 2; a detailed GRADE-CERQual Qualitative Evidence Profile is also presented in the supplementary material). This was due primarily to concerns regarding methodological limitations, adequacy of the data, and relevance of each contributing study to the review question (given the minority of studies including participants with SpA and CTDs and that all data came from high-income countries), for some of the findings.

## Discussion

This is the first study to synthesise findings of qualitative research exploring the lived experience of patients with RMDs who have experienced foot and ankle disorders. Our findings indicate that these disorders are debilitating and affect multiple aspects of life, causing considerable disruption for patients. As presented in Fig. 2, both pain and change in appearance of the feet and ankles directly led to other issues, including activity limitations, social isolation, work disruption, financial burden, issues with footwear and emotional distress, therefore addressing these specific symptoms or manifestations may lead to

**Table 2**
GRADE-CERQual summary of findings.

| Summary of review finding | Studies contributing to the finding | CERQual assessment of confidence in the evidence |
|---|---|---|
| Foot and ankle disorders in RMDs cause pain. | 10, 23–55 | Moderate confidence |
| Foot and ankle disorders in RMDs cause joint deformity. | 10, 23, 24, 25, 26, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 53, 54, 43, 46, 47, 49, 55 | Moderate confidence |
| Foot and ankle disorders in RMDs cause joint swelling. | 10, 24, 26, 29, 30, 32, 40, 44, 47, 54 | Low confidence |
| Foot and ankle disorders in RMDs cause skin and nail complaints, including wounds. | 10, 23, 25, 27, 28, 30, 31, 32, 39, 40, 49 | Moderate confidence |
| Foot and ankle disorders in RMDs limit walking and cause changes in gait. | 10, 23, 24, 26, 27, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 46, 47, 48, 49, 50, 51, 53, 54, 55 | Moderate confidence |
| Foot and ankle disorders reduce physical and domestic activities. | 10, 23, 24, 27, 28, 31, 32, 34, 38, 40, 41, 42, 43, 45, 49, 50, 51, 52, 53, 54, 55 | Moderate confidence |
| Foot and ankle disorders in RMDs cause joint stiffness. | 10, 24, 30, 32, 34, 40, 41, 43, 44 | Moderate confidence |
| Foot and ankle disorders in RMDs reduce social participation. | 10, 23, 24, 27, 29, 30, 31, 32, 34, 33, 36, 37, 38, 40, 42, 43, 44, 49, 50, 51, 52, 53, 54 | Moderate confidence |
| Foot and ankle disorders in RMDs disrupt work. | 10, 24, 25, 27, 30, 31, 36, 40, 42, 43, 45, 46, 47, 48, 50, 53, 54, 55, | Low confidence |
| Foot and ankle disorders impact on footwear requirements. | 10, 23, 24, 25, 26, 27, 29, 31, 32, 33, 34, 35, 37, 38, 39, 40, 43, 44, 46, 48, 49, 50, 53, 54, 55 | Moderate confidence |
| Foot and ankle disorders cause financial burden. | 10, 25, 27, 29, 30, 31, 32, 34, 36, 40, 45, 46, 47, 49 | Moderate confidence |
| Foot and ankle disorders cause emotional distress. | 10, 23, 24, 27, 28, 29, 30, 31, 32, 33, 34, 36, 37, 38, 39, 40, 42, 43, 44, 46, 48, 49, 50, 51, 52, 53, 54, 55 | Moderate confidence |

improvements in others. We formally assessed the confidence in each finding from our review using the GRADE-CERQual framework [21] and consider it likely that our review findings are a good representation of the experiences of people with RMDs who live with foot and ankle disorders.

In congruence with a previous scoping review of outcome domains in existing clinical trials and observational studies [56], pain was the most common symptom reported in our thematic synthesis. In contrast, whilst the scoping review revealed other objective outcomes of potential importance to researchers, such as range of motion, disease activity and gait biomarkers, these findings were not as prominent in the qualitative literature. Furthermore, key findings from our thematic synthesis were that foot and ankle disorders impacted on social and occupational function, footwear requirements, and emotional status. These were rarely specified by researchers as outcome domains to measure in existing clinical trials and observational studies, although they may have been captured in broader measures of function.

Our findings have implications for clinical practice; it is important for clinicians to ascertain what patients with foot and ankle disorders want treatments to achieve, so that clinical appointments can be focussed accordingly. Our review specifically focused on the experiences of patients rather than exploring potential outcome domains of importance to researchers or health professionals. Comparable to previous studies involving patients with RMDs [11,57], the psychological impact of living with foot and ankle disorders was highlighted in our review and should not be underestimated by clinicians.

Our review must be considered in the context of several limitations. Firstly, whilst we pre-specified our methods through registration of our review in PROSPERO and involved at least two reviewers in study screening, quality appraisal and assessment of confidence in the findings, we previously conducted a scoping review to identify outcome domains in the existing foot and ankle RMD literature and acknowledge that this may have influenced our analysis and selection of data for presentation. Offsetting this, our research team included an experienced qualitative researcher who was not involved in this scoping review and is not from a foot and ankle background (CAF) to cross-check our coding and review our themes against all original included studies. Secondly, we limited our inclusion criteria to qualitative studies using interview or focus group data collection methods, thus recognise we may have missed relevant qualitative data ascertained through other methods such as surveys with open-ended questions or consensus studies. However, we intended to conduct an in-depth exploration of the symptoms and impact of foot and ankle disorders on the lives of people with RMDs, and considered it unlikely that studies using other methods would have fully addressed our research aim. Thirdly, although our search had no restrictions on setting or country, we only included studies published in English. All studies included in our review were from high-income countries, whilst only ten included studies reported the ethnicities of participants. Our findings may therefore not represent the views of participants from other ethnic backgrounds, low- and middle-income countries, or non-English speaking participants, and these are key areas for future qualitative research. Finally, the majority of studies in our review included participants with foot and ankle disorders in RA or OA, and whilst our findings appear relevant to the other included RMDs, they may not fully reflect the experiences of patients with conditions that were under-represented in this review. There were no included studies involving participants with systemic sclerosis, or additional MSK disorders affecting the foot or ankle in the absence of systemic disease, such as lesser toe deformities, enthesitis, or capsulitis. Future qualitative studies should also address these gaps in the literature.

Our review provides insight into the breadth and depth of potential outcome domains of importance to patients and will inform a future Delphi consensus study with all key stakeholders, and ultimately an internationally agreed, standardised core domain set for foot and ankle disorders in RMDs [14]. Our findings have shown that patients' experiences of foot and ankle symptoms, and their impact, are similar regardless of the RMD, supporting the suitability of a single core domain set for foot and ankle disorders across multiple RMDs.

## Conclusions

Our thematic synthesis has identified that the lives of patients with foot and ankle disorders in RMDs can be affected by pain, change in appearance of the feet/ankles, activity limitations, social isolation, work disruption, issues with footwear, financial burden and emotional distress. Patients' experiences of the symptoms and impact of foot and ankle disorders are similar regardless of their RMD. This improved understanding of the experiences of patients will inform the development of a core domain set for future research studies. It is also useful for clinicians, helping to focus clinical appointments and measurement of outcomes within clinical practice.

*Unable to distinguish the specific RMD.

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## Declaration of Competing Interest

The authors have no disclosures.

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.semarthrit.2023.152212.

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