

RESEARCH ARTICLE

The role of occupational therapy for the self-management of rheumatoid arthritis: A protocol for a mixed methods systematic review

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Abstract

Background: Occupational therapists can support people with rheumatoid arthritis to self-manage their disease symptoms and engage in daily activities. This protocol reports a review to broaden understanding of what is known about the role of occupational therapy in the self-management of rheumatoid arthritis.

Methods: Studies involving adults with rheumatoid arthritis, having participated in self-management involving occupational therapy, will be included. Patient involvement will help develop the search strategy by identifying patient-centred interventions and outcomes to complement those identified by researchers. An electronic search will be performed using several bibliographic databases, including grey literature from subject-specific, health-related, and social care databases. Searches will run from the database inception until the date that the search is conducted (December 2021–May 2022). Retrieved studies will be de-duplicated, and the remaining titles and abstracts will be screened by three reviewers. Full texts of all eligible studies will be independently reviewed by the reviewers to select papers for data extraction and quality assessment. Outcomes are function, pain, fatigue and lived experience. For quantitative studies, data will be synthesised using descriptive statistics in text and tables, whereas for qualitative studies, data will be synthesised using thematic synthesis.

Discussion: This review will synthesise current evidence on how occupational therapy can help the self-management of rheumatoid arthritis. It will include evidence of best practice, including advice, education and training provided by occupational therapists. These findings can inform future research and the selection of strategies to promote quality of life for people with rheumatoid arthritis.

Systematic review registration: PROSPERO CRD42022302205

KEYWORDS

arthritis, fatigue, function, qualitative research, quantitative research, rheumatology, self-care

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1 | BACKGROUND

Rheumatoid arthritis is a chronic, inflammatory autoimmune disease associated with joint pain, muscle weakness and fatigue (McInnes & Schett, 2011), affecting approximately 13 million people worldwide (Cieza et al., 2021). A cornerstone in the day-to-day care of rheumatoid arthritis is self-management; that is, an individual's ability to adopt strategies to manage the symptoms, the physical and mental impacts, and the lifestyle changes associated with the disease (Barlow et al., 2002; Lorig & Holman, 2003). Common strategies include staying physically active, managing medications, eating a balanced diet, and seeking medical support for flare-ups (Leese et al., 2021).

Occupational therapists are well-placed to support individuals with rheumatoid arthritis to self-manage in their everyday lives (Hammond et al., 2008). Occupational therapists offer strategies to improve the performance of daily tasks and occupations, make choices to support a satisfying balance across different occupations, and to engage in tasks and activities while concurrently managing disease symptoms, such as pain and fatigue (Steultjens et al., 2004). High-quality quantitative evidence suggests occupational therapy interventions can improve function through joint protection guidance (Carandang et al., 2016; Steultjens et al., 2004), and more broadly, with physical activity and psychoeducational interventions (Carandang et al., 2016; Siegel et al., 2017). However, the understanding of what constitutes effective occupational therapy in the self-management of rheumatoid arthritis is limited to quantitative evidence, and less so, an individual's lived experience in their ability to self-manage.

The UK's Royal College of Occupational Therapy (RCOT) (2020) recently reviewed the academic and grey literature to inform its practice guideline on hand and wrist orthoses for those with rheumatological conditions. Although limited to the hand and wrist, the review highlighted the need to evaluate the effectiveness of work-related interventions and occupational therapy involving 'the self' and lifestyle management techniques for inflammatory arthritis. Previous systematic reviews included only quantitative evidence (Siegel et al., 2017; Steultjens et al., 2004), yet in recent years, narrative accounts of the lived experience of rheumatoid arthritis have been published (Donnelly et al., 2020; Toye et al., 2019). The importance of 'renegotiating the self' is now recognised as part of the cognitive and emotional load of self-management after disease onset (Donnelly et al., 2020). It remains unclear which components of occupational therapy for self-management are effective, but these are likely to encompass strategies to support self-esteem, self-efficacy, self-empowerment, and self-perception of the illness. Given that emerging evidence suggests that the Coronavirus (COVID-19) pandemic has severely impacted an individual's ability to self-manage (Berkovic et al., 2020; Leese et al., 2021), the implications of this review will be timely for people living with rheumatoid arthritis, and their family and care providers.

Qualitative studies and grey literature (including policy briefings and government reports) are likely to provide further evidence on occupational therapy interventions, particularly given their complexity and the range of outcomes they target (Murphy

et al., 2009). This review will advance previous work by Siegel et al. (2017), and capture evidence published within the previous 7 years to examine the role of a wide range of occupational therapy interventions (e.g. physical activity, skills training, advice on using assistive devices) in supporting individuals with rheumatoid arthritis to self-manage. The role of practice guidelines particularly for the wrist and hand, in supporting effective self-management will be further understood, and will be incorporated where appropriate into our findings. Our work will also draw upon examples of good practice in mixed methods reviewing on the lived experience of rheumatoid arthritis (Donnelly et al., 2020). To our knowledge, this will be the first review to include qualitative evidence, to gain in-depth insights into how individuals with rheumatoid arthritis experience the influence of occupational therapy on their self-management in the context of their everyday lives.

2 | AIM

This review will aim to broaden understanding of what is known about the role of occupational therapy in supporting self-management for function, pain, fatigue and lived experience of adults living with rheumatoid arthritis.

The review question is based upon the SPIDER framework, that is, Sample (people with rheumatoid arthritis), Intervention/Phenomenon of Interest (occupational therapy for self-management), study Design (including randomised control trial, interviews, focus groups and case reports), Evaluation/outcome (function, pain, fatigue and lived experience), Research type (qualitative and/or quantitative).

3 | OBJECTIVES

- To identify studies where occupational therapy has been used as a stand-alone intervention, or a component of a multidisciplinary intervention for the self-management of rheumatoid arthritis for adults;
- To assess the effect of occupational therapy in the self-management of rheumatoid arthritis;
- To characterise occupational therapy interventions for the self-management of rheumatoid arthritis, based on those found to be most effective in promoting physical and psychosocial health, and
- To broaden understanding of whether occupational therapy in the self-management of rheumatoid arthritis impact people's lived experience.

4 | METHODS

4.1 | Literature searches

The protocol has been registered prospectively with PROSPERO (CRD42022302205). The results of this systematic mixed methods review will be reported in adherence to the Preferred Reporting

Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009).

The following electronic bibliographic databases will be searched: EBSCOhost databases: MEDLINE, CINAHL, AMED, Psycinfo; Web of Science (Core Collection). The grey literature searches will comprise: subject-specific search engines (OTseeker, OTSearch and OTDBase), the LWW Health Library: Occupational Therapy Collection, the Rehabilitation Field and Musculoskeletal Group databases (Cochrane Collaboration), and academic theses, trials databases, and conference abstracts (published and unpublished), where accessible. To complement these, the health-related search engines will be searched (i.e., the Cochrane Library, Evidence search [NICE Library], UpToDate [Wolters Kluwer]; RCOT Library), social care search engines (i.e. Social Policy and Practice, Turning Research Into Practice [TRIP], and Social Care Online), and generic search engines (i.e. Institute for Work & Health, the British Library collection, and Jisc Library Hub Discover).

The search will run from the earliest start date of the individual database until the date that the final search takes place (May 2022). This time frame will include screening reference lists and consulting experts. See Table 1 for the search strategy and Table 2 for the review outcomes.

The Grading of Recommendations, Assessment, Development and Evaluations' (GRADE) Confidence in Evidence from Reviews of Qualitative research (CERQual) approach will be used to assess how much confidence to place in synthesis findings from the included qualitative evidence (Lewin et al., 2018), supported by the Cochrane Review extraction tool (Ryan et al., 2016) adapted for qualitative and quantitative studies.

5 | ELIGIBILITY CRITERIA

5.1 | Population of interest

Adults aged 18 years or over, with a diagnosis of rheumatoid arthritis in any country.

5.2 | Intervention/phenomenon of interest

Interventions involving occupational therapy for the self-management of rheumatoid arthritis, as either: a standalone intervention (i.e., occupational therapy only), or as a multidisciplinary intervention (i.e., a combined programme, involving occupational therapy alongside other professions [e.g. patient education, nursing, physiotherapy, psychology]). Multidisciplinary interventions which do not involve occupational therapy, supporting self-management for rheumatoid arthritis, and/or the targeting of health-related/condition-specific needs (i.e., those limited to targeting educational or social needs) will be excluded.

The 'phenomenon of interest', self-management, is essential in studies. However, the related outcome, self-care (as an example of

lived experience), is desirable to be explicitly stated, but not essential in studies. Other related concepts that imply self-care will also be considered. For example, experiences, attitudes, and perspectives of adults with rheumatoid arthritis towards self-management, self-care, self-medication, self-administration, and/or their self-concept, will be included.

5.3 | Study design

All types of primary qualitative (e.g., phenomenology, ethnography, grounded theory) and quantitative (e.g., randomised controlled trials, crossover and cohort) study designs will be included alongside mixed methods studies. This review will not include systematic reviews and meta-analyses, but will include narrative, case studies and public reports containing data on the topic (including governmental or charity reports). Studies involving people with musculoskeletal diseases other than rheumatoid arthritis (i.e., mixed groups, including osteoarthritis and/or fibromyalgia) will only be included if the results are presented separately for people with rheumatoid arthritis.

5.4 | Settings

No restrictions will be applied to the severity or duration of rheumatoid arthritis. Scoping searches suggest that most research is likely to have been conducted in community or hospital settings, and will have involved non-institutionalised individuals (e.g., prison facilities or care homes). All types of settings will be considered in inclusion, including workplaces.

5.5 | Outcomes

The main outcomes will include the following measures, adapted from previous work (Siegel et al., 2017; Steultjens et al., 2004; see Table 2):

- Function
 - Including: dysfunction, ability or disability, strength, range of motion, physical mobility, functional capacity and occupational balance.
- Pain
- Fatigue
- Lived experience
 - Relating to self-care, depression, quality of life, experience of self-efficacy, self-managing (including problem solving, goal setting, and learning*), occupational balance, and community participation.

*Eligible within interventions and outcome (i.e. lived experience), but not as specific search terms.

TABLE 2 Outcomes for occupational therapy in the self-management of rheumatoid arthritis

Quantitative outcomes	Qualitative outcomes
<p>1. Function</p> <ul style="list-style-type: none"> • Dysfunction or function or fatigue or ability or disability or hand function or grip strength or physical mobility or range of motion or strength or pain or occupational balance or wellbeing or functional capacity • Pinch strength; hand strength • Range of motion, articular • Postural balance 	<p>4. Lived experience</p> <p>Self-care – self administration; self-medication; self-management; self-concept; chronic disease management or disease management or symptom management; patient education or relax^a or prevent^a or adaptive equipment or rehab; body image or self-esteem or self-image;</p> <ul style="list-style-type: none"> • Health literacy • Attitude to health; community participation; satisf^a or value^a or perspective^a or view^a or experience^a or opinion^a or belie^a or perce^a or feel^a or know^a or understand^a or need^a or issue^a or preference^a or concern^a or attitude^a or emotion • Quality of life
<p>2. Fatigue^b</p> <ul style="list-style-type: none"> • Physical endurance; tiredness 	<ul style="list-style-type: none"> • Depression; anxiety • Stress, psychological; dependency, psychological
<p>3. Pain^b</p> <ul style="list-style-type: none"> • Sensation 	<ul style="list-style-type: none"> • Social stigma; social isolation

^aTruncation.

^bOutcome can be assessed both quantitatively and qualitatively.

Some outcomes can be assessed both quantitatively and qualitatively, such as pain and self-efficacy. Both assessment methods will be accepted. The review outcomes were first identified by reviewer JG, and then later revised in consultation with all authors. To ensure that our review was co-produced with the perspectives of people with lived experience of rheumatoid arthritis, we ran a public and patient involvement workshop ($n = 6$; July 2021) to refine suggested primary and additional outcomes. We also partnered with a co-author living with rheumatoid arthritis (ED) from the project's inception to develop our research objective and study design, and subsequently consulted our project advisory group (comprising three people with rheumatoid arthritis). To enhance the reporting of our patient and public involvement in this review we will adopt the Guidance for Reporting Involvement of Patients and the Public (GRIPP) checklist (Staniszewska et al., 2017). Finally, outcomes were agreed upon between authors and used in the pilot search strategy. Based on pilot searches, and to reduce the likelihood of excluding relevant studies (qualitative and quantitative), outcomes will not be included in the final search strategy (see Table 1).

5.6 | Study selection

Selection will involve a two-step process: (i) pilot screening of 20 papers), and (ii) full screening as described below. To test the search strategy and review procedures all three reviewers will conduct a pilot screening. Firstly, one reviewer (LR) will run the search strategy and remove duplicates. Next, three reviewers (LR, VF and JG) will use Rayyan software (Ouzzani et al., 2016) to independently screen 20 randomly selected papers to assess for understanding and consistency when screening. The reviewers will screen the titles and

abstracts of the pilot papers using a pre-defined screening and selection tool, based on the review eligibility criteria. Finally, the reviewers will meet to explain and agree on their decisions for the selected, rejected and uncertain ('MAYBE') decisions using the screening tool; this may be amended based on reviewer feedback in interpreting individual criteria.

For screening, studies retrieved using the search strategy will be transferred to EndnoteWeb for deduplication and storage and then exported to a shared Microsoft OneDrive account (for storage and archiving) and Rayyan (for independent title and abstract screening, and later data extraction). Grey literature searching will be conducted concurrently, and eligible papers (including those from additional sources, such as reference lists) will be exported to the OneDrive account for screening. Titles and abstracts will be divided between, and screened by three reviewers (JG, LR and VF) to identify studies meeting the eligibility criteria stated above, albeit provisionally, pending full-text screening. Full texts of the eligible studies will then be obtained and read by all reviewers using a pre-defined screening and selection tool to select eligible papers for data extraction. Any disagreements will be referred to a clinically experienced reviewer (AH or CB) for a final decision. Snowballing will also be used by reading the reference lists of eligible papers to identify additional papers.

5.7 | Data extraction

Data will be extracted from the eligible studies using a standardised piloted tool for data synthesis and quality assessment. The extraction form is based upon the Cochrane Developmental, Psychosocial and Learning Problems group data extraction form (2018) (quantitative);

the JBI Manual for Evidence Synthesis (Aromataris, 2020); and the Critical Appraisal Skills Programme (CASP) (qualitative), and aligned to the specific research question of the review. Data will be extracted independently by two reviewers (JG and LR) and recorded in a Microsoft Excel document under six categories. These are: general information (including publication type and date), study eligibility, characteristics of included studies, risk of bias assessment, data and analysis, and other information (including author conclusions and recommendations). Please see Supplementary 1 for the full variable list. Disagreements will be resolved by a clinically experienced reviewer (AH or CB). Authors of included studies will be contacted by the lead reviewer (JG) for missing information.

5.8 | Quality assessment

Two authors (JG and LR) will independently assess the quality of each selected study during the data extraction phase (see above for details). The risk of bias (quantitative) and quality assessment (qualitative) sections within the data extraction form are adapted from:

- The Cochrane Developmental, Psychosocial and Learning Problems group data extraction form (2018) for 'risk of bias' in quantitative studies. The seven assessment domains include: random sequence generation (selection bias); allocation concealment (selection bias); blinding of participants and personnel (performance bias); blinding of outcome assessment (detection bias); incomplete outcome data (attrition bias); and selective outcome reporting (reporting bias).
- The CASP checklist for qualitative studies. The 10 assessment domains include: clarity of the aim, appropriateness of the qualitative methodology (section A – are the results valid?); appropriateness of the research, recruitment strategy, and data collection, and consideration of the research-participant relationship (section B – is it worth continuing?); consideration of ethical issues, rigour of data analysis, clarity in the statement of findings (section C – what are the results?); the value of the research (section D – will the results help locally?). Each qualitative study will be scored out of 10, with scores >9 deemed high quality; scores between 7 and 9 deemed moderate quality; and scores <7 deemed low quality (Donnelly et al., 2020).

Following data extraction and quality assessment of individual papers, we will estimate the quality of the overall evidence synthesised in this mixed methods review. Quantitative evidence will be assessed using the GRADE approach in the synthesis according to the following criteria: risk of bias; inconsistency of effect (or heterogeneity); indirectness (including SPIDER and applicability); imprecision (including confidence intervals); and publication bias. The quality of individual qualitative studies will be assessed using the CASP overall score (out of 10). The GRADE-CER-Qual approach for qualitative evidence (Lewin et al., 2018) will be used to assess how much

confidence to place in findings from our qualitative evidence synthesis. The assessment of confidence is based on the following components: methodological limitations; coherence; adequacy of data; and relevance. Papers will be categorised into high, moderate, low, or very low-quality evidence, whether using the GRADE or GRADE-CER-Qual approach.

5.9 | Strategy for data synthesis/analysis

Characterisation and evaluation of the reported occupational therapy interventions involving self-management will be based on those found to be most effective in promoting physical and psychosocial health in people with rheumatoid arthritis. Data from studies will be presented in separate quantitative and qualitative findings tables (Lewin et al., 2018). For quantitative studies, data will be synthesised using descriptive statistics in text and tables, whereas for qualitative studies, data will be synthesised using Thomas and Harden's (2008) thematic synthesis.

6 | CONCLUSION

This mixed-methods systematic review will broaden understanding of what is known about the role of occupational therapy in the self-management of rheumatoid arthritis. It will involve evidence of best practice, including advice, education and training provided by occupational therapists. These findings will inform the design of future research and the selection of appropriate strategies to promote quality of life for people living with rheumatoid arthritis.

AUTHOR CONTRIBUTIONS

James P. Gavin, Vicky Fenerty, Jenny Leese, Alison Hammond, Eileen Davidson and Catherine L. Backman contributed to the study conception and design. Laura Rossiter and Vicky Fenerty developed and tested the search strategy, with all authors contributing on subsequent revisions. James P. Gavin, Laura Rossiter and Vicky Fenerty conducted the pilot searches. James P. Gavin developed the data extraction form, with guidance from Jenny Leese, Catherine L. Backman and Alison Hammond. The manuscript was drafted by James P. Gavin. All authors contributed to and reviewed the final manuscript.

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CONFLICTS OF INTEREST

The author declares that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

This article presents the protocol for a systematic review, whereby no human participants will take part in the research. Ethical approval is not required for this review and participant consent is not applicable.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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