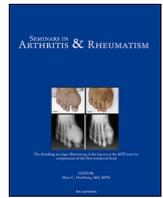




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Defining independence: A scoping review by the OMERACT patient perspective of remission in rheumatoid arthritis group

Thomas Khoo^{a,*}, Bethan Jones^b, Athena Chin^a, Alice Terrett^c, Marieke Voshaar^{d,e}, Wijnanda Hoogland^e, Lyn March^f, Dorcas Beaton^g, Ummugulsum Gazel^h, Beverley Sheaⁱ, Peter Tugwell^h, Caroline-A Flurey^b, Susanna Proudman^{c,j}

^a Rheumatology Unit, Flinders Medical Centre, South Australia, Australia

^b Faculty of Health and Applied Sciences, University of the West of England, United Kingdom

^c Rheumatology Unit, Royal Adelaide Hospital, South Australia, Australia

^d Department of Pharmacy and Department of Research & Innovation, Sint Maartenskliniek and Department of Pharmacy, Radboud University Medical Centre, Nijmegen, The Netherlands

^e OMERACT Patient Research Partner, the Netherlands

^f Sydney Medical School, Institute of Bone and Joint Research, and Department of Rheumatology, Royal North Shore Hospital, St Leonards, Australia

^g Institute of Work and Health, Institute for Health Policy Management and Evaluation, University of Toronto, Toronto, Ontario, Canada

^h Department of Medicine, Division of Rheumatology, University of Ottawa, Ottawa, Canada

ⁱ School of Epidemiology and Public Health, University of Ottawa, Ottawa, Canada

^j Discipline of Medicine, University of Adelaide, South Australia, Australia

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ABSTRACT

Aims: The Outcome Measures in Rheumatology Trials (OMERACT) Remission in Rheumatoid Arthritis (RA) patient perspective working group has previously found that patients prioritised independence, pain, and fatigue as key domains of remission in RA. However, there is currently no clear definition of independence. Consequently, this scoping review aimed to explore how independence is represented in the RA literature.

Methods: A comprehensive search of the EMBASE, Medline, and PsycInfo databases was performed for publications that used independence or autonomy as a disease activity measure, description of disease in remission or treatment outcome. Papers were included if they involved adult participants and were written in English, with no restrictions on study design or publication year. Two reviewers (TK and AC, AT or BJ) independently screened the abstracts. A thematic approach was applied to derive common definitions and descriptions of independence. **Results:** 660 articles were identified, of which 58 (25 qualitative, 28 quantitative, one mixed, and four reviews) met the inclusion criteria. 86% of total participants were female. Ten publications referenced remission. Independence took many forms; in addition to physical and functional capability, it was described in relation to work, social activities, autonomy in healthcare, and household activities. Four common themes describing independence were identified:

1. A return to a state before arthritis.
2. Being physically and functionally able.
3. A sense of freedom without needing to rely on others.
4. Having control over the organisation of one's life.

Conclusion: Although independence is frequently mentioned in the RA literature, it has various meanings, lacks a consistent definition, and is a concept rarely applied to remission. It is multi-factorial, exceeding functional ability alone, and contextualised within sociodemographic and disease factors. This scoping review provides common descriptions of independence to inform future qualitative work towards the development of an outcome measure of independence for the assessment of RA in remission.

* Corresponding author: Flinders Medical Centre, Australia.

E-mail address: thomas.khoo@sa.gov.au (T. Khoo).

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Introduction

Rheumatoid arthritis (RA) is a chronic, inflammatory arthritis of autoimmune aetiology which can affect any of the synovial joints of the body in addition to systemic, non-articular manifestations. It affects approximately 1% of the population and has a female predominance. It has the potential to cause pain, loss of function, and reduced quality of life [1].

Therapeutic options for RA have diversified considerably over the last few decades and the current goal of treatment is clinical remission. Concerns about how remission is defined have previously been raised, particularly pertaining to the lack of the patient perspective in commonly used remission criteria such as the 2011 ACR/EULAR definition [2].

Qualitative work by the Outcome Measures in Rheumatology Trials (OMERACT) 'Remission in RA: Patient Perspective' Special Interest Group (SIG) previously identified three key domains of importance to RA patients in defining remission: pain, fatigue, and independence [3]. Of these, independence has been identified as a domain of particular interest [4] because unlike pain [5] and fatigue [6], it is not clearly or consistently defined and has no validated measurement tool.

A subsequent study was performed by the SIG, reviewing the validity of different instruments for each of the domains of pain, fatigue, and independence, assessing for: construct validity, discriminative capacity (cross-sectional as well as longitudinal), predictive value of future good outcome in terms of physical functioning, and comparison with the ACR/EULAR definition of remission. As an instrument to specifically assess independence was not found, multiple instruments that had the potential to capture independence were analysed (the Health Assessment Questionnaire (HAQ), the EuroQol 5D (EQ-5D), the RAND-36 questionnaire and a novel non-validated numerical rating scale (NRS)) [7]. It was noted that other than the NRS, all of these measures almost exclusively focus on physical functioning. However, qualitative work has previously identified that independence is a domain that is subjective, influenced by contextual factors, and which encompasses other concepts such as family role, socialising, occupation and leisure activities [8].

Consequently, there is a need to better understand what independence means for patients with RA before evaluating if current instruments adequately capture the domain of independence or if a new tool needs to be devised.

Following the guidance of the OMERACT handbook [9–11], a scoping review was pursued with the aims of exploring how independence is represented in the RA literature, and assessing for any common descriptions or definitions of independence, particularly in relation to remission.

Methods

This scoping review was performed with guidance from the Joanna Briggs Institute Manual for Evidence Synthesis [12] and in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (available as a supplementary file) [13]. The PRISMA-ScR states that it is optional to perform a critical appraisal of individual sources of evidence. This was not performed in this scoping review given that the particular focus was on understanding descriptions and domains of independence rather than the effect sizes of specific sources of evidence. A narrative summary and the research protocol have been registered publicly with Open Science Framework Registries (registration DOI 10.17605/OSF.IO/UF3SH).

Search strategy

In June 2021, a comprehensive search of the literature was performed using online databases: EMBASE (via OVID), MEDLINE (via

PubMed), and PsycInfo. To maximise yield given the potentially far-reaching connotations of the term “independence”, there was no restriction on date of publication; the search covered 1947 to June 2021. This search only included results written in English. There were no restrictions on study design; searches included prospective/retrospective data, conference abstracts, case reports, review articles, and special interest group reports.

The search strategy for inclusion was:

Rheumatoid arthritis AND (independence OR autonomy)

Further studies were identified by hand searching the reference lists of publications later identified for inclusion.

Inclusion criteria

The population reviewed was adult participants with RA, for the concept of independence, potentially involving contextual factors such as age, gender, disease duration, disease activity, geographical location and cultural background.

Publications were included if they:

- 1 Involved adult participants with a diagnosis of RA, and
- 2 Used the terms “independence” and/or “autonomy” as a:
 - a measure of RA disease activity, or
 - b description of disease in remission, or
 - c description in relation to a particular activity, occupation or intention, or
 - d treatment outcome.

Exclusion criteria

Publications were excluded if they did not involve any patients with a diagnosis of RA, only involved participants with juvenile forms of arthritis, or made only passing reference to independence without elaborating on its meaning or measurement.

Study selection

Duplicates were removed from the search results. A sample of 10% of the resulting abstracts were independently reviewed using the above inclusion/exclusion criteria by two reviewers (TK and BJ). There was agreement in 83.6% of abstracts with a Cohen's Kappa coefficient of 0.66. Conflicts were discussed and resolved. The remaining abstracts were screened by a single reviewer (TK).

Included abstracts were then independently dual reviewed for full text inclusion amongst four reviewers (TK, BJ, AC and AT) with any conflicts resolved through discussion.

Data extraction

Data were extracted from each of the included publications including study characteristics (authorship, year of publication, country of origin and methodology – qualitative, quantitative or mixed); study population (separating RA patients from other diagnoses groups), demographic data (age, gender) and disease duration; intervention type, comparator and duration for clinical trials; and outcomes.

Data were extracted on any definitions or descriptions of independence included in the publication, forms of independence described, whether loss of independence was the main focus, any tools used to measure independence, and whether any reference to disease in remission was made.

Synthesis

From the data extraction table, demographics and disease characteristics were summarised descriptively. Key phrases, quotes, and statements were identified from the descriptors of independence. A

thematic synthesis was performed where codes were added to summarise notable aspects of this data and then compiled to identify patterns of common meaning. In particular, these were analysed to provide additional meaning to the term “independence”, elaborating on its different forms and perceptions.

Results

The PRISMA flow diagram of this scoping review is shown in Fig. 1. Of 1256 abstracts identified from the initial database searches, 600 were removed due to duplication. From the remaining 656 abstracts, 135 full texts met inclusion criteria for review. 81 of these were excluded with the main reason being the wrong outcome measure (74/81, 91.4%), that is, no significant mention of independence or autonomy in the full text.

Thirty-one further abstracts, not included from the search strategies, were identified as potentially informative from title review of the reference lists of full texts. Of these, four were included after full text review. This resulted in a total of 58 papers included for data extraction.

These papers included 43 original research articles, 13 abstracts and 2 OMERACT reports. Twenty-five of these involved qualitative, 28 quantitative and one mixed methodologies. Thirty-seven papers involved patient groups from countries where English is an official language or widely spoken. Nine publications were multi-national collaborations. Included publications are summarised in Supplementary Table 1.

Patient and disease characteristics

In total, extracted publications involved 11,434 female and 2970 male participants. The reported mean or median ages of participants was typically between 50 and 60 years old though some papers focused on older persons (>65 years) [14-16].

There was significant heterogeneity in the disease characteristics of RA in patient groups from the included publications. Of those where disease duration was clearly documented, some focused on patients with early arthritis (<12 months) [17-20] though predominantly mean or median duration was greater than 10 years [3,15,16,21-31].

Study characteristics

Most included papers were observational cross-sectional studies (42/54). Two of the publications using qualitative methods [18,20] assessed patients at baseline and subsequently at a time point between 12 and 21 months post treatment commencement. Ten of the publications using quantitative methods assessed patients longitudinally with follow-up periods ranging from two weeks to ten years [16,22,31-38]. In three of these, the interventions were medication trials, namely abatacept or adalimumab [32,33], and abatacept or placebo [34]. One involved an intervention of occupational therapy [31] and another, assistive technology/home modification [37].

Ten publications referred to patients in remission [3,4,17,28,34,39-42]. Five of these were previous publications of the OMERACT patient perspective of remission group [3,4,40-42], where the phrase

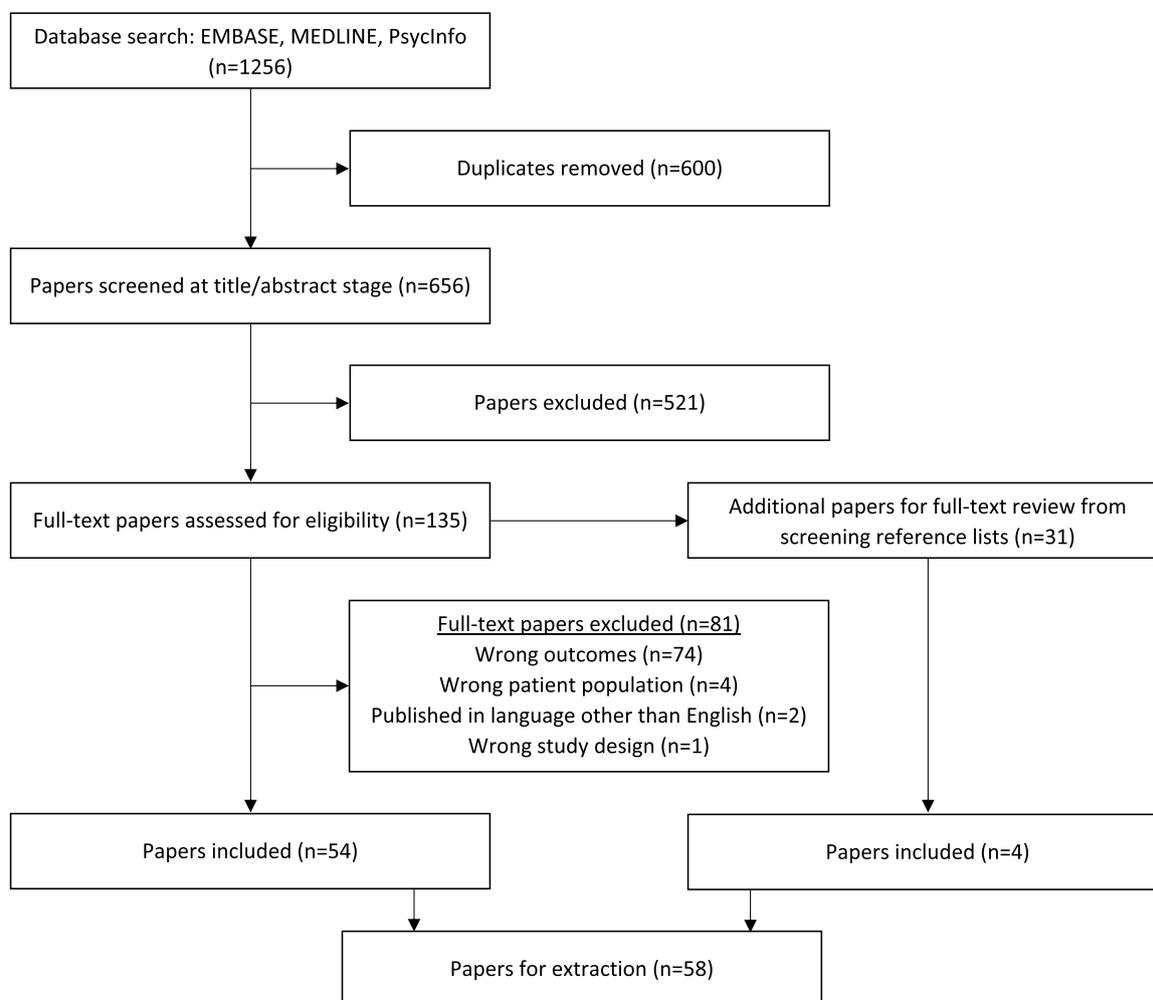


Fig. 1. PRISMA diagram of scoping review.

“disease activity as good as gone” is often used to refer to remission. This was developed in discussion with patient partners prior to the initial qualitative work as the term “remission” is not commonly used in all countries. In the other publications, remission was paraphrased by the original authors as “absence of disease [...] expressed as not being reminded of disease at T1” [17] and “external control of the disease by the given treatment to regain one’s health” [39]. Independence with “valued activities” [43] and “decreased external home help use” [34] was described in association with being in a remission state. However, apart from the OMERACT publications which form the foundations of this scoping review, none of the other publications described independence as a domain of remission.

Forms of independence

Multiple forms of independence were considered in the results of this scoping review. Though physical and functional ability was most commonly described, other forms included independence associated with work/occupation [30,44–49], family life and household chores [3, 41,47,49–52], transport [21,45], social activities [26,45,51,53,54] and healthcare [3,27,55–57].

Descriptions of independence

Descriptions of independence were mainly found in qualitative research papers, drawing on patient perspectives. Though there was no single consistent definition, four main themes were identified in the synthesis.

1. A return to a state before arthritis

This theme was described as a return to a state of normalcy that existed prior to disease onset, being able to do “just about the same things now as I did before I got arthritis” (58). This was viewed in a pervasive sense, “to be normal again, both literally and figuratively” [20] as well as an “ultimate outcome” [19] which reflected a culmination of reductions in specific symptoms such as pain, stiffness, fatigue, swelling and disability [40].

2. Being physically and functionally able

This was a commonly described theme of independence, focusing on the practicalities of “doing things physically, without the help of others, managing yourself” [41]. It encompasses activities of daily living such as “running errands, cleaning the floors, washing clothes or taking a shower at least once every two weeks” [59]. In particular, independence was viewed as the ability to do these functions “and not have to ask others to do things for you” [3] even if this was “with reduced speed but without help” [60].

3. A sense of freedom without needing to rely on others

This theme was infrequently encountered but unique in that it was delineated from the physical and functional activities of Theme 2, encapsulating a “sense of freedom and being able to live without physical, mental, and social limitations” [17]. It captures the psyche of being independent and “not being a prisoner of one’s illness” [21] without necessarily implicating complete physical or functional ability.

4. Having control over the organisation of one’s life

This theme was frequently associated with the use of the term *autonomy*. Though this scoping review searched for this term interchangeably with that of *independence*, Williams and Wood 1988 felt that *autonomy* uniquely implicated a “continuing self-determination manifest even when disability is so severe as to compel greater dependence” [52]. This idea of having the ability to determine one’s life was also reflected in other papers, where patients described “being in charge of their lives” [28] for example, in the ability to “modify a work schedule or hire additional help, or not to work” [61].

Further examples of these themes drawn from the literature are summarised in Table 1.

Table 1

The four main themes identified as domains of independence from this scoping review, with excerpts from the individual papers describing each theme.

Theme	Paper	Excerpt describing independence	
1. A return to a state before arthritis	Parenti et al. 2020 [54]	The idea of life being ‘normal’ prior to disease onset was common in informants’ accounts, suggesting a parallelism between a status of lost ‘normality’ and a status of lost independence	
	Van der Elst et al. 2020 [18]	It was therefore important for them to maintain their independence. Swedish patients, in particular, preferred to maintain their appearance unaffected by RA to re-establish a normalised sense of self.	
	Landgren et al. 2020 [17]	The patients were eager to return to the life they lived prior to the disease at the disease onset and treatment initiation.	
	Santos et al. 2019 [71]	Common illustrative sentences [of the concept of autonomy] include ‘being able to normally do the activities of daily living, by my own’	
	Van der Elst et al. 2016 [20]	Patients with early rheumatoid arthritis ultimately strive to be normal again, literally and figuratively.	
	Van der Elst et al. 2013 [19]	one ultimate outcome: a quality of existence comparable to a status before start of their disease	
	Van Tuyt et al. 2013 [40]	It was important to patients that specific symptoms were reduced (pain, stiffness, fatigue, swelling, disability), but the reduction in impact these led to was more important (independence, able to do valued activities, feeling able to cope, improved mood), leading to a return to normality (work, family role).	
	DeVellis et al. 1997 [58]	‘I can do just about the same things now as I did before I got arthritis’	
	2. Being physically and functionally able	Santos et al. 2019 [71]	Common illustrative sentences [of the concept of autonomy] include: ‘being able to normally do the activities of daily living, by my own’ nevertheless, due to its [rheumatoid arthritis] progressive nature and impact, physical difficulties often come together with expressed needs of feeling autonomous and independent
		Van Tuyt et al. 2017 [3]	independence seems mainly related to physical functioning, that is, ‘the ability to do things you have to do and not have to ask others to do things for you’.
Rasch et al. 2017 [41]		when discussing independence, patients referred to ‘doing things physically, without the help of others, managing yourself.’	
Urbina et al. 2013 [72]		Most patients were semi-independent, that is to say that most patients perform daily living activities with reduced speed but without help.	
Wilson et al. 2009 [37]		‘Independent’ meant [...] without equipment or assistance from another person in performing the activity for the identified time period.	
Westhoff et al. 2000 [59]		independent living would be impossible without, for example, running errands, cleaning the floors, washing clothes, or taking a shower at least once every two weeks.	

(continued on next page)

Table 1 (continued)

Theme	Paper	Excerpt describing independence
3. Freedom without needing to rely on others	Landgren <i>et al.</i> 2020 [17]	Recurring preferences were being able to experience a sense of freedom and being able to live without physical, mental, and social limitations.
	Santos <i>et al.</i> 2019 [71]	Common illustrative sentences [of the concept of autonomy] include: “feeling autonomous and free to do everyday chores”
	Malm <i>et al.</i> 2017 [27]	...being independent was spoken of as a conception of freedom, a physical feeling of maintaining independence without bodily symptoms.
	Burckhardt <i>et al.</i> 1999 [21]	Independence – freedom, mobility, ability to manage, and not being the prisoner of one's illness were mentioned.
4. Having control over life, work and needs	Nyman and Lund 2007 [30]	Informants felt independent because they received assistance only when and in a way they needed during their engagement. In this way, the informants felt that they [...] had control over their occupations.
	McPherson <i>et al.</i> 2004 [28]	...those who had arthritis [...] were found to value being in charge of their lives and their health in some way.
	Yoshida and Stephens 2004 [57]	...noncompliance of rheumatoid arthritic patients is behaviour that satisfies personal goals and it should be viewed as an expression of independence, not deviance.
	Reisine <i>et al.</i> 1989 [48]	In contrast to paid work, women perceived greater autonomy in the family as they reported greater ability to reschedule work or take a day off.
	Williams and Wood 1988 [52]	The notion of independence fails to convey the continuing self-determination manifest even when disability is so severe as to compel greater dependence on others [...] autonomy is preferable as the designation of this state of affairs
	Rogers <i>et al.</i> 1982 [61]	Having the ability to modify a work schedule or hire additional help, or not to work, aids adjustment. In time, patients discover that they can gain more independence by both acknowledging and accepting help from others.

Discussion

Independence is a novel domain of the patient perspective of RA disease activity proposed by the OMERACT Remission in Rheumatoid Arthritis: Patient Perspective SIG [4]. Unlike the other key domains of pain and fatigue for which there are validated measures, independence is potentially less distinct, more pervasive, and complicated to conceptualise. It seems most likely that it is not a binary state of being and may apply to varying degrees in different aspects of life. This scoping review has identified that even prior to considering how it might be measured, independence is a complex, heterogeneous concept in the literature and lacks consistent definition.

Independence is not a concept isolated to the experience of people with RA. Although we initially hoped to gain inspiration from non-rheumatology areas where it may be better explored, there are important differences when considering our patient population. In geriatrics, independence has physical, functional and social components but choice of accommodation and preserving independence in the context of deteriorating cognition also have prominent roles [62]. For patients in

post-stroke rehabilitation, neurological deficit is often permanent and the focus is on adjustment and minimising functional impact [63], which is different from the goal of remission in patients with RA. Overall, though the concept of independence is universal in the goals of healthcare and the themes identified above may apply to other chronic illnesses, the lived experience of patients with RA uniquely demands a separate consideration of the meaning of independence.

The four identified themes of independence in this scoping review correlate with different aspects of independence.

Theme 1, a return to a state before arthritis, reflects a global state of normality that existed prior to disease onset. In considering what this means, Van der Elst *et al.* 2020 described normality as a construct of disease control (absence or stabilisation of joint damage and less medications), physical health (relief of pain and normal joint mobility), social participation (normal everyday activities and role fulfilment within family, work and society), and psychology (normal sense of well-being and identity) [18]. In this way, returning to a normal state involves re-attaining independence but is also broadly applicable to the alleviation of other common symptoms of RA [64].

Theme 2, being physically and functionally able, was the most common description of independence encountered in this scoping review. It centres on the practicalities of being able to “do things you have to do and not ask others to do things for you” [3]. In the papers that considered this theme, the activities mentioned typically focused on necessities such as personal hygiene and daily living activities rather than complex tasks requiring dexterity or coordination, such as crafting or sporting endeavours. Consequently, a patient who believes themselves to be independent may still be unable to do desired occupational or leisure activities.

Importantly, Theme 3 (a sense of freedom without needing to rely on others) and Theme 4 (having control over the organisation of one's life) do not necessarily involve having complete physical ability or function, and would also apply to patients who have irreversible deformities but who nevertheless value “being in charge of their lives and their health in some way” [28].

Theme 4 (having control over the organisation of one's life) is particularly unique because unlike the other themes, it evokes the notion that receiving external help may not necessarily compromise independence and that receiving assistance “only when and in a way [that is] needed” [30] or “acknowledging and accepting help from others” [61] could actually be an expression of self-determination.

Notably, these themes are broad in their consideration of the patient experience of independence and may overlap with currently used constructs for patient-reported assessment of RA disease activity.

From Theme 1, normality prior to disease onset (a time when RA affected the patient not at all and there was no pain) could be a recollection against which patients grade their current state when completing a Patient Global Assessment (PtGA). Though the PtGA is an easily accessible, holistic patient reported outcome measure (PROM), it lacks granularity and is variably applied to global health or disease activity [65].

Theme 2 is incorporated in the Health Assessment Questionnaire (HAQ) but likely retains a separate subjective component in the idea of not needing help and still “managing” [41] suggesting that there are degrees of compromise, adjustment and partial physical functioning which are sufficient to still perform tasks to an adequate degree. Though the HAQ is a useful tool for self-assessment and can be used longitudinally to monitor progress, it uses a discrete numerical scale which may construe the distances between values to be equivalent and covers many, but not all, activities of daily living [66].

Theme 3 and 4 may be partly assessed with tools that focus on Health-Related Quality of Life (HRQOL) but also encapsulate the experience of being removed or distanced from the impact of RA either through adopting a psyche of freedom or practically, through adjusting one's life.

There are several contextual factors which were frequently

encountered in this scoping review. Age influences patient perspective, though no specific comparisons were performed between younger and older patients. Melanson *et al.* 2003 reported that older persons with RA often perceived their primary illness-related stressor to be of physical limitation and the main stress emotion to be of present harm (as opposed to future anticipated threat) [16]. This may occur because older individuals are more likely to have already experienced damage, whether from RA (with longer disease duration), mechanical injuries or other medical and surgical comorbidities.

Duration of disease is also an important contextual factor to the patient perspective. It was particularly noted that qualitative studies focusing on early arthritis (disease duration less than 12 months) had a prominent focus on Theme 1, a return to a state before arthritis [17,18,20], which may not be as clearly recalled or seem as realistic an expectation for those with longer disease duration.

There are also gender, cultural, and geographical biases to recognise in this scoping review. Though RA is three times more common in females than males [67], the populations of the papers included in this scoping review had a much greater female predominance. The priorities of women and men in viewing independence may well differ, influenced by societal perceptions of gender roles. For example, Hewlett *et al.* 2005 asked patients with RA to identify outcomes of importance to their treatment, comparing male and female participants. They found that though independence was equally prioritised, men more frequently identified being able to fulfil their usual role at work as an important outcome [23].

Similarly, it is salient to acknowledge that the papers included in this scoping review mostly came from countries where English is spoken as a main language and populations are predominantly Caucasian. Culturally specific concepts of illness and healthcare are well recognised [68] and this would extend to the idea of independence as well. In focusing on a group of Punjabi speaking participants living in the United Kingdom (6/11 participants were born outside the UK), Sanderson *et al.* 2012 found that although priority outcomes of treatment of RA were comparable to a similar evaluation in a white British population [69], they had a different emphasis with independence more often being framed within the fulfilment of a family role and not being a burden to others [70].

Even within geographically close countries (Belgium, the Netherlands and Sweden), Van der Elst *et al.* 2020 found that Swedish participants, when compared to others, particularly preferred to maintain an appearance of being unaffected by RA to re-establish a normalised sense of self [18]. Consequently, it is highly likely that there are cultural contextual factors which may impact the meaning of independence and this scoping review, in selecting publications written in English, is limited in its consideration of cultural variations.

This scoping review has reinforced the importance of independence as a measure of disease impact in patients with RA and the need for a tool by which it can be measured. It is likely to be defined by a composite of multiple domains covering physical, psychological and social factors. Considering this, there is a need for further qualitative research into patient perspectives on independence, posing the findings of this review to understand what this means to people with RA. This would enable further clarification of the definition of independence to inform the creation and selection of tools for its assessment as a component of RA remission criteria.

Conclusion

Independence is frequently prioritised by patients as an outcome of treatment of RA, but infrequently in relation to disease in remission. It is also not consistently defined or described in the literature. Independence has different forms which are more than just physical or functional ability, though this is the most frequently referenced aspect. Further qualitative evaluation would assist in clarifying how patients with RA perceive their independence. Gathering information on tools to

measure independence was not a focus of this review but would also be helpful for incorporating independence as a domain of assessing RA in remission.

CRedit authorship contribution statement

Thomas Khoo: Investigation, Data curation, Formal analysis, Writing – original draft, Conceptualization, Methodology, Writing – review & editing. **Bethan Jones:** Validation, Data curation, Resources, Writing – original draft, Conceptualization, Methodology, Writing – review & editing. **Athena Chin:** Data curation, Conceptualization, Methodology, Writing – review & editing. **Alice Terrett:** Data curation, Conceptualization, Methodology, Writing – review & editing. **Marieke Voshaar:** Conceptualization, Methodology, Writing – review & editing. **Wijnanda Hoogland:** Conceptualization, Methodology, Writing – review & editing. **Lyn March:** Conceptualization, Methodology, Writing – review & editing. **Dorcas Beaton:** Conceptualization, Methodology, Writing – review & editing. **Ummugulsum Gazel:** Writing – original draft, Conceptualization, Methodology, Writing – review & editing. **Beverley Shea:** Writing – original draft, Conceptualization, Methodology, Writing – review & editing. **Peter Tugwell:** Conceptualization, Methodology, Writing – review & editing. **Caroline-A Flurey:** Supervision, Conceptualization, Methodology, Writing – review & editing. **Susanna Proudman:** Supervision, Conceptualization, Methodology, Writing – review & editing.

Declaration of Competing Interest

There are no competing interests to declare

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.semarthrit.2022.152152.

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