



Review

What do we know about rheumatoid arthritis patients' support needs for self-management? A scoping review



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ABSTRACT

Background: Self-management support is essential to perform self-management behavior. To provide this support in an effective way, insight in the needs for self-management support is necessary.

Objective: To give an overview of self-management support needs from the perspective of rheumatoid arthritis patients to help nurses to improve self-management.

Design: We conducted a scoping review for the period of January 2002 to May 2013 using the following inclusion criteria: (1) studies on adult patients aged 18 years and older, (2) studies from the perspective of rheumatoid arthritis patients, (3) studies reporting results on support needs, and (4) empirical studies using any design.

Data sources: We searched in PubMed, CINAHL, and PsycINFO.

Review methods: Following the steps of a scoping review, we (1) identified the research question, (2) identified relevant studies, (3) selected studies, (4) charted the data, and (5) collated, summarized, and reported results. We incorporated the optional sixth step of consultation of a multidisciplinary panel of professionals and patients to validate our findings.

Results: Seventeen articles were included. Our review shows that rheumatoid arthritis patients have informational, emotional, social and practical support needs. We found an information need for various topics, e.g. exercises and medication. Patients express a need for emotional support in daily life, given through other RA patients, colleagues and supervisors and nurses. For information needs, emotional and social support it is important that it is tailored to the individual needs of the patient.

Conclusion: The most important support needs for self-management mentioned by rheumatoid arthritis patients are more informational, social and practical support and emotional support.

Considering patients' perspective as a starting point for delivering support for self-management can lead to the development of nursing interventions tailored to the needs of rheumatoid arthritis patients.

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What is already known about the topic?

- Chronic patients need to have support for self-management and nurses are increasingly responsible for this.

What this paper adds

- An overview of support needs mentioned by rheumatoid arthritis patients is given.
- Patients mentioned support needs in different areas, but the largest needs are informational and emotional support.

1. Introduction

Rheumatoid arthritis is a chronic inflammatory and systemic disease which affects approximately 0.5–1.0% of the adult population worldwide (Hannan, 1996). Patients with rheumatoid arthritis face several challenging problems, such as pain, stiffness, fatigue, and decreased muscle strength which cause difficulties with daily activities (Krishnan and Fries, 2003). Moreover, rheumatoid arthritis has been linked to various psychological challenges, such as depression, helplessness, and anxiety, and has a considerable impact on quality of life (Boers et al., 2004; Hannan, 1996; Pollard et al., 2005; Rupp et al., 2006). Because of the large impact of rheumatoid arthritis on health status and healthcare expenditures, there is a growing interest in self-management for rheumatoid arthritis patients (Lorig et al., 2001, 2006; Wheeler, 2003).

There is no clear definition of self-management, a commonly used definition is: self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition (Barlow et al., 2002a,b). Thus, self-management encompasses a variety of activities like making lifestyle changes to promote health, such as exercising, communicating with health professionals to improve treatment effects, making daily decisions on the basis of signs and symptoms of the illness, and coping with the impact of the disease to function in important roles and social relations with other people (Wagner et al., 1996). However, taking a central role in these various self-management activities can be a complex task for patients (van Houtum et al., 2013). Therefore, support for self-management is essential (Kennedy et al., 2007). Supporting self-management is effective when it engages informed patients, trained health professionals and health organization policies that support self-management behavior (Kennedy et al., 2007). For this, insight in the support needs for self-management from RA patients' perspective is required. However, an overview of this is currently lacking. Therefore, the aim of this article is to identify the support needs for self-management of rheumatoid arthritis patients, from the available literature.

2. Materials and methods

2.1. Design

We conducted a scoping review, following the steps described by Levac et al. (2010). A scoping review is an

explorative method in which inclusion and exclusion criteria are based on relevance, rather than study quality. Besides that, this methodology has an optional consultation phase in which themes are discussed with professionals and stakeholders to share preliminary findings and validate findings from the literature (Levac et al., 2010). The method contains five steps, namely (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting results. We incorporated the optional sixth step of consultation of a multidisciplinary panel of professionals and patients to validate our findings.

We started with the following research question: *What are the self-management support needs of rheumatoid arthritis patients from the patients' perspectives?* In the next step, we identified relevant studies. For this, we searched PubMed, CINAHL, and PsycINFO for the period between January 2002 and May 2013. We used both MeSH terms and free words texts. Table 1 provides the PubMed search string; equivalent search strings were used in the other databases.

In the third step we selected studies. The search strings for the three databases led to identification of 903 articles (PubMed $n = 549$, CINAHL $n = 217$, PsycINFO, $n = 137$). After exclusion of duplicates, 715 articles were screened on title abstract. A researcher (RMZ) and a research assistant (LB) independently screened the titles and abstracts of 715 articles on the basis of the following inclusion criteria: (1) studies on adult patients aged 18 and older, (2) studies from the perspectives of rheumatoid arthritis patients, (3) studies reporting results on support needs, and (4) empirical studies using any design. Subsequently, 73 studies were considered full text by the same reviewers, and studies were excluded if the content did not meet the inclusion criteria. In case of disagreements, a third reviewer (HRW) was decisive in including or excluding the studies. Fig. 1 shows the process of selecting studies.

In the fourth and fifth step, we collected and charted the data and subsequently analyzed and reported the results. Information regarding publication (year, country), target group (age, gender, disease duration, co-morbidity), sample size, study design, and methods were extracted and organized in a file. Besides the characteristics of the studies, we made an overview of patient-reported support needs described in the studies. We categorized them as support needs related to symptoms, treatment, physical

Table 1
Search string of scoping review.

("Needs assessment"[MeSh] OR needs assessment[tiab] OR need assessment[tiab] OR needs assessment[tw] OR need assessment[tw] OR "needs assessment"[tiab] OR "healthcare needs"[tiab] OR "assessment of healthcare needs"[tiab] OR "assessing needs"[tiab] OR "assessed needs"[tiab] OR "needs assessed"[tiab] AND perception[tw] OR perceptions[tw] OR satisfaction[tw] OR satisfied[tw] OR suggest[tw] OR prefer[tw] support[tiab] ("Self Care"[MeSh] OR selfmanagement[tiab] OR "self management"[tiab] OR "self care"[tiab] OR "self support"[tiab] OR "self management support"[tiab] OR problem[tiab] OR problems[tiab] OR experien*[tiab]) AND (Arthritis, Rheumatoid[MeSh] OR rheumatoid arthritis[tw]).

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