

# Peer Support in Rheumatic Diseases: A Narrative Literature Review

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**Abstract:** Rheumatic diseases are a group of chronic conditions that are associated with significant morbidity, impaired physical function, psychosocial stress, and cost to the healthcare system. Peer support interventions have been shown to have a positive impact on health outcomes in several chronic conditions, but no review has specifically assessed the impact of peer support on rheumatic conditions. The aim of this narrative literature review was to understand how peer support has been applied in the field of rheumatology, with a specific focus on the impact of observational and randomized studies of direct peer support interventions on various outcome measures across rheumatic conditions. We also examined studies exploring patient attitudes and preferences toward peer support. The majority of studies included focused on peer support in rheumatoid arthritis and systemic lupus erythematosus. Generally, patients across the spectrum of rheumatic disease perceive peer support as a useful tool. Peer support interventions, while highly variable, were generally associated with positive impacts on health-related quality of life metrics (both perceived and measured), although these differences were not always statistically significant. Important limitations include variability in study design, selection bias among study participants, and short follow-up periods across most peer support interventions.

**Keywords:** rheumatology, patient preferences, peer navigation, peer support, self-management

## Introduction

Rheumatic diseases are a heterogeneous group of chronic inflammatory conditions that are associated with significant morbidity, mortality, and cost—to both patients and the healthcare system. Rheumatoid arthritis (RA), for example, affects 0.5% to 1% of adults in the United States, and represents a total annual societal cost in excess of \$39 billion (in 2005 United States dollars).<sup>1-3</sup> Systemic lupus erythematosus (SLE), while less prevalent, also exerts a significant financial burden; the average annual direct health care costs for individuals with severe disease may exceed \$50,000.<sup>4-6</sup>

In addition to the physical symptoms associated with these conditions, living with a rheumatic disease can have profound ramifications for an individuals' emotional and psychological well-being. A new diagnosis of RA may leave patients feeling isolated and ill-equipped to cope with their disease.<sup>7,8</sup> Patients living with SLE are subject to disease flares that can lead to organ- or life-threatening complications; these patients can experience severe psychological stress and have a high incidence of comorbid anxiety, depression and psychiatric disease.<sup>9,10</sup>

Individualized needs assessments, patient education and self-management strategies are foundational components of chronic disease management, and these have been incorporated into guidelines for the treatment of rheumatic disease.<sup>11,12</sup> Peer support may represent an opportunity for achieving some of these goals by leveraging individuals' experience living with a disease to support others attempting to do the same. As described in one conceptual analysis, the objective of peer support is the provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population.<sup>13</sup> The introduction of such peer support measures may, through direct or indirect effects, improve health

outcomes and foster a sense of community and belonging for patients that could help reduce the burden on care providers (ie, family and friends) and the healthcare system as a whole.<sup>14,15</sup>

While peer support interventions have been shown to be effective in the management of several chronic conditions (including HIV, chronic kidney disease, diabetes mellitus, and malignancy),<sup>16–22</sup> there is considerable variability in how peer support is defined or applied across studies, even within the same condition. A recent systematic review attempted to categorize peer support interventions and assess their efficacy in chronic conditions; this review found significant inconsistencies in how “peers” and “peer support” are defined, ambiguous study designs, and widely variable outcome measurement.<sup>15</sup> Furthermore, to our knowledge, no literature review has queried the specific impacts of peer support interventions for rheumatic conditions. As such, the exploration of peer support interventions in rheumatic disease represents a key knowledge gap and is the focus of this review article.

While rheumatology-focused literature reviews may be lacking, peer support has emerged as a key component of self-management programs—with demonstrated efficacy in the realm of rheumatology. Foundational research by Lorig et al showed that both a generic Chronic Disease Self-Management program and an Arthritis Self-Management Program were efficacious interventions for patients with arthritis.<sup>23,24</sup> These programs may be considered a form of peer support, as the highly structured programming is administered in a group setting by trained peer leaders. While these programs have been shown to be cost effective,<sup>25</sup> they are considerably resource-intensive. Direct peer support tools may represent a less resource-intensive intervention—requiring less programmatic structure and peer training—with applications in rheumatic disease. Increasingly, the internet has become a popular destination for patients to seek information and support,<sup>26</sup> inviting new ideas for web-based peer support applications. This is particularly relevant for more rare rheumatic conditions, where the internet could facilitate peer-to-peer interactions that would not otherwise be feasible in person.

In this review, we have examined recent literature on peer support interventions in rheumatic disease, with an emphasis on direct peer support interventions rather than those that co-occur within comprehensive disease management programs. We aimed to summarize the documented effects of peer support on rheumatic disease outcomes such as functional status, disease activity, medication adherence, patient knowledge, health care utilization and cost, and other self-efficacy and quality-of-life metrics from both observational and randomized studies of peer support interventions. We also reviewed qualitative interview, survey, and focus-group based studies exploring patient and provider attitudes toward peer support.

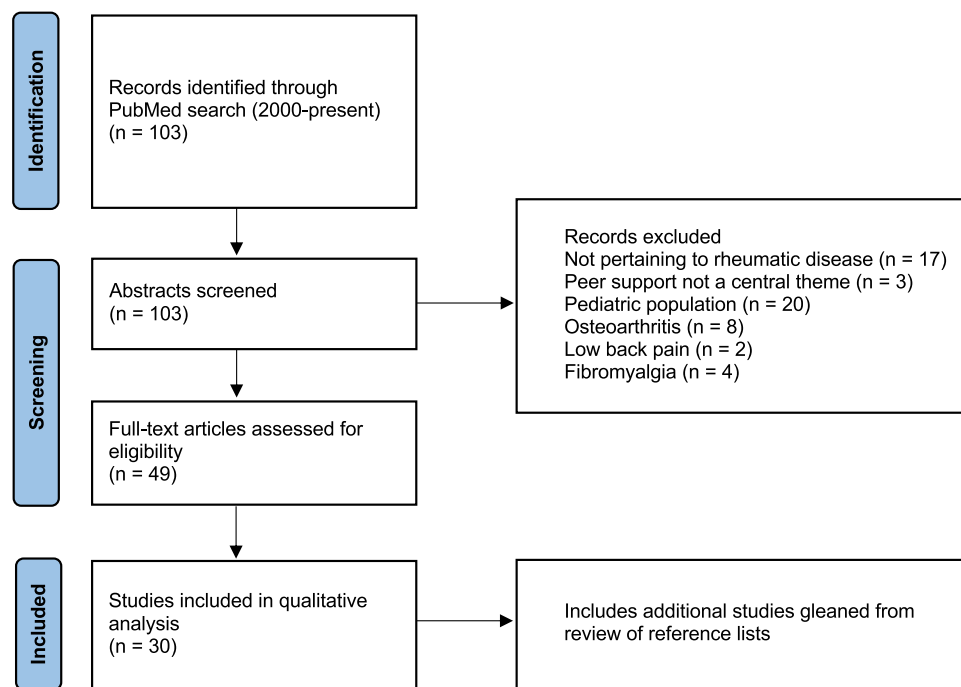
## Methods

We searched PubMed for English-language articles published between 2000 and 2023 that examined peer support in rheumatic diseases. The year 2000 was selected to help capture more recent studies that explore novel, internet-based approaches to peer support. Search terms included rheumatologic disease states (inflammatory arthritis, rheumatoid arthritis, systemic lupus erythematosus, mixed connective tissue disease, systemic sclerosis, ankylosing spondylitis, psoriatic arthritis, vasculitis, dermatomyositis, polymyositis, gout) and their corresponding MeSH terms in conjunction with terms related to peer support (peer support, peer navigator, peer mentor, peer-led, and peer-to-peer).

After the initial PubMed search, one author (NK) reviewed the titles of all articles and applied the following selection criteria: we excluded studies that were unrelated to rheumatic disease or the topic of peer support in rheumatic disease, primarily about pediatric-aged populations, or focused on non-inflammatory conditions, such as osteoarthritis, fibromyalgia, or chronic back pain. While many articles referenced peer support, or discussed interventions that indirectly incorporated peer support modalities, we focused our review on those studies where peer support was a central focus. We reviewed abstracts of the remaining articles (and reference lists from included articles) to identify studies investigating specific peer support interventions and other articles exploring patient and provider preferences and attitudes toward peer support.

## Results

Our initial search yielded 103 full text articles (Figure 1). After applying our exclusion criteria, 52 articles were selected for abstract review. Following review of these abstracts and associated reference lists, we identified 30 articles for inclusion. The majority of these articles focused on peer support interventions (n=9) and attitudes toward peer support



**Figure 1** Study selection flow diagram.

**Note:** Adapted from Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;372:n71. doi: 10.1136/bmj.n71.

(n=8) in RA and other forms of inflammatory arthritis (IA); we identified a smaller body of literature examining the same (n=5, n=1, respectively) in SLE. We also identified articles (n=7) investigating peer support in the context of rarer rheumatic conditions, including vasculitis and systemic sclerosis (SSc). The results of our analysis are organized into the following four sections: peer support interventions in RA/IA, attitudes toward peer support in RA/IA, peer support in SLE, and peer support in other rheumatic diseases.

## Peer Support Interventions in RA/IA

Nine articles described peer support interventions in patients with IA; seven of these studies focused primarily on RA, while two examined patients with ankylosing spondylitis (see Table 1).<sup>27–35</sup> Peer support interventions included online message boards and support groups, peer-to-peer telephone support, in-person support groups, and peer-led educational efforts. Patients with RA included in these studies were predominantly female and greater than 50 years old; those with AS were predominantly male, and younger than 50 years old.

Of the nine total articles, three qualitative studies and one RCT explored online peer support interventions for patients with RA, including social interaction via online discussion board and participation in online support groups.<sup>27,28,32,33</sup> Participants found these internet-based interventions to provide unique and valuable opportunities for information exchange, psychosocial support, and fostering a sense of community among patients with shared experiences living with RA. The one RCT in this category also demonstrated improved perceptions of peer support among participants, though these findings did not translate into significant improvements in the primary outcomes of patient knowledge or self-efficacy.<sup>33</sup> Three additional studies (two feasibility pilots, one qualitative analysis) examined telephone and in-person peer support interventions, either individually or in a group setting.<sup>29–31</sup> Participants reported many benefits in terms of improved social support, coping skills, and disease knowledge. One study showed a non-significant trend toward improvement in measures of functional status and how RA impacts one's life.<sup>31</sup> The only study that assessed the impact of peer support on disease activity and medication adherence did not show any significant effect for those outcomes.<sup>29</sup>

**Table 1** Peer Support Interventions in RA/IA

Author	Title	Year	Disease	N=	Demographics	Design	Intervention	Follow-Up	Outcomes	Findings
Hadert and Rodham <sup>27</sup>	The invisible reality of arthritis: A qualitative analysis of an online message board	2008	RA/IA	87 messages posted by 60 users; 981 replies from 314 users	Not available	Qualitative	Retrospective analysis of an online message board for patients with arthritis	12 weeks	NA	Themes included the “invisible reality” of living with arthritis, having an opportunity for information exchange, the additional support provided by an online community, and online space as unique forum for emotional exchange. Participants discussed a broad range of issues including medications, side effects, and consequences of their disease.
Shigaki et al <sup>28</sup>	Social interactions in an online self-management program for rheumatoid arthritis	2008	RA	30	93% female, mean age 49 years old	Qualitative	Social interactions were evaluated among RA patients participating in online self-management program	10 weeks	Process variables describing social activity in the online environment. Qualitative analysis of board posts was also performed.	Participants utilized discussion board and e-mail features, and community level activity was described as “vibrant”. Chat feature was used less frequently. Participants perceived high levels of support and bonding, and a reported sense of feeling “uniquely understood by others with RA”.
Sandhu et al <sup>29</sup>	Peer-to-peer mentoring for individuals with early inflammatory arthritis: feasibility pilot	2013	RA/IA	18 (9 pairs of peer mentors/mentees)	Mentees 78% female, majority >50 years old, majority completed at least some college	Pilot	Peer support program (telephone or face-to-face) for patients with RA	6 months	Medication adherence, self-efficacy, change in health-related quality-of-life and anxiety, coping efficacy, CDAI, social support, self-management	Mentees showed improvements in self-management, coping, social support, but no significant effect on disease activity or medication adherence. Self-efficacy scores for mentors decreased at 3 months (intervention period) and 6 months (post-intervention follow-up) raising concern that being a peer mentor may be a demanding and potentially stressful experience.

McCarron <sup>30</sup>	An exploration of the perceived effects of a support group for individuals with rheumatoid arthritis	2015	RA	23	96% female, majority >50 years old, majority completed at least some college	Qualitative	Interviews with participants in a monthly peer-support group for patients with RA	6 months	NA	Support group improved participants' perceived quality of life, including improvement in emotional health, increased levels of social support, decreased isolation, increase in disease knowledge and management strategies. Participants with longer-standing RA provided valuable mentorship to those more recently diagnosed disease.
Shadick et al <sup>31</sup>	A Development and Feasibility Study of a Peer Support Telephone Program in Rheumatoid Arthritis	2018	RA	54	Not available	Case-control	Comparing telephone peer support program to standard of care	6 months	Mean adjusted change differences at 6 months in fatigue, pain, self-efficacy, functional status, flare frequency, medication adherence	Non-significant trend toward improvement in functional status and how RA impacts one's life. Participants reported many benefits from peer support: 62% felt less alone, 43% better understanding of their illness, 57% felt part of an RA community; also reported feeling calmer (43%), less sad (24%), more support from family and friends (24%) and maintained healthier lifestyle (24%).
des Bordes et al <sup>32</sup>	Interactions and Perceptions of Patients with Rheumatoid Arthritis Participating in an Online Support Group	2020	RA	90	94% female, median age 54 years old, 83% white	Qualitative	Online support group for patients with RA	5 weeks	NA	Information sharing emerged as a primary theme in online discussions. Patients shared knowledge and experiences around symptoms, medications, coping mechanisms, and frustrations. Study suggests that online support groups may be viable option for providing peer support to RA patients.

(Continued)

Table 1 (Continued).

Author	Title	Year	Disease	N=	Demographics	Design	Intervention	Follow-Up	Outcomes	Findings
Lopez-Olivo et al <sup>33</sup>	A randomized controlled trial evaluating the effects of social networking on chronic disease management in rheumatoid arthritis	2022	RA	210	>90% female, mean age 52 years old, 85% white, majority completed at least some college	Randomized controlled trial	Comparing RA patients participating in peer-moderated social networking group who had access to website with educational materials with a control group (access to educational materials only)	3 months, 6 months	Primary outcome: RA knowledge, self-efficacy, empowerment. Secondary outcome: participation in desired health behaviors, satisfaction w/ peer support, health outcomes, multidimensional health locus of control, mood	Participation in peer-moderated Facebook group significantly improved perceptions of peer support, but this did not translate into significant improvements in primary outcomes (patient knowledge, self-efficacy) for the intervention arm versus control.
Kaya et al <sup>34</sup>	Impact of peer-led group education on the quality of life in patients with ankylosing spondylitis	2016	AS	56	82% male, majority >40 years old	Randomized controlled trial	Patients randomized to peer-led education and booklet or booklet only	6 months	Levels of quality-of-life and depression measured at baseline, after intervention (fourth week), and at 6 months	Participating in peer-led education along with an educational booklet did not change quality-of-life and depression scores compared with an educational booklet alone.
Kaya et al <sup>35</sup>	Peer-led education or booklet for knowledge transfer about disease: A randomized-controlled trial with ankylosing spondylitis patients	2021	AS						Measures of patient knowledge measured at baseline, after intervention (fourth week) and at 6 months	Participating in peer-led education along with an educational booklet did not increase knowledge transfer about AS compared with an educational booklet alone.

The two studies in ankylosing spondylitis patients reviewed findings from a single RCT investigating the impact of a peer-led education program. Neither of these studies showed benefit of the peer-led intervention over the control group in terms of quality-of-life metrics, depression scores, or knowledge transfer.<sup>34,35</sup>

In sum, peer support interventions in RA demonstrated some degree of improvement in self-management skills, quality of life metrics, and a trend toward improvement in functional status, though they have not been shown to modify disease activity or medication adherence, and these findings are not necessarily generalizable to patients with other forms of inflammatory arthritis.

## Attitudes Toward Peer Support in RA/IA

Eight articles addressed patient perspectives on peer support in the context of their RA or other IA (see Table 2).<sup>36–43</sup> As above, the patients with RA were primarily female and over the age of 50 years old. Several themes emerged, including a general interest in peer support groups, a belief that peer mentoring was important (especially in the setting of a new diagnosis), the importance of seeking support from others living with RA (as opposed to family and friends without the disease), and the ability of peer support to help foster group participation (eg in an organized exercise program). One study also assessed the attitudes of clinicians and nurses toward peer support programs, and identified concerns regarding the potential for lack of control and oversight over information that might be shared in peer support settings.<sup>42</sup> In summary, patients living with RA/IA value peer support as an important tool to improve self-efficacy, though there remains some concern from providers about potential negative consequences of these interventions.

## Peer Support in SLE

Six publications, encompassing two patient cohorts, described peer support interventions among patients with SLE (see Table 3).<sup>44–49</sup> The patients in these cohorts were predominantly African American women. Five articles reviewed findings from the Peer Approaches to Lupus Self-Management (PALS) project, a three-month feasibility pilot investigating a weekly, telephone-based peer mentoring intervention for African American women with SLE.<sup>45–49</sup> One abstract evaluated a long-standing telephone-based peer counseling service for woman with SLE.<sup>44</sup>

The PALS pilot study showed statistically significant improvements in participants' anxiety and self-reported disease activity, non-significant improvements in various quality of life measures, including physical function, pain, coping, health literacy, trust, mental health, and trust.<sup>45</sup> Peer mentors were also empowered by participation in this study, and found they were able to discuss topics with mentees that they felt were often ignored or minimized by health care providers.<sup>47</sup> Interesting, preliminary data from this pilot also suggested significant cost savings for participants driven by decreased acute care utilization, including a benefit-cost ratio of >12x (meaning the cost savings to the health care system were greater than twelve times the cost of the program per patient),<sup>48</sup> but the small sample size precluded definitive conclusions. There were no major adverse events during the study, though some mentors found the experience of acting as a role model/support person to be stressful; mentors were also found to have inappropriately provided clinical advice in some instances.<sup>46</sup> An article comparing the PALS cohort with another, patient navigator-based intervention, found that participants in the patient navigator group had significantly increased self-efficacy scores when compared with those in the peer-to-peer intervention.<sup>49</sup>

One study explored SLE patients' attitudes toward peer support. Focus groups were conducted with SLE patients, predominantly from medically underserved areas, regarding potential interventions to improve care. Patients reported feeling isolated at the time of diagnosis, needing assistance to navigate the health care system, and a desire for SLE education. Nearly 70% of those surveyed favored a peer support intervention.<sup>43</sup>

To summarize, peer support interventions in SLE appear to improve—at least in the short term—self-reported disease activity, anxiety and depression, and to yield healthcare cost savings. Patients living with SLE also appear to have a favorable view of these interventions.

## Peer Support in Other Rheumatic Diseases

Seven publications included in our analysis addressed peer support in rarer rheumatologic conditions (see Table 4). One study, a survey of patients with vasculitis, explored the relationship between peer support, medication adherence, and

**Table 2** Attitudes Toward Peer Support in Rheumatic Diseases

Author	Title	Year	Disease	N=	Demographics	Design	Intervention	Findings
Withall et al <sup>36</sup>	Physical activity engagement in early rheumatoid arthritis: a qualitative study to inform intervention development	2016	RA/IA	19	79% female, mean age 60 years old, mean time since diagnosis 3.7 years	Focus groups	Focus groups with RA patients exploring their physical activity needs following diagnosis, experiences relating to physical activity, motivators/facilitators to support physical activity, and suitability of physical activity programs for people with RA	Patients with recent diagnosis of RA are interested in physical activity programming. Group based physical activity programs with a social component may facilitate adherence.
Dures et al <sup>37</sup>	Patient preferences for psychological support in inflammatory arthritis: a multicentre survey	2016	IA	1210	74% female, mean age 59 years old, 41% with disease duration <5 years	Survey	Survey administered regarding preferences for psychological support	48% would participate in peer support groups if offered. 37% of respondents would seek psychological support from peers with arthritis.
des Bordes et al <sup>38</sup>	Assessing information needs and use of online resources for disease self-management in patients with rheumatoid arthritis: a qualitative study	2018	RA	20	85% female, majority >50 years old, 70% white, 85% with at least some college education	Interviews	Exploring RA patients' information needs, acceptance of online resources, and the role for peer support	While family members are important sources of support, RA patients prefer support from others with RA. Online peers support was seen as a potential source for emotional support. There were some concerns around potential privacy and confidentiality issues with online support venues.
Navarro-Millán et al <sup>39</sup>	Perspectives of Rheumatoid Arthritis Patients on Electronic Communication and Patient-Reported Outcome Data Collection: A Qualitative Study	2019	RA	31	94% female, mean age 51 years old, 52% African American, 11% Hispanic, 37% Caucasian	Focus groups	Exploring perspectives of RA patients regarding electronic recording of PROs between clinical encounters, and sharing this information with providers or peers	RA patients were eager to communicate with others with RA to learn about treatment expectations and disease management, and also as a way to reduce isolation. Working with other RA patients may help improve collection of PROs through motivating factors and overcoming technological barriers. Meeting face-to-face is important for establishing trust before engaging in online communication with peers.



Loyola-Sanchez et al <sup>40</sup>	There are still a lot of things that I need: a qualitative study exploring opportunities to improve the health services of First Nations People with arthritis seen at an on-reserve outreach rheumatology clinic	2020	RA/psoriatic arthritis/osteoarthritis	10	Not available	Interviews	Interviews conducted with arthritis patients and health providers and administrators to characterize experiences with the existing model of care, and consider opportunities for improvement	"Building a community of support" emerged as an important theme. Peer support provides important "validation of the 'sick role'" for those with arthritis in this community, which may help improve coping mechanisms and facilitate acceptance of living with a chronic condition.
Swärdh et al <sup>41</sup>	"A Necessary Investment in Future Health": Perceptions of Physical Activity Maintenance Among People With Rheumatoid Arthritis	2020	RA	18	83% female, mean age 67 years old	Interviews	Semi-structured interviews with RA patients regarding their perceptions of physical activity maintenance	Peer support emerged as important mechanism to foster affinity for group participation and maintaining physical activity.
Van der Elst et al <sup>42</sup>	'More than just chitchat': a qualitative study concerning the need and potential format of a peer mentor programme for patients with early rheumatoid arthritis	2021	RA	28	Patients: 60% female, mean age 55 years old; Patient representatives: 100% female, mean age 61 years old, Rheumatology nurses: 100% female, mean age 43 years old; Rheumatologists: 88% female, mean age 45 years old	Focus groups	Exploring attitudes toward peer mentoring in RA among key stakeholders (patients, patient organization representatives, nurses, rheumatologists)	Patient and patient organization representatives feel that peer mentoring can potentially provide newly diagnosed patients with support and practical coping skills. Nurses and rheumatologists see less immediate benefits, and are concerned about the potential lack of control over information provided by peer mentors. Appropriate selection, education and training for coaches is essential.
Feldman et al <sup>43</sup>	Designing an intervention for women with systemic lupus erythematosus from medically underserved areas to improve care: a qualitative study	2013	SLE	29	100% female, all ≥18 years old, 80% African American, 83% from medically underserved zip codes	Focus groups	Focus groups with SLE patients to discuss interventions to improve care	The need for better education for patients and family members emerged as a theme. Chronic pain and depression were seen as obstacles to quality care. Patients emphasized strategies to improve education, peer support, and coordination of care via patient navigators.

**Table 3** Peer Support Interventions in SLE

Author	Title	Year	Disease	N=	Demographics	Design	Intervention	Follow-Up	Outcomes	Findings
Toral et al <sup>44</sup>	Evaluation of a Longstanding Telephone Peer Counseling Service on People with Systemic Lupus Erythematosus and Their Loved Ones	2017	SLE	23	67% aged 40–59 years old, 89% female, 47% Black/African American, 35% White, 31% Hispanic, 18% other race; 94% with SLE >12 years	Qualitative	Survey administered to users of telephone peer-counselor service for SLE patients	NA	NA	68% of users initially accessed service for emotional support and SLE education; 95% felt that their expectations were met. Having someone knowledgeable about SLE was seen as the most valuable aspect of the service (72%). 85% indicated better coping with SLE since being matched to a peer counselor. 66% reported feeling less depressed, with the majority crediting the service for this improvement. 71% reported feeling less isolated. 58% reported their communication and/or relationship with their physician had improved, 100% felt the program was responsible for this change. 94% would recommend this service to others.
Williams et al <sup>45</sup>	Peer-to-Peer Mentoring for African American Women With Lupus: A Feasibility Pilot	2018	SLE	27 (20 mentees, 7 mentors)	100% African American women ≥18 years old	Pilot	One-on-one peer mentoring including 1 hour weekly telephone call	12 weeks	Primary outcomes: health-related quality-of-life, depression, anxiety, perceived stress, social support, self-management, disease activity; secondary measures: scales for treatment credibility and satisfaction with care delivery; demographics, health literacy, coping, and trust also assessed	Non-significant improvements in quality-of-life measures of physical function, role function, social function, mental health, health perception, pain, social support, coping, health literacy, and trust. Significant decrease in anxiety, depression. No significant change in self-management items. Significant decrease in global rating of patient reported disease activity.
Faith et al <sup>46</sup>	Research Ethics in Behavioral Interventions Among Special Populations: Lessons From the Peer Approaches to Lupus Self-Management Study	2018	SLE			Qualitative	Post intervention focus group w/ participants, weekly logs from mentors		Analysis of ethical considerations made in the PALS study	No major adverse events occurred. All mentor/mentee pairs remained same throughout study. Although mentors noted they were trained "not to cross the line" in terms of providing clinical advice, this boundary was crossed in some instances. Some mentors found experience of acting as role model and support person for mentees to be stressful. Some mentors/mentees were dissatisfied over the inclusion of certain topics, namely the sexual health/body image module.

Flournoy-Floyd et al <sup>47</sup>	"We Would Still Find Things to Talk About": Assessment of Mentor Perspectives in a Systemic Lupus Erythematosus Intervention to Improve Disease Self-Management, Empowering SLE Patients	2018	SLE			Qualitative	Mentor logs and mentor interviews with investigator		NA	Mentors took mentorship responsibilities seriously. Mentors desired to work flexibly and collaborative with mentees to overcome obstacles. Mentors able to discuss topics they felt were often marginalized by health care professionals, which was a source of mentor empowerment.
Williams et al <sup>48</sup>	Cost-Effectiveness of a Peer Mentoring Intervention to Improve Disease Self-Management Practices and Self-Efficacy Among African American Women with Systemic Lupus Erythematosus: Analysis of the Peer Approaches to Lupus Self-Management (PALS) Pilot Study	2019	SLE			Cost analysis	NA		Cost of intervention; cost effectiveness ratios for anxiety, depression, disease activity; cost savings pre- and post-two-month hospitalization charges	Total cost per patient was \$1882.81 or \$91.14 per patient per week. Cost effectiveness ratio for anxiety was \$3423 per 1 unit decrease in the GAD score, for depression was \$818 per 1 unit decrease in PHQ-8, for disease activity was \$85.74 per 1 unit decrease in the SLAQ score. Statistically significant difference in pre-hospitalization charges (\$24,289) and post-hospitalization charges (\$872), representing mean charge savings of \$23,426 per individual. Benefit cost ratio of 12.44 (benefits were >12x higher than costs per patient).
White et al <sup>49</sup>	Support Methodologies for African American Women With Lupus – Comparing Three Methods' Effects on Patient Activation and Coping	2021	SLE	114 (100 from PALS, 14 from CALLS)	100% African American women. Median age CALLS cohort 45–54 years old, median age PALS cohort 35–44 years old, majority of patients uninsured	Comparative analysis	Comparing the effect on coping and patient activation of peer-to-peer support (PALS intervention), traditional support group (PALS control), and patient navigator intervention (CALLS intervention)	12 weeks	Patient activation and SLE self-efficacy scores	No statistically significant differences among three intervention methodologies from baseline to post-intervention for patient activation (unadjusted and adjusted). Statistically significant difference in total coping score in the patient navigator group, and differences in scores comparing patient navigator with the support group; only difference in total coping remained significant for patient navigator program in the adjusted model.

**Table 4** Peer Support in Other Rheumatic Diseases

Author	Title	Year	Disease	N=	Demographics	Design	Intervention	Findings
Mendelson and Poole <sup>51</sup>	Become your own advocate: Advice from women living with scleroderma	2007	SSc	11	100% female, mean age 56 years old, 64% white, mean time since diagnosis 16.3 years	Focus group	General focus group conducted with women diagnosed with SSc	Most participants identified support groups as an effective resource for coping; not all participants found them to be available or useful. The small size of SSc community was identified as a reason local support groups may not be available. Factors related to SSc (fatigue, pain) and unrelated to SSc (work and family obligations) were potential barriers to participation. Attendance at support groups could be both supportive and alarming, given potential severity of disease among other participants. Online support groups represented a viable alternative for some participants.
van der Vaart et al <sup>52</sup>	Need for online information and support of patients with systemic sclerosis	2013	SSc/RA	569	65% female, SSc mean age 54 years old, RA mean age 58 years old, SSc disease duration 51% >5 years, RA disease duration 79% >5 years	Survey	Survey assessing internet usage related to rheumatic disease, importance of different online topics, utility of interactive health communication applications	SSc patients demonstrated significantly higher need (compared with RA patients) for online communication with both providers and peer patients.
Alexander et al <sup>50</sup>	The relationship between peer support, medication adherence, and quality of life among patients with vasculitis	2015	Vasculitis	172	75% female, mean age 50 years old, 92% white, 94% insured	Survey	Survey assessing the impact of adherence-related peer support on vasculitis' patients adherence, physical quality-of-life, and mental health	Adherence-related peer support intervention was not predictive of medication adherence or improvements in quality of life after three months
Delisle et al <sup>53</sup>	Reasons for non-participation in scleroderma support groups	2016	SSc	280	86% female, mean age 52 years old, 85% white, 28% college-level education	Survey	Survey assessing reasons for non-participation in SSc support groups	Reasons for non-participation include (1) not interested or no perceived need (36%), (2) no local group available (35%), (3) unaware of group existence (13%), (4) practical barriers to access (6%), (5) emotional factors (4%), (6) uncertainty about whether to attend (4%), and (7) negative perceptions of support groups (3%).

Pépin et al <sup>54</sup>	Reasons for attending support groups and organizational preferences: A replication study using the North American Scleroderma Support Group Survey	2019	SSc	171	87% female, mean age 56 years old, 86% white, mean time since diagnosis 10.1 years, mean time of support group participation 4.9 years	Survey	Survey assessing reasons for participating in support groups among SSc patient in Canada and US	Survey explored reasons for participation in SSc support groups; survey questions fell into three main categories: interpersonal and social support, disease treatment and symptom management, other aspect of living with SSc. On average, participants rated 77% of items as "important" or "very important" reasons for participating in support groups. Respondents emphasized importance of having the opportunity to share feelings/concerns, as well as the educational aspects of support groups. Reasons for attending support groups are similar for patients from Europe, Australia, and North America.
Gumuchian et al <sup>55</sup>	Reasons for attending support groups and organizational preferences: the European scleroderma support group members survey	2019	SSc	213	90% female, mean age 55 years old, 98% white, 66% married, mean time since diagnosis 11 years, mean time of support group participation 6.1 years	Survey	Assess reasons for participating in SSc support groups, and preferences of SSc patients regarding support groups.	SSc patients attend support groups for social support, to learn about treatment and symptom management, and to discuss living with SSc. Patients prefer support groups be held in hospitals or community centers, occur every 1–3 months, last 1–2 hours, have 11–20 members, and have option to include family members or other supports who do not have SSc
Kwakkenbos et al <sup>56</sup>	Reasons for not participating in scleroderma patient support groups: a comparison of results from the North American and European scleroderma support group surveys	2021	SSc	470	European cohort: 87.3% female, mean age 52 years old, 95% white; North American cohort: 84% female, mean age 56 years old, 86% white	Survey	Comparison of survey data of North American and European cohorts regarding reasons for non-participation in SSc support groups	Across cohorts, the most common reasons for non-participation were (1) patients already have enough support (57%), (2) patients unaware of local SSc groups (58%). Compared to North American SSc patients, European patients were more likely to report being unfamiliar with what happens at support groups (46% vs 19%), unable to reliably attend meetings (35% vs 17%), and feeling uncomfortable sharing their experiences in a group setting (22% vs 11%).

quality of life measures. At three months, an adherence-related peer support intervention was neither predictive of medication adherence nor improvements in quality of life.<sup>50</sup> The other six studies, all qualitative analyses of survey data or focus groups, examined attitudes toward peer support groups among different cohorts of SSc patients in Europe and North America.

All studies examining peer support in SSc encompassed predominantly white, female patients with a mean age greater than 50 years old. Two of the six studies explored reasons for participation in SSc support groups in Canada, the United States, and Europe. Across cohorts, patients attended support groups for similar reasons: to gain social support, to learn about treatment and symptom management, and to discuss other aspects of living with SSc.<sup>54,55</sup> A focus group with SSc patients identified online support groups as a viable alternative for those who might not have local access to an in-person support group.<sup>51</sup> Compared with RA patients, SSc patients have demonstrated a significantly higher need for online communication with both providers and their peers.<sup>52</sup> Two other survey-based studies and one focus group also explored reasons for non-participation in SSc support.<sup>56,57</sup> The most common reason for non-participation was lack of interest or no perceived need. A lack of in person support groups (attributed to the relative rarity of the disease) was also a common reason for non-participation. European respondents were relatively less aware of what happens at support groups, and reported feeling less comfortable sharing their experiences in a group setting.<sup>56</sup> Even among focus group respondents who found group attendance to be supportive, there were concerns about potential adverse impacts, including exposure to severe disease complications that may be frightening or cause illness anxiety among those with less advanced disease.<sup>51</sup>

In sum, peer support groups are an important resource for patients living with more rare rheumatologic conditions, like systemic sclerosis, though the impact of these support groups on health outcomes remains unclear.

## Discussion

We performed a narrative review of recent studies exploring peer support interventions and attitudes toward peer support in the context of rheumatic disease. Although there was significant heterogeneity in what constitutes peer support (and the mechanisms by which peer support is delivered), we found that patients' perceptions of peer support were generally favorable across rheumatic conditions, and there exists some signal toward benefit with regard to self-management skills and functional status (in RA/IA) and quality-of-life metrics and health care utilization/costs (in SLE).

Our findings are consistent with existing literature on peer support interventions in the management of other chronic diseases. Studies of peer support for those living with chronic conditions tend to focus on quality of life and self-efficacy outcomes, with most studies reporting positive but non-significant findings.<sup>15</sup> The heterogeneity of peer support, however, poses a significant and foundational challenge to this area of study. Peer support can be incredibly variable; interventions may include professionally-led group sessions, peer-led self-management trainings, peer coaches, community health workers, in-person support groups, as well as telephone- and internet based peer support.<sup>58</sup> Although many studies on self-management include some type of peer-based intervention, these interventions do not occur in a vacuum, and it can be difficult to parse direct effect of peer support from co-occurring disease management strategies. This is particularly challenging when peer support occurs as part of a robust, resource-intensive self-management program. A systematic review of internet-based peer support interventions across conditions, for example, was unable to draw any meaningful conclusions on the effect of web-based peer support interventions.<sup>59</sup> In this review we have attempted to highlight the potential impact of direct peer support interventions, but heterogeneity in peer support intervention, study design, level of peer mentor training and education, and outcomes measured limited the conclusions we could draw about many of the interventions.

The studies of peer support interventions in RA and SLE included in this review are limited by the specific outcomes assessed, selection bias of patients willing to participate, and relatively short follow-up periods—all of which can hinder our ability to detect the true impact of peer support interventions in these conditions. The patients with RA who participated in the studies in this review represent a homogenous patient population of older, white women. The lack of signal for peer support interventions impacting disease activity or medication adherence may illustrate that this particular patient population is less likely to benefit in these domains or that these outcomes do not capture the benefits conferred by peer support. Alternatively, the potential benefits of peer support in this group may require a longer time scale—months to years, rather than days to weeks—before they appear. Conversely, most of the data we reviewed on

peer support in SLE emerges from a single cohort of African American patients. While the data is impressive, the patients in these studies may represent a more vulnerable patient-population relative to the studies involving people with RA and may not be generalizable to all patients with SLE. Peer support has been posited to be particularly beneficial intervention for African American patients with SLE.<sup>9</sup> However, it is important to note that available data suggest benefits in the short term; the durability of this response over time remains unknown.

Much of the data in this review focuses on patient and provider perspectives, though some studies do highlight significant findings with respect to peer mentors themselves. While providing peer support can be a source of empowerment for mentors, it may also carry some risk—particularly when mentors themselves constitute a vulnerable patient population trying to cope with a chronic disease.<sup>46</sup> Prior qualitative reviews of peer support interventions have similarly highlighted the need to be vigilant for any negative effects from these interventions, including the potential impact on both mentors and mentees.<sup>14</sup> Understanding not only the impact of peer support interventions on patients but also potential unintended consequences to mentors is therefore a high priority for future work.

## Conclusion

The literature on peer support in rheumatic diseases is still nascent and the variability in peer support interventions make it challenging to fully evaluate their efficacy or draw comparisons across studies. Future studies should aim to clearly define the intervention, characterize the study population, and identify a minimum set of outcomes, including measures of self-efficacy, shared decision making, and patient satisfaction. To date it has been difficult to detect measurable differences in outcomes, though patients living with rheumatic diseases generally view peer support as a favorable and necessary tool for helping manage their conditions. In addition to perceived benefits to patients, the limited available data suggests that direct peer support may improve self-management skills in patients with RA and help reduce psychological stress in patients with SLE (along with potential cost savings to the healthcare system). The internet will increasingly be utilized as a venue for providing both synchronous and asynchronous peer support, but it should not necessarily supplant more conventional modalities, including telephone and in-person applications. Peer support interventions have the potential to serve as an accessible and dynamic resource for patients with rheumatic diseases, but future studies must attempt to quantify their benefits to justify more wide-spread use.

## Disclosure

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