2018 update of the EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis

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ABSTRACT

To update the European League Against Rheumatism (EULAR) recommendations for the role of the nurse in the management of chronic inflammatory arthritis (CIA) using the most up to date evidence. The EULAR standardised operating procedures were followed. A task force of rheumatologists, health professionals and patients, representing 17 European countries updated the recommendations, based on a systematic literature review and expert consensus. Higher level of evidence and new insights into nursing care for patients with CIA were added to the recommendation. Level of agreement was obtained by email voting. The search identified 2609 records, of which 51 (41 papers, 10 abstracts), mostly on rheumatoid arthritis, were included. Based on consensus, the task force formulated three overarching principles and eight recommendations. One recommendation remained unchanged, six were reworded, two were merged and one was reformulated as an overarching principle. Two additional overarching principles were formulated. The overarching principles emphasise the nurse's role as part of a healthcare team, describe the importance of providing evidence-based care and endorse shared decision-making in the nursing consultation with the patient. The recommendations cover the contribution of rheumatology nursing in needs-based patient education, satisfaction with care, timely access to care, disease management, efficiency of care, psychosocial support and the promotion of self-management. The level of agreement among task force members was high (mean 9.7, range 9.6-10.0). The updated recommendations encompass three overarching principles and eight evidence-based and expert opinion-based recommendations for the role of the nurse in the management of CIA.

INTRODUCTION

In several European countries, rheumatology nursing has developed into a recognised specialty with nurses undertaking both advanced and extended roles.[1–3] Rheumatology nurses operate telephone advice lines, provide self-management support, patient education and counselling.[4–8] Moreover, they participate in disease management, monitor disease-modifying treatments, give intra-articular injections, refer to other health professionals, prescribe drug treatments and help to manage comorbidities.[2 9–12] In some European countries, such as the Netherlands, Denmark, Ireland and the United Kingdom (UK), nurse-led clinics are well established. These add value to patient outcomes and equal the cost of traditional physician-led follow-up.[13–17]

In 2012, the European League Against Rheumatism (EULAR) recommendations for the role of the nurse in the management of chronic inflammatory arthritis (CIA), confined to rheumatoid arthritis (RA), ankylosing spondylitis and psoriatic arthritis, or spondyloarthritis, were published.[18] The 10 recommendations have provided a basis for improved and more standardised levels of professional nursing care across Europe. Evaluation of these recommendations showed a high level of agreement across countries and regions, but large differences in application, suggesting that they are not widely implemented.[19–21] Moreover, some of the recommendations were based on a low level of evidence.[18] Since publication of the recommendations, several studies on rheumatology nursing have been published, which contribute to increased insight and better evidence. The objective of this study was to review the literature from 2010 to date in order to update the EULAR recommendations for the role of the nurse in the management of CIA.

METHODS

The updated version of the EULAR standardised operating procedures for EULAR-endorsed recommendations was followed.[22] These include a systematic literature review (SLR) and a task force (TF) meeting. A steering committee consisting of five members from the former TF appointed a TF representing 17 European countries, including two members from the EMerging EUlar NETwork (EMEUNET). The TF comprised 15 nurses, two patient research partners, one physiotherapist,

one psychologist, one occupational therapist, one medical student and three rheumatologists, one of whom was also a methodologist.

The search strategy from the first recommendations was replicated for the period August 2010 until 1 December 2017. Abstracts from the American College of Rheumatology/the Association of Rheumatology Professionals and EULAR conferences 2016 and 2017 were hand searched. The full search strategies for each bibliographic database are provided in online supplementary text S1. A web-based software platform, Covidence, was used to screen the titles, abstracts and full texts independently by the fellow (BB) and the convener (YvE-H).[23] The selection of titles and abstracts was shared with the TF to check for comprehensiveness before full text review. A detailed overview of the results from the SLR was sent to the TF before the consensus meeting. The steering committee discussed the results from the SLR and prepared a preliminary update of the recommendations before the TF meeting. Only studies providing evidence of higher level than the first recommendations and additional knowledge about rheumatology nursing, were considered. In the 1-day consensus meeting, the preliminary updated recommendations were presented to the TF one at a time with the corresponding new evidence. Consensus was achieved through voting and, if necessary, discussions to reach agreement on final wording.[22] After the TF meeting, the evidence was categorised according to the Oxford Centre for Evidence-Based Medicine into four grades of recommendations from A (highest) to D (lowest) and five levels of evidence (1–5, high–low).[24] Finally, the level of agreement for each of the updated recommendations was assessed by email using a 0–10 numerical rating scale (0 = 'do not agree at all' and 10 = 'fully agree'). A quality assessment of papers that resulted in a higher level of evidence was performed by the steering committee. For critical appraisal, A MeaSurement Tool to Assess systematic Reviews (AMSTAR II), the Cochrane Risk of bias tool for randomised controlled trials (RCTs), the QUality In Prognosis Studies tool for observational studies (QUIPS) and the Consensus on Health Economic Criteria (CHEC) list for the included economic evaluations were used.[25–28] The draft manuscript was reviewed by all TF members and approved by the EULAR executive committee.

RESULTS

The SLR identified 2609 records, 51 of which were included in the full review (see online supplementary figure S2). The selected papers comprised two meta-analyses, nine RCTs (14 papers), 18 observational studies (20 papers), eight surveys, two mixed-method and five qualitative studies. The quality assessment of the studies that enhanced the level of evidence is presented in online supplementary text S3.

The TF achieved consensus on the final wording of the updated recommendations. Only one former recommendation remained unchanged; six recommendations were reworded; two were merged and one was reformulated as an overarching principle (online supplementary table S4). Two additional overarching principles were formulated, resulting in a total of eight recommendations and three overarching principles.

Overarching principles

During the discussions, the TF identified certain themes considered to apply to all recommendations and agreed on three overarching principles (as presented in table 1):

1. Rheumatology nurses are part of a healthcare team

Rheumatology nurses do not work in isolation, but in close collaboration with the patient (and family/significant others, as appropriate), the rheumatologist and, if applicable, a wider healthcare team, with a common focus on care and outcome.[29]

Table 1 2018 update of the EULAR recommendations for the role of the nurse in the management of CIA

Overarching principles Rheumatology nurses are part of a healthcare team Rheumatology nurses provide evidence-based care Rheumatology nursing is based on shared decision-making with the patient				
Recommendations		**Level of Evidence***	**Grade of recommendation***	**Level of agreement† (0–10)**
1	Patients should have access to a nurse for needs-based education to improve knowledge of CIA and its management throughout the course of their disease	1B	A	10.0±0.2 [9-10]
2	Patients should have access to nurse consultations in order to enhance satisfaction with care	1A	A	9.7±0.6 [8-10]
3	Patients should have the opportunity of timely access to a nurse for needs-based support; this includes tele-health	1B	B	9.7±0.6 [8-10]
4	Nurses should participate in comprehensive disease management to control disease activity, reduce symptoms and improve patient-preferred outcomes; this leads to cost-effective care	1A	A	9.7±0.5 [8-10]
5	Nurses should address psychosocial issues to reduce patients' symptoms of anxiety and depression	1B	A	9.6±0.7 [8-10]
6	Nurses should support self-management skills to increase patients' self-efficacy	1A	A	9.8±0.4 [9-10]
7	Nurses should have access to and undertake continuous education in the specialty of rheumatology to improve and maintain knowledge and skills	2C	B	9.8±0.7 [7-10]
8	Nurses should be encouraged to undertake extended roles after specialised training and according to national regulations	1A	A	9.7±0.6 [8-10]

*According to the Oxford Centre for Evidence-based Medicine - CEBM 'Levels of Evidence 1'.
†Expert agreement achieved by all members of the Task Force upon the consensus meeting (data are mean ±SD, [range]).
CIA, chronic inflammatory arthritis.

2.Rheumatology nurses provide evidence-based care

Rheumatology nursing is based on the principles of evidence-based practice. Evidence-based care integrates different sources of knowledge in practice: (i) research evidence, (ii) clinical nursing experience, (iii) patients' experiences, preferences and values and (iv) the local context.[30 31] Providing evidence-based care is broader than care based on protocols and guidelines. To emphasise this breadth the task force decided to remove former recommendation No 7 (online supplementary table S4) and formulated this as an overarching principle.

3.Rheumatology nursing is based on shared decision-making with the patient

Patients' values and preferences are part of the comprehensive process of proper knowledge exchange and consensus on treatment decision.[32 33] Although evidence-based practice also includes taking patients' values and preferences into account, the TF wanted to emphasise this strongly.

Updated recommendations

Table 1 also presents the recommendations, including the level of evidence, grade of recommendation and the level of agreement among TF members. Compared with the first recommendations, the level of evidence increased for five recommendations (online supplementary table S4). The level of evidence ranged from 1A to 2C and grade of recommendation ranged from A to B. The level of agreement within the TF was high for the individual recommendations, ranging from 9.6 to 10 in this update, compared with 8.4 to 9.9 in the first recommendations (online supplementary table S4). The first three recommendations are formulated from the patients' perspective, and the remaining five from the nurses' perspective.

Recommendation 1: Patients should have access to a nurse for needs-based education to improve knowledge of CIA and its management throughout the course of their disease

Patient education covers a wide variety of educational activities including therapeutic and health education as well as health promotion.[5] Besides improving knowledge and disease control, the goal is to enable patients to manage their life with a chronic disease.[5] The updated SLR confirmed a high level of evidence for this recommendation.[34–37] One RCT showed that the use of the Educational Needs Assessment Tool (ENAT) to identify and prioritise patients' individual educational needs significantly increased the effect of patient education delivered by nurses.[36] It was proposed to add 'needs-based' to the revised recommendation, which is also in accordance with the EULAR recommendations for patient education for people with CIA.[5] There was some discussion by the TF as the term 'needs-based' might ignore the possibility that some patients may require information first to be able to determine their educational needs. The TF emphasised the importance of individualised patient education, and that there may be other ways of assessing patients' individual educational needs than the ENAT. High level of evidence for improved self-management skills, increased self-efficacy and global well-being in patients with RA confirmed the beneficial outcomes of patient education.[34 36 37] These effects remained up to 1 and 2 years when supported by subsequent outpatient nurse-led follow-up.[7 8] Additional evidence from RCTs supported positive effects on pain, fatigue, illness perception, quality of life and sedentary time from nurse-led patient educational programmes and involvement of nurses in self-regulation coaching in a multicomponent, action-focused intervention.[35 38] Moreover, cohort studies and one cross-sectional study presented the beneficial outcomes of nurse-led patient education, such as the development of more and timely educational activities for patients, improving patients' adherence to treatments.[39–44]

Recommendation 2: Patients should have access to nurse consultations in order to enhance satisfaction with care

Patients satisfaction can be an indicator of he quality of care.[45] Evidence from a meta-analysis showed a significant positive long-term (2 years) effect of nurse consultations on patients' satisfaction.[3] In a recent RCT, patients with RA were equally satisfied with tele-health follow-up delivered by nurses compared with rheumatologist delivered tele-health or conventional physician-led follow-up for tight control of disease activity.[6] Given the strength of evidence for patient satisfaction the steering committee suggested prioritising satisfaction with care over 'continuity' and 'communication' in the previous recommendation. Additionally, four qualitative studies in RA outpatients reported positive experiences of the continuing relationship with the nurse that promoted a sense of confidence, familiarity, security and participation.[46–49] Nurses' holistic and professional approach to care, patients' confidence in nurses' competence, and a supportive, and less factual interaction style than consultations with physicians were emphasised.[46–49] The TF interpreted this to be closely related to patients' satisfaction.

Recommendation 3: Patients should have the opportunity of timely access to a nurse for needs-based support; this includes tele-health

The unpredictable, fluctuating nature of rheumatic and musculoskeletal diseases and expanded treatment options with increasing complexity of therapeutic strategies, such as "treat-to-target" (T2T), require rapid and timely access to care.[50] Nurses have an important role in the T2T principles. This was shown in two recent RCTs with nursing-staffed/managed helplines incorporated into different modes of follow-up care.[6 8 37] The accessibility to care, traditionally ensured by telephone helplines, provided a valuable clinical service as an adjunct to face-to-face consultation.[51] In a qualitative study, patients expressed the view that this was linked to their feeling of confidence in access to personalised support from a competent healthcare team.[47] The steering committee agreed that this recommendation should focus on timely access in general, rather than specific focus on telephone support lines, as timely access can also include other opportunities for support. Tele-health, defined as a generic term for remote delivery of healthcare by a range of options, including landline or mobile phones and the internet, enables accessibility and appropriate care and has provided new modes of communication with patients, and other opportunities for support and monitoring.[52] Tele-health follow-up by nurses was found to be non-inferior to conventional physician-led follow-up for tight control of disease activity in RA.[6] The TF added the wording 'tele-health' to this recommendation also including telephone as a mode of support, and the established respect of telephone help-lines—for example, the hours allocated to operate them.

Recommendation 4: Nurses should participate in comprehensive disease management to control disease activity, reduce symptoms and improve patient-preferred outcomes; this leads to cost-effective care

With new treatment possibilities and available evidence, management of RA has become increasingly complex.[50 53] The involvement of nurses as part of multidisciplinary team care is needed in a T2T strategy for proactive disease management based on patient education, tight disease monitoring and adjustment of the pharmacological treatment.[50 53 54] The level of evidence was high for this recommendation and it was further strengthened by two meta-analyses and one RCT

with long-term follow-up.[3 8 37 55] These studies and additional RCTs that compared nurse-led and physician-led follow-up, and cohort studies, showed that nurse-led care resulted in equivalent or improved control of disease activity in patients with RA.[6 8 16 37 42 55 56] Nurse-led care was cost neutral or slightly less costly than physician-led care but no evidence for cost savings was found.[14 16 57–59] Therefore, the TF decided to add cost-effectiveness to recommendation No 4 and delete the former recommendation No 10 on cost savings (online supplementary table S4).

For patient-preferred outcomes, there were no significant differences in fatigue, physical disability or quality of life between nurse-led and physician-led follow-up.[3] Additional evidence from various studies supports the distinct role of the nurse for patients with RA. Nurses have an established role in joint examination, management of comorbidity screening, strengthening of adherence to vaccination regimens, early detection of arthritis, interpretation of laboratory results, and initiation and adjustment of the pharmacological treatment.[11 60–68]

Recommendation 5: Nurses should address psychosocial issues to reduce patients' symptoms of anxiety and depression

Psychological distress among people with arthritis has a significant negative effect on their physical well-being and needs to be acknowledged.[69] Furthermore, depression is a well-known comorbidity and should be addressed.[70] One RCT examined depression and found non-inferiority of nurse-led care compared with rheumatologist-led care.[16] Qualitative studies emphasised that patients valued the opportunity to discuss the wider implications of their condition with a nurse.[47–49 67] The TF perceived that addressing these needs includes assessment and identification of psychosocial problems, counselling and referral to other health professionals when needed, which are key components of nursing care, and described in one report of practice experience.[71] The TF suggested adding the word 'symptoms' to change the recommendation into a more preventive approach to incorporate more than just an established diagnosis of anxiety or depression. As earlier reports support interventions to reduce anxiety and depression, the TF decided to replace the word 'minimise' in the previous recommendation with the word 'reduce'.[72 73]

Recommendation 6: Nurses should support self-management skills to increase patients' self-efficacy

Self-efficacy is essential for patients to remain in charge of their life, despite the unpredictable course of their condition, and the concept is linked to the patient's self-management skills.[74] Self-management support offers patients the opportunity to gain the necessary knowledge, skills and confidence to deal with physical and psychosocial consequences of living with a chronic condition and make preferred lifestyle changes.[75] Supporting the patients' self-management is a collaborative activity that expands the role of the healthcare team from delivering information and traditional patient education to include activities that support self-management.[76 77] Higher level of evidence supported the statement that nurse-led interventions can improve patients' self-efficacy.[3 7 34 36] A long-term RCT comparing planned nursing consultations with shared care and physician-led follow-up in RA, showed significantly increased self-efficacy among patients in the nurse-led group after 2 years' follow-up.[8] Evidence from RCTs also showed that nurse-led care improved patient activation, self-efficacy for physical activity and motivation, as well as patients' self-assessment.[7 11 34 35] A recent cohort study and several descriptive studies found that nurse-led interventions enhanced patients' confidence in facilitating their daily life, behavioural change and coping with disease fluctuations.[47–49 67 78–80] The TF discussed the terms 'empowerment' and 'sense of control', which were used in the former recommendation No 6 (online supplementary table S4). Because the SLR did not identify additional evidence for these concepts, the TF decided to confine this recommendation to self-efficacy, which increased the strength of this recommendation.

Recommendation 7: Nurses should have access to and undertake continuous education in the specialty of rheumatology to improve and maintain knowledge and skills

The level of evidence for this recommendation increased owing to new evidence from cohort studies. Educational programmes for rheumatology nurses were associated with increased knowledge, skills and improvement of practice.[81–83] Some tasks, traditionally performed by rheumatologists and physiotherapists, such as joint examinations or musculoskeletal examinations, the identification of RA signs and symptoms and the ability to distinguish abnormalities, can be learnt by nurses through structured training.[64–66 83 84] However, the SLR also revealed that some rheumatology nurses lacked understanding of the T2T strategy and confidence to perform examination of joints.[85] Moreover, nurses lacked confidence to provide support for disease modifying antirheumatic drugs, promote physical activity and deal with sexual concerns.[86–89] The TF recognised a need for specific generic and rheumatology training. Rheumatology nursing is not a formal specialty in every country. To provide a workforce that can meet evolving needs in rheumatology clinics, global recognition and development of this specialty is needed. Therefore, the wording 'in the specialty of rheumatology' was added to the recommendation. The TF discussed whether the formulation 'access to' was necessary. In some countries however, there is no access to formal rheumatology education for nurses and the TF felt that access is crucial to develop this nursing capability.

Recommendation 8: Nurses should be encouraged to undertake extended roles after specialised training and according to national regulations

The wording of this recommendation remained unchanged. However, the level of evidence increased based on two meta-analyses showing the effectiveness of nurse-led follow-up, which represents an advanced level.[3 55] The TF discussed the definition of 'basic nursing' and 'extended' and 'advanced' practice roles. Three cross-sectional surveys described the breadth and complexity of rheumatology nursing, including prescribing and administering pharmacological treatments (oral, subcutaneous, intra-articular, intravenous), patient education and providing support for patients and their family/significant others.[60 85 90] The TF agreed that extended and advanced practice roles comprise a broad spectrum of nursing activities determined by the complex needs of patients, from disease assessment, monitoring the impact of the disease and the effects of treatment to long-term support for self-management and prevention of complications.

Research agenda

Through discussions, the TF updated the research agenda (box 1), which reflects research topics to collect and strengthen the evidence for the value of the nurse in the management of CIA.

Educational agenda

The educational agenda (box 2) supports educational opportunities as a prerequisite for quality in nursing care, and also specifies educational needs within all levels of nursing care and the need for the awareness of rheumatology as a medical specialty in the educational system.

Box 1 Research agenda

- To study the nursing contribution in improving access to care, using different modes of healthcare delivery
- To study the nursing contribution in facilitating the patients' effective use of healthcare provided by members of the multidisciplinary team
- To study the nursing roles in optimising treat-to-target treatment strategies in patients with CIA
- To study the nursing contribution in improving patient-preferred outcomes, including psychosocial issues, in both short- and long-term outcome studies
- To identify different components of nursing knowledge and competencies in each European country
- To study further the cost-effectiveness of nursing across different European countries.
- To study the nursing contribution to patients' employment status and social participation
- To study the nursing contribution in the screening and management of risk factors and comorbidities
- To study further the nursing contribution to patient empowerment and self-efficacy
- To undertake implementation and evaluation studies of nursing interventions
- To provide the evidence for these nursing recommendations in patient populations with different rheumatic and musculoskeletal disease
- To study systematic ways to assess patients' individual educational needs throughout the course of their disease

DISCUSSION

The EULAR recommendations for the role of the nurse in the management of CIA have been updated according to the current evidence. Three new overarching principles relevant for all eight recommendations were formulated. Different European studies have contributed to an increase in the level of the evidence and generalisability of the eight updated recommendations. This update represents even stronger consensus among the experts than the previous recommendations.

The SLR confirmed the contribution of rheumatology nurses to healthcare via tele-health, thus providing new opportunities for accessible and sustainable healthcare.[6 91] Moreover, person-centred care and partnership with patients are important dimensions, supporting a sense of confidence in nurse-led care.[46–49 92]

The broad scope of rheumatology nursing was also shown in a recent SLR.[93] Outcomes from rheumatology nursing interventions in RA were found in multiple health domains, such as disease status, symptoms, physical and mental functioning, and patient safety. Furthermore, rheumatology nursing affects the quality of care in several dimensions. In another SLR, nurse-led care for patients with RA was shown to be highly acceptable, equally effective, efficient and safe compared with traditional physician-led care, and seemed appropriate and accessible from the patient's perspective.[94] However, extended roles should be responsive to patients' needs therefore not abandoning nursing care, which is valued by patients. Good organisation of care is needed to avoid the risk of excessive workload which may lower the quality of care.

Following the publication of the first recommendations, rheumatology nursing has gained increased attention in several countries. In the TF for this update, we were able to include members from more countries across Europe in which rheumatology nursing is now part of routine care. This is a strength of the process and will help to facilitate wider implementation of the updated recommendations. In contrast to the previous recommendations, we assessed the risk of bias of the studies that contributed to the new level of evidence. These were mainly of moderate to good quality, which strengthens our results.

There are limitations we need to address. Most study populations were outpatients with established RA and low disease activity. It is unknown if the results can be transferred to patients with early RA and to patients with other inflammatory rheumatic diseases, who have a higher risk of structural damage. Therefore, the updated recommendations should still be regarded as points to consider for these patients. In addition, costs and measures of health-related quality of life vary across countries and healthcare systems, and this may hamper transferability.[95 96]

Studies reporting nursing interventions that focus on healthy lifestyle and work participation were rare. The research agenda aims to examine these areas. Furthermore, we excluded studies where effects of nurse interventions could not be isolated from those of a multidisciplinary team. This reflects the current practice where nurses play an important, yet sometimes not clearly visible and distinguishable, role as part of multidisciplinary teams. Differences in the available skill mix in rheumatology teams in different countries or regions can determine who does what, and this may affect the quality of care received.[97] Increasingly the importance of nurses' communication skills for supporting patients in treatment decisions—for example, switching to biosimilars, is recognised.[98 99] However, literature on this topic is still lacking. Finally, in the included RCTs, the definition of 'nurse-led care' varied. In the UK, nurse-led care was defined as a practice model in which nurses provide education, monitoring and support for a certain group of patients, in collaboration with physicians and other members of multidisciplinary teams such as physiotherapists, occupational therapists and psychologists.[15] This definition was not recognisable in all the included studies where the competence of the nurse was most often explained by their title only. Therefore, the minimum competences (eg, the required education or skills needed for rheumatology nurses) to achieve similar results are unknown.

To date, standardised education and training for rheumatology nurses is not available in every European country. The educational agenda aims to support access to well-defined basic, extended, and advanced practice level nursing education. Besides, sufficient training and supervision are required when undertaking extended and advanced practice roles. Education should reflect the complexity of tasks and activities performed by nurses.[100] Moreover, the level of competences should be aligned across Europe. The current EULAR online educational course can address knowledge of rheumatic and musculoskeletal diseases, but it does not address all educational needs of nurses undertaking extended and advanced practice roles. Furthermore, the English language can be a barrier to many European nurses and therefore translation of the online education into several languages may be necessary.[101]

Box 2 Educational agenda

- To develop a competency framework for rheumatology nursing
- To develop rheumatology basic, advanced and extended level nursing education programmes
- To raise the profile of rheumatology nursing within undergraduate and postgraduate educational programmes

The previous recommendations were translated into several languages and efforts were made to implement them in different countries.[19] Similar initiatives to implement these updated recommendations are important and need national and international support from stakeholders such as EULAR. Moreover, recommendations that focus on a broader range of rheumatic and musculoskeletal diseases are needed. This may be considered in future updates.

In conclusion, this update of the 2012 EULAR recommendations for the role of the nurse resulted in three overarching principles and eight recommendations. The updated recommendations can further emphasise and optimise rheumatology nursing and contribute to more standardised levels of professional nursing across Europe.

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