Dissemination and evaluation of the European League Against Rheumatism recommendations for the role of the nurse in the management of chronic inflammatory arthritis: results of a multinational survey among nurses, rheumatologists and patients

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Abstract

Objectives. The aims of this study were to disseminate, assess agreement with, assess the application of and identify potential barriers for implementation of the European League Against Rheumatism (EULAR) recommendations for the role of nurses in the management of chronic inflammatory arthritis (CIA) using a survey of nurses, rheumatologists and patients.

Methods. A Web-based survey was distributed across Europe and the USA using snowball sampling. Levels of agreement and application were assessed using a 0–10 rating scale (0 = none, 10 = full agreement/application). Reasons for disagreement and potential barriers to application of each recommendation were sought. Regional differences with respect to agreement and application were explored.

Results. In total, 967 nurses, 548 rheumatologists and 2034 patients from 23 countries participated in the survey. Median level of agreement was high in all three groups, ranging from 8 to 10 per recommendation. Median level of application was substantially lower, ranging from 0 to 8 per recommendation. Agreement and application were lowest in Eastern and Central Europe. The most commonly reported reasons for incomplete agreement were too many other responsibilities (nurses), doubts about knowledge of the nurse (rheumatologists) and fear of losing contact with the rheumatologist (patients). The most commonly reported barriers to the application were time constraints and unavailability of service. Rheumatologists responses suggested that nurses had insufficient knowledge to provide the recommended care.

Conclusion. The EULAR recommendations for the role of nurses in the management of CIA have been disseminated among nurses, rheumatologists and patients across Europe and the USA. Agreement with these recommendations is high, but application is lower and differed across regions.

Key words: nurses, rheumatology nursing, guideline, inflammatory arthritis.
Introduction

Recently, 10 European League Against Rheumatism (EULAR) recommendations have been developed for the role of the nurse in the management of chronic inflammatory arthritis (CIA) [1]. The recommendations aim to achieve harmonization in rheumatology nursing care across countries, covering the contribution of nurses to the care and management of patients with CIA and requirements for their professional performance.

A successful change of clinical practice in accordance with these recommendations requires an effective implementation strategy in which the key stakeholders delivering and receiving care, i.e. nurses, rheumatologists and patients, are involved [2]. Apart from dissemination, this includes a multifaceted approach focussed on hindering factors for this care at the level of the health professionals and of the social, organizational, economic and political contexts [3–7]. In order to develop tailored interventions, knowledge about potential barriers for acceptance and application of the recommendations in daily practice is essential [3, 7–9].

The objectives of the present study were to disseminate, assess agreement with, assess the application of and identify potential barriers for implementation of the EULAR recommendations for the role of nurses in the management of CIA among nurses, rheumatologists and patients.

Materials and methods

The study was performed by means of a cross-sectional survey among the target population across Europe and the USA. The study was approved by the Medical Ethical Committee of Maastricht University Medical Centre, Maastricht, the Netherlands. If necessary, national ethical approval was asked for by the principal investigators (PIs) in the respective countries.

Development of questionnaires

The survey was developed with three slightly different English versions of the questionnaire for nurses, rheumatologists and patients. The questionnaire items comprised the 10 recommendations, each followed by questions on the level of agreement, level of application and barriers to implementation. The levels of agreement and application were rated on a 0–10 scale, with 10 being the highest level of agreement or application. Reasons for incomplete agreement or incomplete application were sought. A predefined list with potential reasons or barriers was offered, based on the findings of a previous EULAR health professional survey [10] and on clinical experience from the members of the steering committee, with the opportunity for respondents to add items. The questionnaires were piloted among 18 nurses, 9 rheumatologists, 15 patients and 4 other health professionals from different countries. Their comments were used to refine the final versions of the questionnaire, which were then translated into 17 different languages and subsequently made available online (administered as a Web-based survey) to the target group between June and August 2012.

Distribution of the questionnaires

A national PI and a key leading rheumatologist were appointed for each participating country across Europe and the USA. They were jointly responsible for translation of the questionnaires into their respective language (if applicable) and for dissemination of the questionnaires in their country. The participants in the survey were asked to send the Web link of this questionnaire to their colleagues or to fellow patients (snowball sampling technique) [11]. During the survey period, PIs and key leaders were reminded on two occasions to increase, where possible, dissemination of the questionnaires. Convenience sampling was used and as many participants as possible were included.

Statistical analysis

Descriptive analyses were used to calculate conceptual agreement with, application of, reasons for incomplete agreement with and barriers to the application of each recommendation. The participating countries were grouped into six regions: Northern, Western, Southern, Eastern and Central Europe and the USA, and differences in the level of agreement and level of application between the regions were assessed with non-parametric Kruskal–Wallis tests within the group of nurses, rheumatologists and patients, respectively. All analyses were performed using IBM SPSS Statistics version 20.0 (IBM, Armonk, NY, USA).

Results

Population

In total, 3594 persons responded: 967 nurses, 548 rheumatologists and 2034 patients, from 23 countries. The largest number of nurse respondents was from the USA (n = 142), while the largest number of rheumatologist (n = 65) and patient (n = 384) respondents was from France. The proportion of patients with access to nursing care varied widely across countries, from 5.1% in Cyprus to 88.9% in the UK (see supplementary Table S1, available at Rheumatology Online). Characteristics of the study population are presented in Table 1. The nurses had a mean of 10.4 years (S.D. 9.7) of clinical experience in rheumatology and for the rheumatologists this was 16.4 years (S.D. 9.7). The majority of the patients had RA with a mean disease duration of 14.4 years (S.D. 11.9).

Level of agreement and level of application

Fig. 1 presents the level of agreement and the level of application per recommendation from nurses, rheumatologists and patients, respectively. Overall, the level of agreement was high (median 8–10) across the three groups, with rheumatologists’ responses displaying the largest variation. In contrast, the overall level of application was substantially lower (median 0–8) and the variation was much larger in each group and for each recommendation.
Reasons for incomplete agreement and barriers to application

The most frequently reported reasons for incomplete agreement (i.e. level of agreement <10) were having too many other responsibilities (nurses), doubts about knowledge of the nurse (rheumatologists) and fear of losing contact with the rheumatologist (patients). The most frequently reported barriers to application of the recommendations (i.e. level of application <10) were lack of time (nurses), insufficient number of nurses (rheumatologists) and the service is not offered or no nurse available (patients). In addition, lack of economic resources was reported by nurses and rheumatologists, whereas rheumatologists also reported insufficient knowledge of the nurses to provide care as stated in the recommendations. Supplementary Tables S2 and S3, available at Rheumatology Online, present the two most frequently reported reasons for incomplete agreement and barriers to application per group and per region.

Regional differences

Regional differences with respect to the level of agreement and level of application were explored for each recommendation and in the three groups (see supplementary Tables S4 and S5, available at Rheumatology Online). The level of agreement was high in each region and varied from 6 to 10 among nurses, from 5 to 10 among rheumatologists and from 8 to 10 among patients.

The lowest levels of agreement were found in Eastern and Central Europe for almost all recommendations, except for recommendation 6 (Nurses should promote self-management skills), where the rheumatologists’ level of agreement was lowest in Southern and Central Europe; recommendation 7 (Nurses should provide care that is based on protocols and guidelines), where the rheumatologists’ and patients’ level of agreement were lowest in Central Europe and the USA; and recommendation 9 (Nurses should be encouraged to undertake extended roles), where the rheumatologists’ level of agreement was lowest in Western and Southern Europe.

The level of application of the recommendations was substantially lower in each region and varied from 3 to 9 among nurses, from 0 to 10 among rheumatologists and from 0 to 8 among patients. The level of application was lowest in Southern, Eastern and Central Europe for almost all recommendations, except for recommendation 8 (Nurses should have access to and undertake continuous education), where the nurses’ level of application was lowest in Northern, Southern and Eastern Europe.

Discussion

A large number of nurses, rheumatologists and patients participated in this survey that evaluated agreement with and application of the EULAR recommendations for the role of the nurse in the management of CIA. The survey achieved a good range of participants across Europe and the USA, although the highest number of responses was from Northern and Western Europe. The level of agreement was high, but the level of application was substantially lower. Many barriers for acceptance and application were reported and regional differences were explored.

The level of agreement was highest among nurses. The main reason nurses gave for incomplete agreement was having too many other responsibilities, which provides an indication of their perceived workload. The use of protocols and guidelines has been found to increase efficiency and therefore may reduce workload [12, 13]. However, lack of appropriate protocols was frequently reported by nurses and rheumatologists.

Across countries, a wide variation in the role of the nurse was found. Agreement among rheumatologists and patients was highest in regions where rheumatology nursing care on an extended level is well established, which has been shown in earlier studies [14, 15] to result in confidence and satisfaction of patients.
Many barriers to application of the recommendations were identified. All three groups mentioned lack of time, lack of sufficient number of nurses or lack of resources, which all refer to the financial investments that are required if a minimum standard for rheumatology nursing care is to be implemented. The high level of agreement with the recommendations demonstrated within this survey, as well as the level of evidence for the effectiveness of nurse-led care [16–19], justifies investment in the education and training of nurses.

Further research is needed to develop targeted interventions for implementation and to evaluate their effectiveness. Specific interventions for implementation of the recommendations will likely differ by region and by subgroups and should be governed by the barriers identified. On a national level, key leaders can play an important role in serving as role models, in questioning existing values and in encouraging best practices [3]. They can also contribute to defining specific interventions for further implementation in their countries. In addition, interventions are required on an international level.

Access to continuous education is one of the EULAR recommendations for the role of nurses [1]. The high level of agreement with this recommendation shows that the knowledge base of nurses is considered important by nurses, rheumatologists and patients in all countries. Standardized and transparent nursing curricula would improve the knowledge, skills and self-confidence of nurses and might improve confidence from rheumatologists and patients. Easy access to affordable and clinically relevant rheumatology nursing courses is required in order to guarantee the availability of appropriately trained rheumatology nurses.

Minimum standards of care have been formulated in the recommendations, but they need further definition and refinement. Several initiatives to support rheumatology nursing and multidisciplinary collaboration regarding these issues have already been undertaken by the members of the former EULAR nursing task force. EULAR can play an active role in encouraging and supporting further implementation of rheumatology nursing care for patients with CIA. A follow-up survey in 5 years is recommended to evaluate if the intended strategies for implementation have had the desired effects.

The survey has several limitations. First, despite efforts to include as many EULAR countries as possible, not all participated in the survey. However, we were able to include all countries in which rheumatology nursing is well established and several countries where it is still in its infancy. Second, responses varied widely across countries and regions, and given the number of responses received, it is likely that many eligible people did not participate in the survey. Given that snowball sampling was used to disseminate the link to the survey, it was not possible to estimate a response rate. Selection bias may have occurred [11]. Third, the formal forward–backward translation approach was not used in translating the questionnaires from English to target languages [20]. However, the
questionnaires were translated by the PIs and local rheumatologists in the participating countries as accurately as possible. Finally, <50% of the patient respondents had access to rheumatology nursing care. Nevertheless, all participants provided comments and important information with respect to barriers for the acceptance and application of rheumatology nursing care, which can be used in defining further implementation strategies.

In conclusion, the EULAR recommendations on the role of the nurse in the management of CIA have been disseminated among nurses, rheumatologists and patients throughout Europe and the USA. The level of agreement was high in all three groups, but the level of application was substantially lower. Agreement and application varied across regions and were lowest in Eastern and Central Europe. Also, topics were identified that can be used to develop tailored strategies supporting further implementation of rheumatology nursing care.

**Rheumatology key messages**

- Agreement with the recommendations among nurses, rheumatologists and patients was high; application was lower and varied across regions.
- The most common barriers for application of the recommendations were time constraints and unavailability of the service.

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**Supplementary data**

Supplementary data are available at *Rheumatology* Online.

**References**


