EULAR efforts to define quality of care

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Received and accepted on September 7, 2007.

Clin Exp Rheumatol 2007; 25 (Suppl. 47): S14-S17.

Key words: EULAR, quality of care quality indicators, recommendations.

Competing interests: none declared.

ABSTRACT
EULAR is deeply involved in the field of quality of care of musculoskeletal disorders via numerous initiatives. EULAR has promoted initiatives in the different steps involved in improving/facilitating quality of care (e.g. original studies (basic, translational, clinical research studies), meta-analysis/systematic literature research, elaboration and dissemination of recommendations, ...).
Moreover, EULAR is promoting educational programs and is lobbying at the European Community level in order to improve the recognition of musculoskeletal disorders.

Introduction

In order to better understand the activities of the European League Against Rheumatism (EULAR) in the area of quality of care, it seems appropriate to define clearly the EULAR terms "quality of care", "quality indicators" and "techniques to evaluate quality of care".

Definition of quality of care: quality and indicators

Issues of quality have generally been classified and discussed in the scientific literature in terms of three domains: structure, process, and outcome. A primary question in this area is whether we should define quality of care based on results/outcomes or surrogate markers/tools (structure, process). We can attempt to clarify this matter using the example of the treatment of rheumatoid arthritis (RA).

The use of outcome measures to define quality of care in RA

As a first approach, one could define the final endpoint as the prevention of disability. The Health Assessment Questionnaire (HAQ) is an optimal tool to evaluate disability (1). One could also define a HAQ value below < 0.5 as an "acceptable" condition. In this case, one could consider the percentage of RA patients with a HAQ value below 0.5 after, say, a disease duration of 10 years as the measure of quality of care. However, such a measure (i.e., the percent of patients with a HAQ < 0.5) might be thought too stringent, and therefore one could propose as a measure the percentage of visits for RA in a rheumatologic outpatient clinic for which such information (HAQ) is available. In this case, one could adjudge that as soon as the measurement has been collected, one might expect that the goal (value < 0.5) will be targeted. However, this may not always be the case, and rheumatologists could collect data merely to satisfy the requirement without necessarily trying to achieve a particular recommended score.
This approach, in restricting the definition of quality of care in RA patients to a single component, might be considered as too simplistic. Therefore, the prevention of co-morbidities such as cardiovascular events could be added; for example, the percentage of RA patients without cardiovascular morbidity after a disease duration of 20 years might be regarded as relevant to the definition of quality of care.

Use of surrogate markers to define the quality of care

We have seen that an optimal and definitive endpoint can usually be evaluated only after a long period of disease monitoring (*e.g.*, 10 years for HAQ, 20 years for cardiovascular events in our previous example). For this reason one might adopt surrogate indicators, such as recognized predisposing factors to the endpoint rather than the endpoint itself.
In RA persistent activity is recognized as a predisposing factor for subsequent disability. Therefore, either the percentage of patients with low disease activity and/or at least the percentage of visits during which such activity has been collected could be considered as reflecting such quality of care. Howev-

er, predisposing factors for subsequent disability are numerous. Therefore, and as a non-exhaustive list, one could also consider as potential quality indicators any initiative aimed at:

– Evaluating/increasing the number of rheumatologists
– Evaluating/increasing the number of health professionals working in the field of musculoskeletal disorders
– Evaluating/increasing the level of education/information of patients.

Gap between guidelines and daily practice

Most studies have clearly shown that a significant gap exists between evidence-based medicine guidelines and daily practice (2, 3). It would appear to be of considerable interest to understand why such a gap exists (4). Many groups have studied this matter, using different terms such as quality assurance (QA), technology assessment (TA), clinical epidemiology (CE), and continuous quality improvement (CQI).

Most of these observers conclude that such gaps can probably be explained in large part by the facts that the proposed recommendations are too distant from the reality in which the physician operates, and that the proposed guidelines often contain large amounts of information that the clinician has no time to digest.

Moreover, there are gaps between those who practice and those who manage health care.

Evaluation of the quality of care in daily practice

As soon as quality indicators are identified, it is possible to study their implementation in order to evaluate the so-called quality of care. Different designs for such studies have been proposed:

The "actor" patient: In this type of study, an "actor" patient visits a doctor with a specific question that can be used to evaluate whether the doctor satisfies the *a priori* defined quality indicators, such as whether he/she collects information permitting calculation of the HAQ or DAS, and/or measures the "patient's" blood pressure. This technique is very powerful, but is quite time-consuming and expensive.

Evaluation of medical records: In this type of study, it must be decided whether to rely on an "auto-evaluation" performed by the rheumatologist in person or a "hetero-evaluation" performed by another rheumatologist doctor/health care professional (5).

Different steps in the quality of care

Finally, one could consider the following steps when dealing with quality of care (Fig. 1).

1. The first step is to facilitate the conduct of basic, translational or clinical research in order to better understand the disease. This would include the citrullination of proteins (basic research), the demonstration of antibodies directed against citrullinated proteins (translational research), and evaluating the importance of antibodies directed against citrullinated proteins in determining the diagnosis and/or the prognosis of early arthritis (clinical research).
2. The second step is the pooling and analysis of information from separate original studies. This can be carried out by a systematic literature search and/or meta-analysis; *e.g.,* with regard to anti-CCP, evaluating the sensitivity and specificity of this test in the diagnosis of RA (6). Based on the results of the second step, recommendations/guidelines can be proposed to rheumatologists working in daily practice; *e.g.*, for anti-CCP, to recommend the measurement of this biological parameter in cases of early arthritis (7).
3. Based on how they have been formulated, the recommendations could be "translated" into clearly defined quality indicators. In the example of anti-CCP for the diagnosis of early arthritis, one criterion for in- and outpatient clinics could be to check the percentage of patients visiting a doctor for undifferentiated early arthritis clinic over a certain period of time (say, the past year) in whom such an evaluation has been performed.

EULAR initiatives in the field of quality of care

EULAR is fully cognizant of the issues outlined above, in particular the points presented in Figure 1, and is actively engaged in addressing most of the steps required to achieve quality of care. The organization and its specific standing committees are dedicated to facilitating this process.

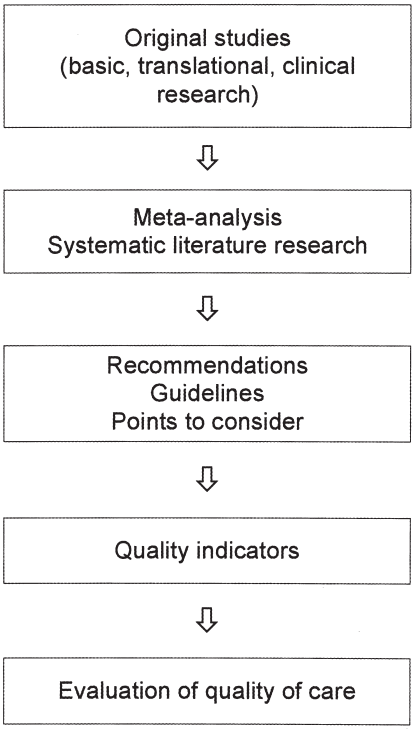

Fig. 1. The different steps involved in improving/facilitating quality of care.

Original studies

EULAR is deeply involved in the furthering of basic, translational and clinical research studies. Two EULAR standing committees have been created for this purpose: one in the sphere of investigative rheumatology, mainly devoted to basic and translational research; and the other in epidemiology, which seeks to promote studies in cohorts of patients suffering from musculoskeletal disorders.

EULAR recommendations

This is perhaps the area of quality of care in which EULAR is the most proactive. One strength of the EULAR recommendations is that they attempt to address from the outset the weaknesses inherent in most of the available recommendations (unrealistic EBM guidelines, differences between those who practice and those who manage health care, complexity of the recom-

mendations). Furthermore, all the EULAR recommendations were developed using a strict methodology and an evidence-based approach.

1. *Format of a EULAR recommendations initiative*

In order to integrate these two aspects – evidence-based medicine on one hand and inclusion of practitioners from the beginning of the project on the other – each initiative has the following format:

– a convenor, who is usually a key opinion leader in the field;
– a clinical epidemiologist who may be totally new to the field of interest, but a highly experienced person in the field of clinical epidemiology and/or systematic literature research;
– a research fellow in charge of the systematic literature search, working under the supervision of both the convenor and the clinical epidemiologist;
– experts in the field of interest, *i.e.*, rheumatologists with extensive clinical experience who monitor patients in daily practice.

2. *Evidence-based medicine approach*

For each topic (*e.g.*, management of early arthritis), the experts select 10 to 15 relevant questions, usually via a Delphi technique.

Then the research fellow and the clinical epidemiologist rephrase the questions in clinical-epidemiological terms. For example, if the question selected by the experts is: *What is the value of such a therapy for this condition?* the re-phrasing process might result in the following: *What is the effect size of such therapy in this outcome measure observed in randomized placebo controlled trials?* together with: *What is the Number-Needed-to-Harm of this therapy in such a condition?*

Thereafter, a systematic search of the literature is performed using a standardized procedure (key words, databases, quality scoring of the selected manuscripts, etc.); the results are presented to the experts, and the conclusions may eventually be published as an independent report (8).

3. *Expert's opinion*

The experts are selected by the convenor on the basis of their recognized level of expertise. Most of these experts are European rheumatologists, but this is not a prerequisite; *i.e.*, EULAR task forces are free to bring together non-rheumatologists (such as nephrologists, ophthalmologists), non-European rheumatologists, and non-European non-rheumatologists.

Two categories of experts are considered to be crucial by the EULAR Executive Committee: health professionals and patients. It is current policy that health professionals and patients be invited to collaborate in each new initiative. At the EULAR level this is facilitated by the fact that each category has a dedicated EULAR Standing Committee: the EULAR Standing Committee of Health Professionals and the EULAR Standing Committee of Social Leagues [which will be soon called PARE (Patients with Arthritis in Europe)].

Moreover, for each initiative the chairperson of the European Standing Committee for International Clinical Studies Including Therapeutics (ESCISIT) must ensure that the experts are representative of the whole of Europe, with a balanced number of participants from north to south and east to west.

4. *Presentation of the results*

In the presentation of the results a basic dilemma must be dealt with:

In order to be accepted, a recommendation has to be based on evidence. Such evidence must be derived from a literature search of high quality. The manuscript should present in detail the results of this research (with tables containing all the publications on a specific question, data such as effect sizes, odds ratios, 95% confidence intervals, etc.). However, these tables and presentations may be too numerous and too complicated for practitioners to grasp without careful study.

Therefore, *in order to be applicable*, the recommendations must be presented in as simple a manner as possible.

Because of this dilemma, there is now a trend to publish the results of systematic literature searches in a separate manuscript and to present the recommendations as "bullets" (a maximum of 10 to 15 short sentences in a single table).

5. *Dissemination of the EULAR recommendations*

EULAR is promoting the EULAR recommendations in different ways.

– Every new set of EULAR recommendations is presented during the annual EULAR meeting.
– These recommendations are also publicized at one of the press conferences organized by EULAR during the meeting.
– The final recommendations are published in the EULAR journal (*Annals of the Rheumatic Diseases*).

Moreover, EULAR is delighted to see various independent initiatives undertaken to evaluate and disseminate these recommendations (9).

6. *Collaboration with other scientific societies*

EULAR is happy to collaborate with other scientific societies in order to improve the quality of care of rheumatic patients. In the area of recommendations, we can cite the following:

– collaboration with ASAS (ASsessment in Ankylosing Spondylitis) in the development of recommendations for the management of ankylosing spondylitis (10);
– collaboration with the EFORT (European Federation of National Associations of Orthopaedics and Traumatology) task force in drafting recommendations for the management of acute swollen joints;
– collaboration with the ACR (American College of Rheumatology) task force that is currently drawing up points to consider on the issue of reporting disease activity in RA clinical trials.

7. *EULAR procedures and results*

To support these initiatives, standardized operating procedures have been developed, which have been endorsed by the EULAR Executive Committee (11). To date, the results of ten different initiatives have been reported (6, 9, 12-19). Seven other studies are ongo-

ing and their findings will be published in the near future.

Other EULAR initiatives

In terms of quality of care and potential quality indicators, EULAR is deeply involved in two areas:

– *EULAR educational programs*. These programs have been extremely successful to date. At the moment a EULAR online course combining the efforts of many European rheumatologists is also being prepared, which will facilitate continuing education for colleagues who cannot attend EULAR meetings in person (20).
– *EULAR initiatives at the European Community level*. EULAR has decided to engage in efforts to obtain recognition of the musculoskeletal disorders as a major disabling condition to be included in the European Framework Program. Such recognition would make it possible to obtain EC financing for research in rheumatology.

Quality indicators and evaluation of quality of care

EULAR is not directly involved in these areas, but does support initiatives by other groups by providing a forum where results in this area can be presented. Two examples from the EULAR 2007 annual scientific meeting may be cited:

– The results of QUEST-RA were presented and highlighted during one of the EULAR press conferences. The QUEST-RA study compared DAS and HAQ scores in RA patients from 21 different countries (21).
– EULAR provided the venue for the meeting to launch METEOR, a European initiative to enable the daily monitoring of RA patients via a website in which relevant information such as the HAQ and DAS can be easily collected.

Conclusion

Like other international scientific societies in the field of rheumatology, EULAR has included "quality of care" in its mission statement. EULAR is deeply committed to all the steps required to improve the quality of care for rheumatic patients, from supporting basic research to the lobbying for rheumatology at the European Community. These activities could have a powerful impact because they combine the formidable forces of experts from different backgrounds – not only basic researchers, translational researchers, and clinical researchers, but also practitioners, health professionals and patients.

EULAR has also understood that in order to improve quality of care, collaboration with sister societies such as the American College of Rheumatology would be invaluable for our patients. Several promising initiatives have been undertaken in this respect.

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