



Patient Perception, Preference and Participation

Patient participation in a Clinical Guideline Development for Systemic Lupus Erythematosus



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ABSTRACT

Objective: To incorporate patients' perspective in the design of a clinical practice guideline (CPG) for Systemic Lupus Erythematosus in Spain.

Methods: A systematic review (SR) of literature and a Delphi-based consultation to patients were carried out.

Results: From the SR, most relevant health problems are classified as physical, psychological, familial, and socio-economic. Dissatisfaction is mainly due to unmet information needs and limited access to care. In the consultation ($n = 102$), most frequently reported health problems were pain, fatigue, photosensitivity, mood disorders, renal damage, poor concentration, and memory loss. Dissatisfaction with poor coordination between primary and specialized care was reported. Information to improve self-management and on alternative therapies was requested. Relevant topics from both sources were merged and discussed by the guideline development group (including a patient representative) to set the key questions underpinning the CPG.

Conclusion: Patient involvement in CPG development by a combination of methods can enhance patient-centered care by achieving clinical practice responsive to their needs.

Practice implications: Involving patients in CPG development is feasible and useful to improve the advance of Health Services toward patient-centered care. A multicomponent strategy for involvement is suggested to address the gap between the available evidence and contextual current patient needs and preferences.

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1. Introduction

Systemic lupus erythematosus (SLE) is a complex chronic and multisystem disease in which various cell types and immunological pathways are deregulated explaining its variable clinical presentations, course, and prognosis. SLE affects over half a million people in Europe and a quarter of a million people in the USA, based on a prevalence rate of 30–50 per 100,000 [1]. Because of the systemic nature of SLE, several medical specialties are involved in the care of those affected. To reduce medical practice variations,

the unwanted effects of care fragmentation, and optimizing clinical management of SLE patients, the European League Against Rheumatism (EULAR) Task Force developed in 2008 a set of 12 key evidence-based clinical recommendations to guide clinical decision making [1]. Two other guidelines for SLE were developed in 2011 [2] and 2013 [3] in Spain and Chile, respectively, with a lower degree of methodological transparency.

The complexity of SLE together with the challenge of the required clinical coordination among several medical specialties, the recent devolvement of new and expensive drugs for its treatment, the limited spectrum of clinical questions included in the EULAR recommendations, as well as the need of bringing up to date these evidence based recommendations [1], justify the decision of the Spanish Ministry of Health to support the development of a Clinical Practice Guideline (CPG) for SLE management. The CPG was commissioned to the Planning & Evaluation Unit of the Canary

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According to the 2011 definition developed by the Institute of Medicine of the USA, CPGs are statements that include recommendations intended to optimize patient care that are informed by a systematic review (SR) of the evidence, and an assessment of the benefits and harms of alternative care options [4]. CPGs have the potential to facilitate decision-making, improve patient care and optimize the use of available resources. Many studies recommend active patient participation in the process of CPG development to make guidelines more patient-centered [5]. Patients can identify issues that may be overlooked by health professionals and highlight areas where the patient's perspective differs from the views of health professionals, ensuring that key issues of concern to those affected are considered. Patient engagement in CPG development could also improve its translation into clinical practice. The CPGs Program supported by the Spanish Ministry of Health (<http://portal.guiasalud.es/web/guest/informacion-pacientes>) promotes patient involvement in the CPG development process as a preliminary step for patient empowerment and informed decision making. Earlier, this participative and instrumental approach had been adopted by countries such as Australia, the United Kingdom, and the Netherlands among other countries [6–10].

This paper describes both the process used and the outcomes obtained by involving patients in the development of a CPG for SLE management from the earlier steps of identification and priority setting of topics and clinical questions that should be answered by the CPG. Patient involvement was addressed to identify the main health problems and needs of care related to SLE to warrant that the contents of the CPG are really patient-centered.

2. Methods

Three different but complementary activities were performed. First, a SR of the international literature focused on health problems and perceived health care needs by SLE patients. Second, in order to receive feedback from people living with SLE in Spain, a consultative and consensus process was carried out. Third, a patient representative was recruited for the guideline development group (GDG) from the beginning to the end of the CPG development process. This study was approved by the Ethics Committee of the University Hospital Nuestra Señora de la Candelaria (Tenerife, Canary Islands, Spain).

2.1. Systematic review

Electronic searches were conducted in Medline and PreMedline via OVID (1966 to January 2014), EMBASE via Elsevier (1974 to January 2014), PsycINFO via Ebsco host (1806 to January 2014), CINAHL via Ebsco host (1982 to January 2014), and Social Sciences Citation Index (SSCI) via Web of Science (1956 to January 2014). We used a combination of free text terms and controlled vocabulary. Initially, the search strategy was developed for Medline (Table 1) including the search filter for patient issues developed by the Scottish Intercollegiate Guideline Network (SIGN) to identify both qualitative and quantitative studies exploring patients' experiences, needs, and preferences [11]. Once defined and tested, the search strategy was adapted for application in the other databases. We extended the search strategy by means of hand search into all reference lists of selected studies. The full search strategy is available from the study authors.

We included studies published in English or Spanish providing SLE-related experiences and care needs from the patient/caregiver perspective (including diagnosis, use and access of treatments, follow-up care and quality of life; unmet health care needs;

information needs and preferences; participation in decision making about treatment; and satisfaction with the care received). Observational epidemiological studies, autobiographies, non-primary research articles (letters, commentaries and narratives), conference abstracts, and studies that did not elicit data from adults with SLE were excluded.

Titles and abstracts of the references identified by means of the search strategy were screened independently and in parallel by two authors. The full text of potentially relevant studies was read and evaluated for inclusion. Doubts and discrepancies between the reviewers were resolved after discussion, and when no consensus was obtained a third reviewer was consulted.

A data extraction form was developed by the authors, pilot-tested on two studies and refined accordingly. One review author extracted the following data from included studies: characteristics on design, methodology, participants (selection criteria, demographics, and comorbidities) and results. A narrative synthesis of results was performed.

2.2. Consultation to patients

A consultation was run between October and November of 2013 with a sample of SLE adult patients recruited from different regions of Spain. To efficiently maximize patient enrolment, patient recruitment was managed by the Spanish Federation of Patient Associations of SLE (FELUPUS, www.felupus.org/). Invitation was extended via e-mail to all registered patients with Internet access. Patients were formally informed about the study aims and the proposed methodology, and invited to the consultation by means of a cover letter signed by the president of FELUPUS and the principal investigator of the project. Participants were consulted using the Delphi consensus method with three rounds [12]. The three successive templates were built on SurveyMonkey[®] Data Analysis tool and distributed by Informed consent was obtained from each patient to participate in the process. The principal investigator was responsible of all information exchange with patients to warrant protection of information and confidentiality.

The first round used a structured questionnaire with three open questions to explore (1) the main health problems and self-perceived needs of care associated with SLE, (2) unsatisfactory aspects of health care for SLE patients in the Spanish National Health Service (NHS), and (3) specific therapies of interest beyond conventional treatments. Individual reasons to explain each proposal were also requested. For every question, all first round answers were merged into mutually exclusive categories, ranked according to decreasing frequency of citation by patients and sent back to participants for the second round. The second Delphi round was targeted at setting priorities from the ranked list of categories. For every question each participant was asked to assess the overall order and give, as a new answer, a reordered ranked list fitted according to personal experiences and preferences. Answers were ranked according to the degree of importance using the median value, given its robustness to treat extreme values and because data were not normally distributed. To establish order differences among categories having the same median value, we used the 10th–90th percentile range (10–90 PR), since factors having a lower 10–90 PR express a greater consensus among the study participants. The third Delphi round had the purpose of reaching a final consensus. To do so, the overall results obtained in the second round, after ranked, were returned to all participants with additional indications of each individual's previous assessment. Participants reviewed their earlier answers in light of this information. Majority voting was adopted to analyze final responses, given its value to offer reliable findings and to demonstrate controversial issues in large Delphi panels [13].

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