EXTENDED REPORT

EULAR recommendations for patient education for people with inflammatory arthritis

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ABSTRACT

Objectives The task force aimed to: (1) develop evidence-based recommendations for patient education (PE) for people with inflammatory arthritis, (2) identify the need for further research on PE and (3) determine health professionals’ educational needs in order to provide evidence-based PE.

Methods A multidisciplinary task force, representing 10 European countries, formulated a definition for PE and 10 research questions that guided a systematic literature review (SLR). The results from the SLR were discussed and used as a basis for developing the recommendations, a research agenda and an educational agenda. The recommendations were categorised according to level and strength of evidence graded from A (highest) to D (lowest). Task force members rated their agreement with each recommendation from 0 (total disagreement) to 10 (total agreement).

Results Based on the SLR and expert opinions, eight recommendations were developed, four with strength A evidence. The recommendations addressed when and by whom PE should be offered, modes and methods of delivery, theoretical framework, outcomes and evaluation. A high level of agreement was achieved for all recommendations (mean range 9.4–9.8). The task force proposed a research agenda and an educational agenda.

Conclusions The eight evidence-based and expert opinion-based recommendations for PE for people with inflammatory arthritis are intended to provide a core framework for the delivery of PE and training for health professionals in delivering PE across Europe.

INTRODUCTION

Patient education (PE) is recommended as an integral part in established recommendations for the management of early arthritis and ankylosing spondylitis (AS).1 2 PE comprises all educational activities provided for patients, including aspects of therapeutic education, health education and health promotion.3 Previous systematic reviews on various PE interventions in patients with rheumatoid arthritis (RA) documented significant short-term improvements in knowledge, coping behaviour, pain, disability and depression, but long-term effects were inconsistent.4 5

During the last decades there has been an ongoing development within healthcare, moving away from the view of health professionals (HPs) as the only experts and providers of knowledge and patients as passive recipients towards a more collaborative approach. Patients have been recognised as active agents in managing their illness and own healthcare.8 The principle of ‘shared decision making’ allowing patients and their providers to make healthcare decisions together, based on the best scientific evidence available, as well as the patient’s values and preferences, is increasingly accepted.9 The primary goal of PE is no longer only knowledge transfer and disease control, but also to enable patients to manage their illness, adjust to their condition and maintain quality of life.10 11

Moreover, PE has been influenced by scientific developments and changes in society. Biomedical advancements, new pharmacological treatment options, and better knowledge about the risk for developing comorbidities require new approaches to communicate with patients in a timely and meaningful way.12 13 In several countries, larger healthcare teams with more specialised HPs have been established to meet the complexity of the healthcare needs of patients with rheumatic diseases.14 15 Furthermore, the development of e-health and the use of mobile telehealth platforms have introduced new possibilities for communication and delivery of information, which are increasingly applied in PE. Finally, the increase in immigration and cultural diversity in many European countries is challenging for planning and facilitating effective PE for all patients.8

Informal discussions among multidisciplinary HPs at the European League Against Rheumatism (EULAR) annual congress in 2012 and succeeding email correspondences revealed that great variety exists in the content and modes of delivery of PE across European countries. In some countries PE is still limited to providing knowledge in order to improve patients’ adherence to treatment. Additionally, there seems to be a large variation in HPs’ involvement in PE.15 To what extent different HPs participate in PE is likely to depend on their competency, availability and education, as well as the organisation of the healthcare system.16 Based on these initial discussions, an EULAR task force was convened with the following objectives: (1) to develop a set of recommendations for PE for people with inflammatory arthritis (IA) (2) to identify the need for further research and (3) to define
HPs’ educational needs for providing evidence-based PE. The recommendations would allow standardisation and improvement of PE for people with IA across Europe. The target groups for the recommendations are rheumatology HPs including rheumatologists, patients with IA, policy makers and patient and professional organisations.

**METHODS**
The EULAR standardised operation procedures for the elaboration, evaluation, dissemination and implementation of recommendations were followed.

**The task force**
The multidisciplinary task force comprised 15 experts including three patients, five nurses, two occupational therapists (OTs), two physiotherapists (PTs), a psychologist and two rheumatologists/epidemiologists with clinical experience and/or academic knowledge in the field of PE. They represented ten European countries (Austria, Czech Republic, Denmark, France, the Netherlands, Norway, Portugal, Sweden, Switzerland and UK). People who had taken part in the initial discussions, but were not included in the task force, were invited to participate in a ‘consultation group’. This group comprised 20 HPs, such as OTs, PTs, nurses and rheumatologists, but no patients were included.

Before the first task force meeting in 2013 one of the members was tasked with reviewing the literature of existing PE definitions. An overview was presented and thoroughly discussed during the meeting. Common elements in the definitions were identified and the following definition was formulated, based on consensus among the task force members: “PE is a planned interactive learning process designed to support and enable people to manage their life with IA and optimise their health and well-being.” This interactive learning process includes a wide range of educational activities, such as provision of knowledge, written material, e-health, self-management programmes (SMPs), cognitive behavioural therapy (CBT), mindfulness, stress management, individual consultations with HPs, sharing experiences among patients, motivational discussions, exercise counselling, lifestyle change interventions and self-help courses. Moreover, the task force agreed that the recommendations should be based on the principle of shared decision making. Following this consensus process, the task force formulated 10 research questions to guide the systematic literature review (SLR) (see online supplementary file 1).

**Systematic literature review**
An extensive systematic literature search in Medline, Embase, PsycINFO, Cochrane Library and CINAHL from January 2003 up to September 2013 of publications in English, German, French or Spanish describing any kind of PE activities, was conducted (details provided in online supplementary file 2). No limitations regarding study type or research design was conducted. The inclusion criteria were IA, confined to RA, AS and psoriatic arthritis (PsA) and adults (age ≥18 years). All abstracts were independently read by two reviewers, and by a third reviewer in case of disagreement. The papers of the included abstracts were reviewed in full-text. Papers were excluded if they did not include any formal PE intervention (as defined above) or did not address the patient perspective on PE. The task force members were asked to review the final list of included papers and could add studies that were not captured by the SLR.

**Developing the recommendations**
The results of the SLR were presented and discussed during the second task force meeting in 2014 and eight recommendations were developed. The strength of each recommendation was based on the categories of evidence defined by the EULAR standardised operation procedures, graded from A (highest) to D (lowest) (see online supplementary file 3). The recommendations were emailed to each task force member for final independent voting and approval. The level of agreement was recorded on a 0–10 point scale (0=no agreement at all; 10=full agreement, table 1). In addition to the task force, the consultation group was invited to independently rate their level of agreement with each recommendation to obtain an indication of the agreement among people who are supposed to use the recommendations in clinical practice.

**RESULTS**
Figure 1 shows the flow chart of the SLR. In total, 115 publications were included, comprising 11 systematic reviews/meta-analyses, 36 randomised controlled trials (RCTs) (reported in 44 papers), 7 controlled clinical trials (CCTs), 9 pre-post-test studies, 23 cross-sectional surveys and 21 qualitative studies. The majority of patients in the included studies was female (58–100%), diagnosed with RA (82%) and had relatively long disease duration (mean 6–16 years). Ten studies included patients with AS and/or PsA and five studies included only patients with early disease duration (<2 years).

**Recommendations**
Two overarching principles and eight evidence-based and expert-opinion based recommendations were developed, four of which achieved strength A. A high level of agreement was achieved for all recommendations; mean range 9.4–9.8 in the task force and 8.2–9.2 in the consultation group (table 1).

**Recommendation 1: PE as an integral part of standard care**
The task force agreed that PE should be an integral part of standard care for people with IA. Category I evidence showed that various individual and group educational interventions had beneficial short-term effects in patients with RA. Three RCTs and one CCT showed that individual or group PE enhanced adherence with pharmaceutical treatment and knowledge of medication side effects. Moreover, one meta-analysis and four RCTs concluded that group educational programmes significantly improved disease knowledge, coping skills and physical and psychological health status. Several RCTs and CCTs demonstrated that PE supplementary to physical therapy or joint protection exercises had positive influence on physical function and activity, and reduced pain. Furthermore, consistent evidence showed that CBT and stress management programmes improved psychological health after intervention and at follow-up (4–18 months).

Finally, there was consensus in the task force that PE would increase patients’ involvement in their disease management, but this was only supported by one cross-sectional study, in which high levels of perceived knowledge of the disease were positively associated with involvement in healthcare.

**Recommendation 2: PE throughout the course of the disease**
The task force emphasised the importance of offering timely PE. Individual patients’ educational needs may vary, related to their disease stage and to fluctuations in their physical and global health status. The recommendations were emailed to each task force member for final independent voting and approval. The level of agreement was recorded on a 0–10 point scale (0=no agreement at all; 10=full agreement), in addition to the task force, the consultation group was invited to independently rate their level of agreement with each recommendation to obtain an indication of the agreement among people who are supposed to use the recommendations in clinical practice.
Recommendation 1: tailored and needs-based PE

The task force stated that PE should be tailored to the individual patient’s needs. Several RCTs supported that individual counseling with a competent HP, either in one-on-one consultations or in combination with group sessions, had beneficial health effects. Cross-sectional and qualitative studies exploring patients’ needs and expectations described a wide range of educational needs, such as knowledge and management of the disease, knowledge of side effects and risk factors, non-pharmacological treatment, pain control and self-help methods, as well as activity regulation, physical exercises and behavior change.

In general, patients’ levels of knowledge about the disease were low to moderate and patients expressed they had received insufficient information. Patients with IA wanted to be recognized as more than their disease, to be enabled to use their own resources and to re-engage in previously abandoned activities. Moreover, PE should include discussion on emotional issues and support from HPs in coping with emotional distress.

Recommendation 4: modes of delivery of PE

The SLR showed that PE is provided in various modes; individual face-to-face meetings, combination of the two, and online. Category I evidence was found for individual counseling. Interactive individual education by rheumatologists improved adherence to medication regimen. Individual counseling by OTs and PTs led to increased use of self-management strategies, such as hand exercises, joint protection and activity regulation. Individual counseling by psychologists reduced depression, anxiety and total use of healthcare. Individual counseling supplemented to physical exercise improved health status, adherence with exercise programmes and physical activity recommendations. Individual counseling by nurses, supplementary to group education improved disease knowledge, well-being, pain and self-management behaviors.

Various group interventions focusing on active coping with emotional distress and daily life stressors improved functional and emotional health status, patients’ coping strategies and perceived social support. Finally, two RCTs and one pre-post-test study demonstrated that interactive online programmes contributed to improvement in health status, pain, physical limitations and levels of physical activity.

Recommendation 5: theoretical framework and evidence for PE

The task force agreed that PE should be based on a theoretical framework and be evidence-based. Four categories of PE interventions were described in the included studies: educational programmes (32 studies), psychological interventions (21 studies), social support (9 studies) and stress management programmes (6 studies). The educational programmes mainly aimed to enhance knowledge, adherence to treatment, performance of physical function, joint protection and healthy lifestyle. The methods used were primarily didactic, instructions, counselling and practical exercises. These programmes were typically based on clinical experience and knowledge and were not underpinned by a theoretical framework. In contrast, the SMP and CBT interventions were based on
frameworks derived from social cognitive theory and cognitive behavioural theories. In addition to provision of knowledge, these programmes were targeted at improving coping and psychological health status, facilitating behaviour change and adoption of health promoting behaviours. Participants were actively involved in goal-setting, problem-solving, group discussions and in preparing action plans. Furthermore, CBT interventions focussed on cognitive restructuring of beliefs. The stress management programmes were mainly adapted from ancient Buddhist practices including yoga and breathing exercises, training of mindfulness meditation and acceptance. The main aims of these programmes were to enhance well-being by improving stress management skills, alleviate emotional distress, and promote a constructive relationship with positive and negative emotions.

Recent systematic reviews have concluded that various group programmes (SMP, CBT and stress management) demonstrated small, but positive impact on self-reported physical activity levels, pain, disability, depressive symptoms, anxiety and fatigue at follow-up (4–18 months).

**Recommendation 6: outcomes of PE**

The task force agreed that in order to provide evidence-based PE, the various PE programmes need to be evaluated. To ensure valid evaluation the outcomes must reflect the programme objectives. The SLR revealed a great variation in evaluation criteria and use of outcome measures in the included studies. The specific educational objectives of the programmes were not always clear, making it difficult to judge whether the reported outcomes were matched to the educational objectives. For example, some studies reported the disease activity score with 28 joint counts (DAS-28), which are unlikely to be directly influenced by PE, at follow-up (4–18 months).

Many of the PE programmes can be characterised as complex interventions, which intend to influence various aspects of the...
Recommendation

7. Competency in delivery of PE

The task force agreed that PE should be delivered by competent HPs and patients. The majority of the studies included, comprised PE interventions delivered by HPs within a healthcare context. However, PE may also be delivered by trained patients and in community settings. Sixteen of the PE programmes were delivered by multidisciplinary HPs, and 10 programmes were delivered by two different professionals, that is, OT and PT (3 studies), nurse and rheumatologist (1 study), OT and rheumatologist (1 study), psychologist and nurse (1 study), psychologist and OT (1 study), pharmacist and nurse (1 study), and nutritionist and OT (1 study). Trained patients were involved in, or delivered two SMPs, two online programmes and one patient-led interactive workshop. The remaining interventions were provided by one HP. Which professionals should be involved, and how many, will depend on the aim, the topic and the context for the education. For example, physical exercise programmes provided by PTs may be combined with group educational sessions by other HPs, as appropriate and some CBT programmes are provided by psychologists only. Other programmes are independent of profession, but require specific training in methods, such as CBT techniques and mindfulness.

8. Training competency for delivering PE

The task force agreed that teaching competency is necessary alongside clinical expertise to deliver high quality PE. Only a few studies reported what skills and training providers of PE need. Qualitative studies exploring patients’ perspectives on PE indicated requirements for knowledge and skills by educators. For example, patients wanted to receive clear explanation about test results, medication and self-management techniques. HPs should have the ability to provide emotional support and to focus on acceptance of the patient’s illness and its consequences. Moreover, patients experienced that the use of creative learning methods, such as guided discovery, metaphors, poetry, music and visual materials in groups facilitated their emotional and behavioural change processes and they wanted to have the possibility to exchange knowledge and experiences with other patients. HPs, on the other hand, perceived that their delivery of knowledge and advice was influenced by their own attitudes and their abilities to interact with the patients.

Research and educational agendas

Box 1 presents the research agenda proposed by the task force, based on areas with only weak or limited evidence for PE. The two overarching principles (see Table 1) should be applied when addressing each of these topics.

Box 2 presents the educational agenda, which encourages the development of training programmes to enhance and support HPs’ opportunities to improve their educational competencies.

DISCUSSION

Eight recommendations for PE for people with IA were developed based on a SLR and expert opinions. The recommendations were formulated to be practical and feasible for providing evidence-based PE across all European countries. The strength of evidence supporting the recommendations varies and a research agenda is proposed for areas with lack of evidence. A high level of expert agreement was achieved for all recommendations. An educational agenda was also formulated to support the development of competencies of HPs providing PE.

The included studies showed a trend towards greater inclusion of behavioural, cognitive and emotional aspects in the PE programmes during the last decade. This trend is reflected in the PE definition that the task force formulated as an overarching principle, stating that PE should enable people to manage their life with IA and optimise their health and well-being rather than be limited to the disease. Some previous PE definitions have stated that PE is designed to improve patients’ health behaviours. However, the patient representatives in the task force felt that
this was rather patronising and therefore it was not included in the consensus definition. The definition emphasises that PE is an interactive learning process, not a one-way delivery of knowledge. Substantial evidence has shown that interactive counselling, either in combination with group sessions or in one-by-one consultations with a competent HP, has beneficial effects in terms of adherence to treatment regimens, behavioural change, use of self-management strategies and well-being.19 37 49 72 108 In order to adherence to treatment regimens, behavioural change, use of self-
sultations with a competent HP , has bene
either in combination with group sessions or in one-by-one con-
Substantial evidence has shown that interactive counselling,
interactive learning process
results on health status and levels of physical activity.82 84 In our
develop their communication skills, and patient representatives
ensure the application of shared decision-making, HPs need to
consider
studies was female, diagnosed with RA and had relatively long
disease duration. The task force recognises that at present there
is limited evidence for patients with AS and PsA. It is therefore sug-
gested that the recommendations should be regarded as “points to
consider” for this population. Furthermore, little is known about
special educational needs for men, patients with minority ethnic
backgrounds and patients with lower literacy levels, which needs
attention in future research. A great diversity in the type of educa-
tional programmes was observed, varying from interventions with
a primary focus on increasing knowledge and improving perform-
ance, to more therapeutic oriented interventions aiming at behav-
ioral change and improving mental health status.3 5 103 Also, a
wide range of outcome measures was used and most studies
reported multiple outcomes, limiting comparison of the effective-
ness of the programmes. To be able to evaluate the programmes
more stringently and to compare relevant interventions, the task
force recommends harmonisation of outcomes, tailored to the pro-
grame goals and content and to the patients needs. Furthermore,
the task force has proposed that existing outcomes should be eval-
uated, and new outcome measures should be developed, if needed.
The task force was not aware of any unpublished studies with
negative results. Nevertheless, due to publication bias some posi-
tive effects of PE may potentially have been overestimated.

A methodological limitation of the SLR is that the task force
decided to include all types of studies that could give insight in
PE, resulting in a great methodological variety. Consequently, it
was not possible to use one formal quality scoring system. Four
recommendations were of strength A and the remaining four
were of strengths C to D, that is, based on qualitative and cross-
sectional studies or expert opinions. However, the qualitative
studies may provide valuable insight into the individual patient’s
needs and expectations, which should be regarded as the core of
PE programmes.

The use of a multidisciplinary task force, including patients, is
one of the strengths of this study. Ideally, the task force should
also have included a dietician and a pharmacist as the educational
activities comprise lifestyle changes and adherence to medication.
However, we believe that these issues have been addressed by the
comprehensive SLR. Another strength is the high level of agree-
ment with the recommendations among the members of the task
force and the consultation group. However, the level of agree-
ment will have to be further evaluated in a wider population of
patients and HPs with interest and expertise in this field during
the dissemination and evaluation of the recommendations.

The task force agreed on a research agenda to gain further insight
in the qualitative and quantitative aspects of PE, including
working mechanisms of PE, developing and harmonising PE
outcomes, economic evaluations and cross-cultural acceptability
of PE programmes across European countries. The educational
agenda states that providers of PE need regular updates of their
skills in order to deliver effective PE. The task force proposes
that training of educational skills should be integrated in
EULAR courses for HPs and rheumatologists.

Effective dissemination, implementation and evaluation of these
recommendations across European countries demand a clear
implementation strategy. Barriers and facilitators for implemen-
tation of PE as an integral part of standard care for all
people with IA must be assessed within each country and appro-
priate support and education must be provided. This strategy
will need further support from EULAR.

In conclusion, eight evidence-based and expert-opinion-based
recommendations for PE for people with IA were developed.
The dissemination and application of the recommendations
should allow establishment of core standards for PE across
Europe. Further evaluation will be necessary to ensure relevance
and effective application.

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Contributors HAZ was the research fellow for the project, undertaking the SLR.
AP and AEI were the project convenors, AEI being the epidemiologist directing the
SLR. All authors have contributed substantially by participating in the development
of the recommendations, revising the manuscript critically for important intellectual
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REFERENCES


I am not only a disease, I am so much more.


Recommendation


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