

# Putting patients first: the need for evidence-based and patient-centered standards of care in rheumatoid arthritis

“...active patient involvement in healthcare may be a crucial issue to achieve common standards of care in various countries.”

**KEYWORDS:** extended roles ■ innovative models of care ■ nonphysician health professional ■ outcomes research ■ patient perspective ■ patient research partners ■ qualitative research

All over the world, musculoskeletal diseases have major individual, societal and economic implications [1]. Musculoskeletal diseases require the attention of several medical disciplines such as rheumatology and rehabilitation, including both physicians and nonphysician health professionals. However, it is not only these ‘specialists’, but also the patients themselves play an important role in musculoskeletal care. Apart from shared goal-setting, for example, when a new medication is prescribed, patients need to be actively involved in rehabilitation care: a considerable number of interventions such as appropriate pain management, activity pacing, enhancing physical activity, maintaining a range of activities, performing activities in a joint protective way, using assistive devices, and so fourth, will not be successful if they are not administered in a patient-centered and patient actively involving way. Furthermore, there is initial qualitative evidence that people who are more actively involved in decisions about their musculoskeletal disease may have a better health outcome [2]. Involvement of patients is thus a crucial issue in rheumatology and rehabilitation.

Patients should not only participate in their own care, but can – if interested – take on different roles in research projects. Patients can contribute essential parts in qualitative research in that they report about their experiences in daily life (and thus allow researchers, specialists and experts to share their views), but can also take on even more ‘equal’ expert roles such as being a ‘patient research partner’ in the advisory boards of all kinds of research projects or become scientific authors themselves [3]. Qualitative action research claims that the active involvement of all stakeholders in a certain research project is essential [4]. However, this is still rather uncommon in many countries such as Austria. Austria

is a ‘traditional’ central European country with an almost only biomedically focused healthcare system. For a long time, patients have not been involved in active roles in healthcare in Austria.

Healthcare systems differ in several aspects all over the world. Even in Europe, where experiences of patients with hand osteoarthritis did not differ substantially in terms of culture and functioning in one of our qualitative multicenter studies [5], healthcare systems do not have common standards. In the recent years, an increasing number of studies focusing on the similarities and differences in healthcare systems have been conducted and supported by the EU. One example is the eumusc.net-EU-project, which aims to establish common standards of care for people with rheumatoid arthritis and osteoarthritis in Europe. A specific aim of this EU project was to provide these standards of care in patient understandable language so that patients are able to take active roles in the care that they are receiving [6]. The lay version of the so-called ‘user-focused’ standard of care for rheumatoid arthritis is available in 23 languages of the EU and should contribute to the harmonization of rheumatoid arthritis treatment across Europe by actively involving patients [101]. Built out of evidence-based guidelines with high-quality and expert (including patient experts!) consensus, a target of these standard of care studies was to reduce the inequalities in Europe through spreading evidence-based information in a way that could be understood by medical laypeople, as patients usually are.

Challenging for this work was, for example, the term ‘health professionals’. Health professionals include physicians, but also nonphysician health professionals. In different European countries, different interventions are delivered by different professionals. The target in the formulation of

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the standards was to find the appropriate terms that provide enough information without being too constraining. Rheumatology nurses and/or nonphysician health professionals specialized in musculoskeletal conditions, for example, do not exist in some countries. Evidence on extended roles include consultant roles and advanced clinical tasks [7–15] delivered in rheumatology and rehabilitation by nurses, physiotherapists and occupational therapists. Extended roles of nonphysician health professionals are well received by patients [16], lead to multidisciplinary interventions that focus on the daily life and functioning of patients, facilitate innovative models of care and are thus one step towards active patient involvement. However, despite the growing evidence base, extended roles have so far not been implemented in a large number of European countries [17]. In Austria, for example, the first specialist course for nonphysician health professionals in rheumatology has just started in autumn 2013. Traditional models of care and

status and standing of certain professions inhibit this development.

Taken together, active patient involvement in healthcare may be a crucial issue to achieve common standards of care in various countries. Several factors support or inhibit this development, such as the existence of active patient organizations, the persistence of traditional models of healthcare, the existence of patient experts in advisory boards of research projects, but also nonphysician health professionals taking on extended roles.

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#### Website

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