

Social Participation and Osteoarthritis: The Foundations Have Been Laid — Where Next?



The disease we call “osteoarthritis” (OA) manifests itself as pain in joints and restricted function. Rheumatologists have long been aware that such impairment and limited movement have consequences for the extent to which people with OA can engage in domestic and social life. And yet the social consequences of OA remain relatively under researched. Closing this gap in our knowledge is important. As Gignac and colleagues point out in this issue of *The Journal*, the ability to fulfil social roles and obligations is what matters to people with OA¹.

There is a clear argument for using participation in social roles as an outcome in OA intervention studies and as a measure of success of healthcare and prevention programs for OA. This argument holds if the interventions are targeted at impairments such as pain severity or cartilage loss (“Will my joint replacement allow me to play golf again?”). But it also holds if, as writers on this topic have highlighted in the past²⁻⁴, impairment and functional limitation persist but the potential for preventing participation restriction can be addressed (“Even though I still get pain and I cannot move about like I used to, can I still do the job that I love, in the way I want to?”). Gignac’s report provides an example of how research is developing on this topic, and here we consider some of the issues it raises.

There is a need for clear conceptual models to drive research on this topic. Although there is no single clearly specified and widely agreed on concept that encompasses the notion of participation, the publication of the World Health Organisation’s International Classification of Functioning (ICF)⁵ has done much to raise awareness of the topic. Gignac and colleagues take a different starting point and use psychological theories and empirical studies of social roles as the basis for measuring social role participation. Their social role participation instrument has yet to prove its psychometric mettle and comparative advantage in what is already an expanding area for questionnaire development^{6,7}. Their theoretical standpoint, however, encour-

ages us to think about the many and varied roles of people with OA — not simply as patients, but as worker, parent or grandparent, spouse or partner, friend, carer, team-mate. It also provides a helpful classification of at least 2 distinct aspects of social roles that might be important to persons with OA — salience (what is the importance of a particular role for this individual?) and satisfaction (Gignac’s results suggest that satisfaction with time spent in a role and performance of that role may be aspects of a common underlying construct).

There is a paradox here, however, in the idea of measuring something as a group characteristic that is so “individual” in its content. One option is to identify “social norms” for various roles such as work or leisure-time. However, it is difficult to define what “normal” might mean because of the wide range of individual roles, needs, aspirations, and expectations in society. Comparing individuals’ own accounts of their level of participation in social activities against a reference standard of what is expected as normal for society, or for certain subgroups in it, assumes that problematic consequences occur when individuals deviate from “norms”; this assumption may be incorrect. Gignac and colleagues adopt a different starting-point by measuring the “individual’s own perception” about social roles and their participation in these roles. “Normality” is thus an individually defined concept, and individuals themselves judge whether or not their social roles are maintained or fall below what they expect⁸. Other researchers have used in-depth qualitative interview methods to capture the highly individual nature of “desirable” participation, while the use of individual goal setting — goals often highly idiosyncratic to a particular patient — is a well accepted part of clinical rehabilitation practice. However, if participation is to be used as an outcome in intervention research, then methods such as those of Gignac and colleagues and others⁶⁻⁸ which incorporate structured questions about individual perceptions of social roles across a range of domains, seem a sensible way forward.

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There are some issues raised for OA researchers in Gignac's report. One is how to avoid over-medicalizing social participation. Gignac's study sampled only people with OA. It is possible that there is the same level of dissatisfaction with participation among persons without OA. Epidemiological studies indicate that OA has an adverse effect on functioning that is independent of a wide range of other actual and potential determinants⁹. Whether this is true also of satisfaction with social role participation remains to be seen. A related issue is the authors' incorporation of the patient's report of whether participation restriction is "due to arthritis." This attribution of cause may be problematic given the frequency of comorbidity in persons with OA. There is a surprising dearth of information on how people with multiple co-occurring causes of disability apportion cause when prompted with the ubiquitous "due to your —" (e.g., asthma/visual impairment/poor quality housing).

Future research needs to consider whether different strategies are needed to maintain or improve participation in different areas of life among persons with OA, and whether correspondingly different targets need to be set. Gignac's article carefully emphasizes that individual approaches to improving social participation will need to incorporate the clinical [e.g., address the link between impairment (pain severity) and satisfaction with time and performance in a social role], as well as psychological and social care.

However, it is also important that a focus on clinical interventions in OA, and on well characterized individual strategies for tackling satisfaction with social roles, should not obscure the potential importance of social and environmental change as a means to improve participation among persons with OA. We should avoid locating the problem of social role participation exclusively with the individual, and look at the potential role of change in the physical, social, and cultural environment. The importance of such change in influencing social role participation in people with OA is testified by, for example, the way in which change in building design and regulation has successfully improved access for persons with limited mobility. In addition to acknowledging the role of individual health and psychological factors, comorbidity, and activity limitation, we should therefore also identify (1) which subgroups are more likely to become restricted with respect to age, gender, and socioeconomic and demographic characteristics, and (2) the key environmental influences on participation. This may lead to investigation of particular social roles and domains because the environmental factors that influence different roles will vary. For example, employment law and employer attitudes are specific to work participation. There is an interesting public health argument here. Environmental change (such as extended work programs or improved public transport) would apply to whole populations and not specifically target people with OA. However, given that musculoskeletal and rheumatic diseases are the commonest cause of morbidity

and disability throughout the world¹⁰, that OA is the most frequent of these conditions in older adults¹¹, and that the proportion of older adults in developed countries is increasing, change in the social and environmental determinants of participation is likely to have most effect on participation restriction related to OA sufferers.

A clear positive message from Gignac's study confirms that despite people having OA and joint pain, many continue to be satisfied with their time and performance in valued social roles; many people with OA continue to participate as and when they want⁴. Future research needs to find out how and why this happens, in order to inform interventions to maintain or improve participation among those individuals who are not satisfied with their social roles.

The article also highlights persons with an important gap between the high level of importance they ascribe to a social role and the low levels of satisfaction with their time and performance in this role; understanding how such individuals could best be helped presents another obvious research target.

People and their roles in society change, and it is likely that perceptions of their social roles change also; these are moving targets. To further our understanding of social role participation, the authors rightly emphasize the need for longitudinal research. Such research is needed to establish cause and effect, describe transitions between and within social roles, and identify potential targets for intervention in persons with OA to maintain participation and reduce restriction in social roles. As concepts and measurement and identification of determinants of participation are addressed, the research focus needs to switch to intervention studies. Such research, and the development of the interventions for study, will need to involve not just people with OA and their clinicians, but a wide range of health and social care professionals, as well as politicians, architects, policymakers, and other stakeholders in the idea of social participation as one important measure of health.

The foundations for this exciting field of research have been laid. Gignac and colleagues' report in this issue of *The Journal* contributes to our understanding of social role participation and provides us with questions and directions to take this important research further.

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