

Rheumatoid Arthritis and Participation — The Social Animal Revisited



Human beings are social animals by nature, and human society is a natural fact as already recognized by Aristotle (384 BC–322 BC)¹. Participation in various social areas such as partnership and family, work, leisure, religion, economy, or politics is essential to personal identity. “Self and society are twin born”², and personal identity is negotiated in social interaction³. Participation is thus of central importance to individual quality of life and well-being.

While the patterns of participation that are valued most depend on people’s preferences as well as on their cultural background⁴, participation in general is a constitutional element of the human condition. Satisfactory and culturally appropriate social participation is a prerequisite for the building and maintenance of resources relevant to individual health such as social networks, social capital and support, self-esteem, and self-efficacy^{5,6}. Restrictions to valued domains of participation will cut off an individual from important emotional and cognitive resources and may result in adverse health consequences⁵.

The World Health Organization (WHO) has acknowledged the centrality of social participation in human life with its International Classification of Functioning, Disability and Health (ICF)⁷. Participation is defined as one of 3 major components of functioning. Accordingly, participation restrictions contribute to the experience of disability. The complex role that social participation plays in functioning, disability, and health of people with a health condition is accounted for by the integrative model of the WHO. In this model the participation component can be influenced by and may influence the other components of functioning, i.e., activities, body functions, and body structures. In particular, it is also recognized that participation is influenced by personal and environmental factors, which may in turn be modified by participation patterns. Therefore, the ICF model offers a comprehensive perspective on human functioning that accounts for the complexity of people’s life worlds.

Rheumatoid arthritis (RA) provides a vivid illustration: on one hand, participation restrictions such as work disability, absenteeism, or other aspects of productivity loss, which are

highly prevalent in RA⁸, contribute to the experience of disability in their own right. On the other hand, problems with or restrictions to culturally appropriate participation such as reduced work productivity or leisure activity may cause, for example, psychological distress⁹. Respective physiological correlates may then exacerbate disease activity and impairment in body function and structure¹⁰. These may in turn contribute to further losses in work productivity and so on. Moreover, stress may be buffered by social support¹¹ and self-efficacy expectations. However, these may be difficult to uphold due to participation restrictions, leading to a cycle of self-perpetuating disability.

Participation restrictions not only contribute to individual experiences of disability; they also generate serious social costs and lost opportunities. For example, economic loss due to work disability may have severe effects on the families of people with RA¹². Society as a whole is affected by losses, both in productivity¹³ and in creative resources. In its Resolution R114 on “Disability, including prevention, management and rehabilitation,” adopted in May 2005 by the 58th World Health Assembly, the WHO accordingly highlights that “people with disabilities are important contributors to society and that allocating resources to their rehabilitation is an investment”¹⁴. In the ICF, participation is correspondingly addressed as [an individual’s] “involvement in a life situation” and as “the societal perspective on functioning.”

The ICF⁷ and the ICF Core Set for RA¹⁵ thus provide a promising starting point for a systematic review on RA and participation, as presented by Geuskens and colleagues in this issue of *The Journal*¹⁶.

The authors show that only 2 categories from the preliminary Comprehensive ICF Core Set for RA that (in their opinion) address participation have been extensively examined in studies with relatively high methodological quality. These have been “remunerative employment,” and “recreation and leisure” and “socializing,” respectively. In summation, restrictions to participation in both areas seem to be more common in people with RA compared to the general popula-

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tion. Restrictions to work participation occurred early after the onset of RA and increased over time, while no time trends were observed for socializing¹⁶. The authors also report trends regarding positive effects of early and “intensive medical treatment” (“prompt start with DMARD therapy, combination treatment, and/or biologicals”¹⁶) on participation. However, this clearly needs to be examined further through properly designed studies.

First of all, the review by Geuskens and colleagues¹⁶ confirms the importance of restrictions to work participation in RA, which is also acknowledged by the preliminary Comprehensive as well as the Brief ICF Core Set for RA¹⁵. It also shows that recreation and leisure or the subcategory socializing are negatively affected in RA, which confirms the inclusion of recreation and leisure in the Comprehensive ICF Core Set and makes it a candidate for the final Brief ICF Core Set.

It is important nonetheless to mention that the relative importance of a given category is decisive for its inclusion into the Brief ICF Core Set for RA, and not the fact that this category is frequently studied and that significant differences between RA and reference populations can be found. It may still be that socializing, for example, is of minor relevance in comparison to other domains of participation that have not yet been extensively studied. It is also possible that socializing is strongly correlated with other variables that have already been included in the Brief Core Set such as “intimate relationships” and that are more important to patients with RA.

From the results of Geuskens, *et al*¹⁶ it becomes clear that the systematic study of the many other domains of participation relevant to people with RA is only in the early stages, not to mention the personal and environmental context of participation. The review of Geuskens also provides important insights regarding the future study of participation that are not immediately obvious.

Similar to the famous Nagi scheme¹⁷, the authors correctly state that participation is related to social roles¹⁶. Indeed, participation in and contribution to human society is only possible through the incumbency of social roles and positions such as child, father, wife, employee, customer, etc., which may provide more or less leeway for development and expression of individuality¹⁸. Social roles comprise normative expectations towards certain positions in a socio-cultural structure as well as behavior oriented towards these expectations, e.g., a husband is expected to love his wife and should show this through certain behavior. In each culture certain basic roles such as gender or age roles exist. These roles also encompass cultural expectations concerning the margins of the total constellation or set of roles suited to individuals of a certain sex and age: e.g., up to what age people should work. It can be assumed that average role sets and role performances of healthy reference populations more or less represent these role expectations, since at least in the long run no society can afford normative expectations that cannot be met by

most of the people they are directed at. It is thus well noted by Geuskens, *et al*¹⁶ that meaningful cross-sectional studies on the consequences of RA for social participation need to include a comparison with a healthy reference population. In discrepancy with Geuskens, *et al*, however, we are convinced that the importance of reference values also applies to longitudinal studies. If longitudinal studies are supposed to provide information about changes in participation over the course of the disease, this can only be done in comparison to a reference population, otherwise changes observed may be related to aging or general environmental changes such as fluctuations in the labor market.

That meaningful studies on the participation of people with RA should provide comparisons to adequate reference populations is an insight that relates to a number of new challenges. While reference values from the general population concerning remunerative employment are relatively easy to obtain from federal statistics offices, for example, reference data for other domains of participation such as intimate relationships are seldom officially available. It is thus no surprise that Geuskens and colleagues did not find a great variety of studies on different domains of participation.

From the outset, studies that truly advance our understanding of participation in RA should address the issue of appropriate reference data. Even if data from a reference population are studied, the question of the difference between average and optimal participation (from an individual’s perspective)¹⁹ stays untouched.

We can also learn from Geuskens and colleagues’ attempt to differentiate between activity and participation categories in the preliminary Comprehensive ICF Core Set for RA¹⁶. They choose one of several approaches discussed in the ICF. In their approach it is assumed that some chapters concerning the ICF component activity and participation solely contain categories addressing activities, while others only refer to participation, with the remaining chapters addressing both. If this could be done so easily, there would be one part addressing activities and another addressing participation in the ICF. For good reason, however, a final attribution is made neither in the ICF nor in the preliminary ICF Core Set for RA. Indeed, it may be a matter of interpretation as well as cultural and situational background if a category is interpreted as activity or participation. Let us consider, for example, the categories “acquisition of goods and services,” “doing housework,” and “preparing meals,” which are seen to represent activities by the authors¹⁶. On one hand, all these categories refer to value creation through unpaid work, which could easily be subsumed under participation. Moreover, each of these categories displays an important segment of the social role of the househusband or wife. On the other hand, one could also think of a number of tasks related to the categories that could rather be addressed as activities, such as chopping carrots, pushing vacuum-cleaners, or carrying a beer crate. If, for example, a person is limited in holding a knife to chop vegetables, one would

hardly speak of a participation restriction. To make the issue even more complicated, role performance includes the proper execution of activities, and activity limitations might add to a participation restriction.

The individual perspective is embedded in the societal perspective and vice versa. Individual problems with doing housework can entail decreased role performance, role loss, feelings of not contributing to family life, etc. We therefore suggest that the ambiguity in the participation activity distinction be upheld, and that investigators decide from case to case which aspect of functioning should be focused on. The traditional perspective, with emphasis on the biomedical aspects of functioning, might prefer the activity focus. However, by definition, the comprehensive perspective, based on the integrative model of functioning, has to consider both, and particularly their relationship. In the development of measures of participation, consideration should also be given that, e.g., running errands and shopping (Health Assessment Questionnaire) or pushing a vacuum-cleaner (Medical Outcomes Study Short Form-36) may represent an activity for one respondent and participation for another. The individual differentiation between activity and participation is made in the context of both personal and environmental factors.

In conclusion, the comprehensive perspective on human functioning in RA goes far beyond a perspective based on the consequences of disease. In turn, it accounts for mutual interactions between all components²⁰, e.g., for the interplay between impairment and participation restrictions. We therefore need to start from more comprehensive theories and models on functioning in RA. It is also necessary to continue current efforts in classification and measurement of functioning such as the development of ICF Core Sets and to develop a true epidemiology of functioning in RA. The study of participation in RA will thus profit from the newly emerging scientific field of the human functioning sciences^{18,21}, which is committed to the comprehensive understanding of functioning and disability, and vice versa. We believe that the rediscovery of the social side of humans through medicine will importantly contribute to a more complete understanding of disease, functioning, disability, and health in RA.

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