

The impact of ankylosing spondylitis on the life of patients

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Valorisation addendum

Background

Participation and physical activity (PA) receive much attention in our society. Over the past years, the Dutch society has shifted or at least attempted to shift from a care taking-policy (zorgstaat) into a society in which participation of citizens has a more central place. Arguments in favor of this change were that the government policy insufficiently enabled individuals to take responsibilities in overcoming their health-related limitations in important aspects of life, such as work. Also, the government was ambitious in striving for a more cohesive community in which initiatives of people helping, aiding or assisting predominantly people with a disease or limitation were stimulated. However, little research had been done on attitudes and challenges of persons with chronic diseases in relation to participation in social roles (1, 2).

A prerequisite to participate in social roles is the ability to perform PA. That is, almost all participation areas such as work, social life, sports, traveling, care taking activities, and hobbies require movement of the body. Moreover, low PA has a negative impact on health. Worldwide, the consequences of insufficient PA may have caused major health-, economic- and societal problems, and this may be particularly true for patients with chronic diseases (3).

This thesis contributes to the evidence base of participation and PA in patients with ankylosing spondylitis (AS). The chronic auto-inflammatory rheumatic disease AS, has an onset in the third decade of life, characterized by pain, stiffness and mobility impairments in the spine and often also in the large joints. The early age at onset implies that patients with AS usually perform a relatively active role in society. Results of our research into social role participation, physical activity (PA) and body composition are described in chapters 2–7(4-7). The findings, research approaches and areas for further research are discussed in chapter 9. Here we describe the valorisation of the research presented in this thesis, which is defined as “the process of value creation from knowledge, by making it applicable and available for economic or societal utilisation, and by translating it in the form of new business, products, services, or processes”.

Value of the findings related to social role participation and physical activity

In the Social Participation in Ankylosing Spondylitis Study (SPASS) study, patient research partners of outcome studies of the department of Rheumatology of the MUMC, were involved. Especially in the organizational stage of the study, the partners had an important role in carefully selecting which participation questionnaire, among available (English) instruments, would best reflect participation needs of Dutch patients with AS. The Social Role Participation Questionnaire (SRPQ) was preferred, because it captures most comprehen-

sively essential aspects of participation in patients with a chronic disease like ankylosing spondylitis (AS). Specifically, it addresses the full diversity of roles relevant to patients and focuses on different aspects/dimensions such as importance, difficulties and satisfaction. The collaboration with patients is worthwhile and contributed to the face validity of the final findings. The translated and validated Dutch version of the full-length SRPQ as well as a short version, which has been developed following the work in this thesis, are now freely accessible for researchers and provide a well-performing instrument to measure participation in AS, and likely also for patients with other chronic conditions. Momentarily, the short version of the SRPQ is being applied in a larger Dutch longitudinal study.

For daily practice there is an ongoing discussion among health professionals whether and which participation roles should be measured. Until now, there is only consensus to ask patients about their work participation, which, in contrast to other roles, has a more apparent relation with health impairments and has clear economic relevance for the individual and society when accounting for the increased risk for sick-leave and work-disability of persons with AS. On that line, several interventions have been developed to support 'persons at risk for adverse work outcome'. The amount of evidence on the importance and prevention of adverse work outcome in persons with rheumatic diseases resulted in 2015 in the guideline 'Worker Participation and Rheumatoid Arthritis', by the Dutch Society of Rheumatology (Nederlandse Vereniging voor Reumatologie; NVR (8). During the period of this thesis, in 2013, data from the SPASS study, provided a broader view on social participation and were presented during the annual scientific meeting of the NVR. Also a special discussion session was organized around social role participation, opening the conversation whether other roles in addition to work participation should receive attention of the clinical team, for example in an annual review of the patient. It was felt that (indirect) benefits of social role participation on life satisfaction could be brought under the attention of patients as part of self-management programs.

Regarding PA, results of the studies reported in this thesis showed that patients with AS perform overall similar total amounts of PA, but only 47% of the patients as compared to 60% of the directly compared controls met the recommended minimum amount of 150 min/week moderate to vigorous PA (MVPA). Objectively assessed evidence of habitual PA and patterns of patients with AS have been indicated in this thesis. The relevance of patients performing less MVPA might also be related to possible disease related symptoms like involuntarily accelerated muscle loss, which is more common in several chronic diseases like rheumatoid arthritis (RA). That is, strength training, which is usually performed in intensities which are at least moderate PA, seem to have a protective effect against possible disease related muscle loss. This is in line with the recently proposed renewed Dutch guidelines for PA by the Dutch health council, who stressed the importance of performing musculoskeletal strength exercises on a weekly basis (9). As there is substantial evidence that (moderate) exercise helps to maintain known muscle loss in RA, increasing time spent

in moderate PA might improve muscle mass and protect the aging patients against sarcopenia and frailty.

Further, it was striking to find that patients experience considerably more difficulty and fatigue in performing daily tasks and activities when compared to controls, despite a similar amount of total PA at lower intensity. These findings have led to more research, studying the basic relationship of fatigue, PA and basal metabolic energy expenditure and cardiovascular fitness. This research aims to contribute to evidence based insight and interventions related to fatigue of patients with AS.

With this thesis, we addressed important aspects of the lives of patients with the chronic disease AS. Hopefully this work contributes to appreciate the importance of PA as well as other social roles alongside work participation in patient-related care and research.

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