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Living with Rheumatoid Arthritis

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Summary

This thesis studied patients diagnosed with rheumatoid arthritis (RA) who face the burden of RA in their everyday lives. RA is a chronic disabling disease with an unknown cause and an unpredictable course. The symptoms of RA such as pain, fatigue and functional disability create a considerable burden which affects the patients physically, psychologically and socially. The overall impact of RA often leads to decreased well-being and a worse health-related quality of life (HRQoL). Psychological manifestations may often be characterized by feelings of hopelessness, loss of control and uncertainty about the future course of the disease. Overall the symptoms constitute a significant stressor which predisposes RA patients to increasing levels of psychological distress and especially to depression, anxiety or a negative perception of themselves. While medical treatment of the RA symptoms has progressed, existing damage still cannot be cured. Rather the treatment focuses on alleviating the symptoms and on inhibiting the progress of the disease process. In the end, the resources of the patient and his/her social environment might have a significant influence on how each individual patient manages to live with RA.

Based on this notion three main aims concerning personal and social resources were formulated and addressed within five chapters of this thesis. By focusing on the role of personal and social resources, emphasis was put on the association with psychological distress at different points of the disease duration. Personal and social resources were studied based on social support, self-efficacy and coping theories that have been frequently used in the context of chronic diseases. Furthermore, the thesis focused on the restriction of social participation in relation to disease related variables and HRQoL.

Theoretically guided by the International Classification of Functioning Disability and Health ICF this thesis concentrated on the role of patients' resources and especially on how they might be associated with the disability process as defined in the model. The ICF provides a general model that is in line with the repeatedly shown findings that show the existence of a diminished HRQoL among RA patients. The diminished HRQoL can be understood within the terms of vicious cycles or self-reinforcing loops which maintain a recurring association between RA symptoms and psychological distress. Due to the multidisciplinary nature of the problem, the concept of vicious cycles can be viewed as an integration of medical and social science research addressing psychological and social reactions to the disease process.

The research aims of the study focus on three areas of interest. The first aim was to investigate the pattern of the course of psychological distress and its associations with the disease symptoms in RA patients. Secondly, it was to explore the role of social support as an important social resource in

relation to psychological distress and depression. Our results showed that the course of psychological distress was relatively stable with significant cross-sectional correlations with disease activity, joint tenderness, pain and functional disability. Longitudinally, psychological distress at the follow up was most strongly predicted by the initial level pain, the emotional support and the initial level of psychological distress (Chapter 3). Finally, emotional support was found to be significantly negatively associated with depression and certain evidence for moderating the impact of RA on depressive feelings was found (Chapter 4).

The second research aim focused on personal resources of the patients, and particularly on self-efficacy of patients regarding their coping resources in stressful situations. The construct of coping self-efficacy was assumed to be negatively associated with depression and anxiety. The results showed that patients who reported higher self-efficacy to carry out coping behavior reported lower anxiety and depression levels. This finding remained significant regardless of the disease activity and personality differences among the patients showing its unique contribution to accounting for variance in distress (Chapter 5).

The third research topic focused on social participation. Thus, the final aim of the thesis was to explore whether differences among patients could be found regarding disease related variables and personal resources between patients who report different levels of restriction regarding social participation and also how social participation is related to HRQoL. This study showed that patients with different levels of perceived restrictions in social participation differed in their experience of pain, fatigue and functional disability. It was found that patients who reported more restrictions regarding opportunities to participate in life situations in comparison to their healthy peers had the tendency to report more pain, higher fatigue and worse functioning. Patients with higher personal mastery and self-esteem reported fewer restrictions in social participation (Chapter 6). In addition, social participation was also found to be associated with the broader measure of HRQoL and particularly with its physical and mental components (Chapter 7).

This thesis has contributed to the research supporting the importance of personal and social resources in RA. It has specifically contributed by introducing the new construct of coping self-efficacy and the peer comparison based approach to addressing social participation in the context of RA. The associations produced by personal and social resources clearly imply that patients' resources need to be addressed during the treatment. The findings are in favor of the need for partnership care giving more competencies and involvement to the patients. This is highly relevant especially for the Slovak health care context which still largely paternalistic with low patient involvement. Finally a close cooperation between rheumatologists and health psychologists could be of great benefit for identifying and supporting patients' personal and social resources while living their life with rheumatoid arthritis.