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Living with Rheumatoid Arthritis

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Discussion

This thesis has addressed personal and social resources in persons with rheumatoid arthritis (RA) especially with regard to their health related quality of life (HRQoL) and psychological distress. Guided by the International Classification of Functioning, Disability and Health (ICF) model, the individual topics were formulated as specific research questions and were addressed longitudinally and cross-sectionally as presented in Chapters 3-7. The general discussion firstly provides a brief overview of the main findings (8.1). The following part then attempts to connect the individual findings and link them to the applied model and empirical research (8.2). The discussion further reflects on the contribution of this thesis to the context of current research, theory and practice. Finally, the strengths and the limitations (8.3) as well as recommendations for future research and practice implications are suggested and outlined (8.4).

8.1 Main findings

Research question 1a: What is the course of psychological distress and how strongly is it associated with disease-related variables over time?

The course of psychological distress was studied over a four year period and was observed to be relatively stable, and no significant differences were found at the group level between the four consecutive measurements. Significant cross-sectional correlations of psychological distress were found with disease activity, joint tenderness, pain, functional disability and psychological distress. However, disease activity was not found to be associated with psychological distress longitudinally. Prospectively the best predictor of psychological distress was found to be the initial level of psychological distress along with pain and emotional support (Chapter 3).

Research question 1b: Are emotional and instrumental types of social support associated with psychological distress?

Social support in general, and especially emotional and instrumental types of social support addressed in this thesis, have been found to be highly relevant for RA patients. The results concerning social support revealed that emotional support was found to be related to psychological distress cross-sectionally and prospectively over the period of four years. Moreover, this association remained significant even when the sociodemographic variables, disease activity, functional disability, pain and levels of initial psychological distress were statistically controlled for. The effect of instrumental support was found to have a much weaker association with psychological distress.

While certain evidence was shown for a cross-sectional relationship, prospectively this relationship was found to be weaker than in emotional support and insignificant when relevant variables were statistically controlled for (Chapter 3).

Research question 1c: Can emotional support and instrumental support ameliorate the negative impact of RA via a moderating effect?

Chapter 4 addressed the issue of the moderating effect of social support. This was considered as highly relevant due to the fact that RA patients generally face a decrease in function and their disability can become a significant stressor eliciting depressive feelings. The findings of this study suggest that especially emotional support may constitute a moderating effect and decrease depressive feelings prospectively. This chapter shows that patients with lower levels of emotional support were found to experience more depression within the period of four years. However, instrumental social support was not found to support this assumption. Instrumental support generally showed weaker association with depressive feelings than emotional support and evidence for a moderating effect was not detected.

Research question 2: Is coping self-efficacy negatively associated with psychological distress after controlling for relevant personality differences and disease related variables?

The study presented in Chapter 5 unraveled that coping self-efficacy was found to be negatively related to both anxiety and depression. When the socio-demographic variables, the disease related variables and even personality variables (neuroticism, extraversion) were controlled for, this association remained significant. It was found that patients reporting higher self-efficacy to carry out different coping behaviors reported lower anxiety and depression levels. This was held true regardless of the disease activity and personality disposition towards experiencing negative emotions (neuroticism). However, certain differences were observed regarding disease duration. Among patients with shorter disease duration a large amount of anxiety could be attributed to high neuroticism and low coping self-efficacy. Such pattern was not observed in the established group.

Research question 3a: Can differences be found in disease related variables such as pain, fatigue, functional disability and personal resources such as self-esteem and mastery between patients who report different levels of restriction regarding social participation?

In Chapter 6 the study found that patients with different levels of perceived restrictions in social participation varied in reported levels of pain, fatigue and functional disability. 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 functional status. Personal mastery consistently reflected the level of participation restrictions and sensitively differentiated even between patients without restriction and mild restriction. Levels of self-esteem were also found to follow similar patterns.

Research question 3b: Are restrictions in social participation associated with health related quality of life?

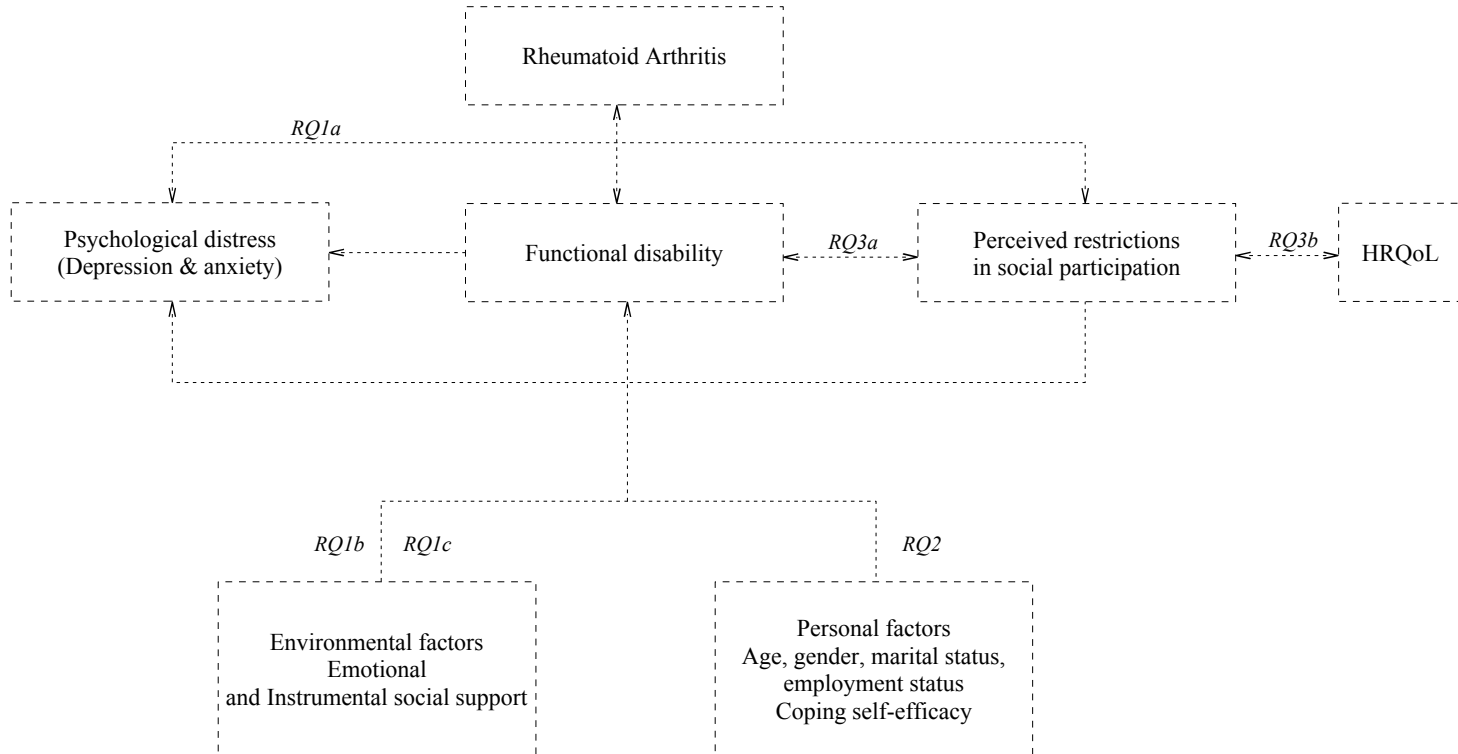
The results presented in Chapter 7 showed that restrictions in social participation were found to be significantly and negatively correlated with the mental health component as well as the physical component of Health Related Quality of Life (HRQoL). These findings were shown in both studied groups of early and established RA patients. This pattern of associations was observed between social participation and both aspects of HRQoL and was found to be similar in both the pattern and strength. According to the proposed models the highest amount of explained variance could be attributed to pain and fatigue. However, a different pattern was observed in the early and the established group. Fatigue was found to be related to the mental health component and pain was related to physical health component in the established group while no such distinction was shown among the early RA group where both associations were equally strong. The findings presented in Chapter 7 suggest that the physical and mental component of HRQoL in the established form of RA is associated with different symptoms.

8.2 Discussion of the main findings

This thesis focuses on social and personal resources in relation to selected aspects of Health Related Quality of Life (HRQoL) in RA patients with special attention paid to psychological distress. The findings are grouped into three broader topics; these topics structure this Discussion. The first topic concerns psychological distress and its relation to RA related variables. The second topic concerns the role of personal and social resources especially regarding their impact on psychological distress. Social resources were addressed by social support and personal resources were operationalized by the concept of coping self-efficacy. Finally, the third topic focuses on social participation as a new concept contextualizing the disability into individual's life circumstances. These three topics fit into the ICF model.

Application of the ICF model provides a general framework that puts emphasis on disability as a process which can be influenced by environmental and personal factors. Furthermore this model stresses the existence of complex interactive relationships which may have a positive or negative impact on this process resulting in different levels of restrictions in participation. While predecessors of the ICF applied handicap as a consequence of the disablement process, the ICF defines disability as a universal human experience in which personal and social resources can make a difference in the consequential impact of a disease on the life of an individual patient. The ICF does not establish specific links concerning how social and personal variables affect the disablement process but provides a general framework.

Figure 8.2 Interactions between the components of ICF model as studied in the thesis



Psychological distress in RA

Psychological distress in our previous studies was observed to be relatively stable over time and consistently associated with social and personal resources. Psychological distress constitutes a relevant problem for RA patients. This has been shown in many studies applying cross-sectional as well as longitudinal analyses [1-3]. In the longitudinally studied sample the psychological distress was measured by the anxiety and depression subscales of the GHQ-28 which have been also commonly used to assess a broader concept of psychological well-being in RA. The mean scores reached in our sample were found to be relatively low and no statistically significant changes could be detected at the group level over the studied period. Similar results were found in other countries and the formulation of the items has been discussed as a possible reason for the lower scores especially on the depression subscale [2,3]. The relevance of the problem has been underlined by the fact that even subclinical levels of psychological distress were found to be related to lower levels of HRQoL and greater mortality [4-6]. The cause of elevated levels of anxiety and depression has been attributed to various factors. While higher levels of psychological distress have been reported in the early phases after diagnosis, once the disease becomes established the levels of anxiety and depression are prone to decrease over time on the group level [7]. The present findings are in line with current research and other longitudinal studies that have been carried out up until now [2,7]. However, it must also be mentioned that the used data did not allow a detailed analysis of the process of adaptation before receiving the initial treatment for RA. At such a moment the highest levels of psychological distress might occur before becoming more stable during treatment [2,8].

The variables directly related to the course of the disease such as disease activity, joint tenderness, pain and levels of functional disability have been previously viewed as direct contributors to psychological distress [9-12]. These associations were found in our study with the strongest association with functional disability. Pain as well as joint tenderness were associated with distress. However, disease activity was associated with distress either only weakly or no significant relationship was found [7-9]. Generally the relationship between disease-related variables and psychological distress is understood to be interactional and not unidirectional and also not direct [5,14]. Current research in line with the ICF emphasizes the need for more sophisticated pathways acknowledging the role of moderating and mediating variables that influence how the disease is manifested [7,13].

Social support as a moderator of functional disability on depression

From the two studied types of social support this study showed that emotional support moderated the impact of disability on depression. The social support theory suggests that such support is beneficial for mental and physical health in the general population. As already mentioned it has been empirically shown that social support is associated with HRQoL among the general population as well as among the chronically ill [16,17]. Social

support has been recognized as highly relevant especially among incapacitating diseases and substantial support for its direct effect has been found in rheumatic diseases and empirical evidence has been provided among RA patients as well [2,3,7, 15]. In addition to a direct effect a moderating effect has been also shown but the findings are less conclusive. It has been suggested that a functional and a structural approach to social support must be carefully distinguished especially regarding direct and moderating effects [2,7]. This thesis adapts the functional view and attempts to contribute to the knowledge and like similar studies it shows that the functional points of view on social support are important [1,7].

Social support as an important moderator of the impact of stress on mental and physical health has been very frequently studied among the general population as well as among specific populations especially chronic diseases [3,18]. The moderating effect where social support serves as a protection against stress has been supported in health research and studies conducted on samples of chronic patients showed relevance of this effect as well [13,14]. For example, the EURIDISS project in multicenter and multinational projects addressed this issue within the RA context. Individual studies that resulted from this project as well as from other longitudinally and cross-sectionally based studies provided rather inconsistent results. For example Doeglas et al. repeatedly showed insignificant results in their moderation analysis [3,7].

This study emphasizes the importance of distinguishing different types of social support even within the functional view. Different functions might play different roles and serve as moderators with different relative strength. In Chapter 4 certain evidence was found for a moderating effect of emotional support. The analysis showed a significant effect of emotional support on depressing feelings. These results suggest that emotional support might ameliorate the effect of functional disability on levels of depressive feelings. Concerning the clinical significance of these findings it should be stated that the level of depressive feelings was relatively low and there are limitations with regard to making conclusions about the diagnostic level of depression. In addition, the relatively low levels of depression might be related to the applied measure as mentioned earlier [3,7]. Nevertheless, the study design allowed for a prospective analysis showing the practical utility of identifying patients at risk for depression in the future course of the disease. A moderating effect was not found regarding instrumental support. Despite this finding it ought to be mentioned that instrumental support has been generally found to have a stronger association with functional disability within a specific area [18,19]. This may be due to the fact that instrumental support may not produce a direct association with depressive feelings like emotional support. For example, it has been suggested that a mediator such as valued activities and may be necessary to show how it affects psychological functioning [19]. The analysis of this study focused on the impact of generally measured disability rather than focusing on limitations in specific activities.

Coping self-efficacy in relation to anxiety and depression

The findings of this study showed that coping self-efficacy was strongly associated with anxiety and depression in the studied RA samples. The applied instrument to assess levels of depression and anxiety was the Hospital Anxiety and Depression Scale which allows for detecting probable clinically significant levels of depression and anxiety [21]. Our results showed that in the early RA group (disease duration 4 years or less) about 10% fell into the category of cases regarding depression and 19% regarding anxiety. In the established RA group (disease duration 12 years or more) only 6% fulfilled the criteria for depression and 18% for case in anxiety. Overall anxiety constituted a more serious problem for the studied samples with a prevalence reported similar to other studies [13, 21]. The concept of self-efficacy as confidence in the ability to perform certain task has been mostly applied to self-management behaviors. Similarly coping styles for dealing with stressors have been addressed in the context of RA separately. The relatively new concept which emphasizes the importance of being efficacious in performing coping behavior in addition to studying coping strategies solely has been introduced within the context of chronic diseases relatively recently [22]. Previous studies focused on the importance of self-efficacy regarding the ability to reduce pain and perform specific exercises or other similar self-management activities [24,25-26]. Studies addressing coping focused mainly on differences in preference of coping styles emphasizing inter-individual differences [8,13].

Coping self-efficacy has not been extensively studied in RA and constitutes what can be considered a relevant personal resource in the context of this incurable and incapacitating disease. The findings of this study thus address a new part of research showing the importance of self-efficacy in coping behavior and especially its relevance regarding anxiety and depression. The findings in Chapter 5 confirm the benefits of active coping strategies on psychological well-being and extend it to the concept of self-efficacy [23,24]. Furthermore our findings are in line with studies where the concept of self-efficacy has been applied to disease specific coping behaviors such as beliefs about controlling pain or other aspects of RA in the studies of Barlow et al. and Lorig and Holman [25,26]. In addition our study stresses the aspect of self-efficacy in the engagement of general coping behaviors which are relevant for a broad spectrum of chronic diseases. In line with the recently published review by Evers et al. [27] the findings presented in Chapter 5 are stressing the importance of monitoring patient's confidence and ability to cope with stress especially in relation to psychological functioning. However, on the other hand it is yet difficult to evaluate specifically the clinical aspects of the explored effect without addressing the concept of change, especially regarding the improvement of coping self-efficacy by an intervention.

Social participation

Perceived restrictions in social participation among the studied RA patients show a tendency of reflecting the level of disease related variables as well as personal resources. Social participation has become the key construct for studying the disability process and is highly relevant especially for incapacitating diseases like RA. Various approaches have been used to assess social participation; [28-33] and the debate regarding different approaches that defined social participation at best is ongoing. In our study social participation was assessed on the basis of comparisons with healthy peers and this way identifying perceived restrictions in participation [31]. Many other studies focus directly on different aspects such as work, education, hobbies and so forth. This thesis provides some support for the suitability of the chosen approach. The relevance of this approach can be also seen in the fact that social participation reflected disease related variables was found to be related to personal resources and to a standard measure of mental and physical components of HRQoL.

The findings of this study show that perceived restrictions in social participation tend to reflect important aspects of RA such the level of disability, pain, fatigue as well as the level of personal mastery and in part self-esteem. Participation has been shown to be a complex and multidimensional construct that in it self does not only include characteristics of a specific individual but also the interaction of the individual and his/her environment. The presented findings show a relevant trend which supports the important role of participation especially by taking into account the point of view of the individual and taking into account the specifics of his/her environment. This approach might thus help to identify which areas of participation are most affected by RA and need to be addressed. The ICF model constitutes an interactive multidimensional framework allowing an integration of an individual and his social surroundings in light of opportunities or restrictions to be part of and participate in life tasks and activities [34]. This view is a significant shift from the bio-medical point of view which emphasized impairment and is also a step further from the disability models that emphasized restriction of a function in the light of its impact on social life. In the ICF model social and personal factors are much more clearly shown to be important not only in addressing how the health condition is related to them but also how it affects an individual's life in terms of participation in social life which has many implications for rehabilitation and care.

The ICF model is a general framework that was not designed to overrule more specific models and theories but to integrate them across disciplines. Within this thesis we have applied the social support theory, coping theory and self-efficacy theory [16,17,35,36] in order to address social and personal resources. Social comparisons were applied for addressing social participation. Currently, a generally accepted approach to assess and measure these constructs is not available. However, our findings show that adaptation of social support and coping theories as well as social comparisons for addressing social participation produced results compatible with the general

model of ICF.

8.3 Methodological remarks

Strengths and limitations of the thesis are addressed below. The text is organized to address applied measures and study design.

Applied measures

Firstly, the measures applied in Chapters three and four of this thesis had been selected for the EURIDISS project [37]. This questionnaire was subsequently administered in all countries participating in the EURIDISS project including Slovakia. This provided a great benefit of comparing the findings with other published studies involved in this project especially Strating et al. and Doeglas et al. [2,3]. The measures were also adopted into Slovak language and validated [38]. In addition, further cross-sectional explorations were conducted and newly developed constructs were included. In particular coping self-efficacy as an important personal resource was shown to be closely associated with depression and anxiety. Furthermore, the Social participation scale based on peer comparison was used and was found relevant in association to disease related variables as well as personal resources. The application of these newly developed measures provided an opportunity to explore their contribution in the RA context. Although population norms based regarding the Slovak population are not available which imposes certain limitations for generalization of the findings especially regarding the newly applied measures. A further validation of these measures especially among different chronic diseases and comparing with the general population is necessary. In addition to the methods of classical test theory more advanced methods such as item response theory tested across a broader spectrum of chronic diseases could provide more information about reliability and validity.

Secondly, the data sets used for analysis in this thesis spread over a period of 16 years and certain changes took place that ought to be addressed. Within the first period of the data collection used for the longitudinal analysis, a comprehensive score for disease activity such as the DAS-28 (Disease Activity Score) [39] was not available. Thus, disease activity was monitored by erythrocyte sedimentation rate, CRP and the number of tender joints which are good indicators of disease activity. An additional issue concerns the criteria for the diagnosis of RA. The new guidelines have recently been published which was after the data collection [40]. All patients in this study were diagnosed for the sake of the comparability over time on the ACR criteria.

Thirdly, functional disability was studied as a general stressor of RA (especially in Chapter 4). It was chosen because it reflects the impact of many symptoms related to or caused by RA, such as pain, fatigue and other symptoms. Many studies can be found to support this indicator as conservatively accurate, although additional information about stress caused

by life events and not only stress imposed on patients by RA could provide a more elaborate picture. Personal and social resources were assessed by self-report measures generally emphasizing the subjective perception. It might have been beneficial to include information from relatives or caregivers, especially partners of the patients [41].

Finally the conceptualization of social participation using peer comparisons requires attention. While this approach of assessing social participation was shown to be relevant and the presented studies confirmed it by producing meaningful and significant results certain limitations must be addressed. There has been much debate as how to integrate objective and subjective parts into the concept of participation. The presented studies applied peer comparisons as the method favoring the subjective perception of an individual. However, a combination of potentially controllable data such as actual participation in work, hobbies, public events, social events and subjective perception of restrictions in participation might provide a more detailed view.

Study design

The thesis is based on longitudinal and cross-sectional data sets which contain both strengths and weaknesses. The longitudinal design consisted of a baseline and three follow-up measurement points which provided a strong basis for analyses. This design made it possible to examine the changes in psychological distress and its associations with disease related variables over time as well to build strong models with measuring the dependent variable prospectively. Even though, not all of the patients participated during all waves of data collection even though the loss to follow up was not extensive. This design also allowed prospective analysis for testing the moderation effect of social support (Chapter 4). Lastly the role of historical factors was unavoidable and patients from the longitudinal sample could not have benefited from treatment with biologicals, which has recently become an important means of decreasing the disease activity in RA. The patient selection was based on the EURIDISS protocol and early RA patients were considered those of disease duration four years or less and patients entered the study after they were treated. This imposes certain limitations on interpreting the early RA as “recent” or “acute” but can be rather interpreted as early years of living with RA.

Furthermore, the longitudinal approach was supplemented by a cross-sectional study. This design allowed exploring more closely the role of personal resources and social participation in relation to psychological distress as well as broader domains of HRQoL. Patient selection was based on the aim of selecting patients with shorter disease duration or early RA with disease duration four years or less (the same as in the EURIDISS) and established patients with disease duration of twelve years or more. This design made it possible to test the models on both samples and analyze the differences. Within this thesis longitudinal and cross sectional designs were applied to address social and personal resources in RA patients at different stages of disease duration. However, it must be noted that the studied groups

of early RA collected in 1994 and from 2006 to 2010 differed in socio demographic characteristics. It cannot be ruled out that historical and societal factors played an important role in patients' willingness to participate in our research during these periods. While in the early nineties the response rate was very high, the later sample fell about twenty percent which might have partly caused these differences.

The chosen study design did not include a control group that would allow making comparisons with general population (or other chronic disease) regarding the severity of disease symptoms as well as levels of psychological distress [42-44]. Additional information retrieved from a control group respecting the cultural and societal specifications that would supplement the two studied samples of early and established RA patients could have improved the specificity of the findings for the RA context.

Since the 1990s the criteria for early RA have changed significantly and while to begin with early RA was considered up to 5 years of disease duration currently it is often less than 12 weeks from the onset of RA [45-58]. A limitation that needs to be addressed is that the mean disease duration of the patients in the early group was relatively high. For ethical reasons the patients were approached after they were treated for the acute symptoms of RA and that could have influenced the findings especially regarding the level of disease activity which was likely to decrease after treatment and presence of psychological distress.

8.4 Implications for practice and for future research

Implications for practice

Health care systems in developed countries show a tendency of shifting from paternalistic to partnership models of care which emphasize the involvement of the patient in his/her treatment. This is in line with the WHO definition of health and the ICF model which is also applied within this study [38]. Partnership models of care which give more competencies and involvement to the patients are highly relevant for all chronic diseases and in particular for rheumatoid arthritis which is so far incurable and often manifested in an unpredictable erratic pattern. 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. This thesis contributes to the importance of this notion especially in three areas where the thesis findings show support for these implications in practice.

Firstly, our findings regarding psychological distress imply that early detection and treatment of psychological distress in the context of patient's social and personal resources might be highly relevant. Routine screening for psychological distress in the rheumatologist practices might be useful to identify those patients that might require more psychological help in adapting to their RA. Enhancing the treatment of psychological distress, via

participation in support groups and supporting patients to take part in social activities may prevent an increase in feelings of depression and anxiety. Within the Slovak context the paternalistic model is still very dominant and the rheumatologists – seen as sole experts by the patients - are often overwhelmed with the number of patients in their practices. A multi-disciplinary approach integrating the medical and psychological treatment with greater involvement of the patient him/herself empowering his/her own personal and social resources could be very beneficial.

Secondly, the thesis addressed the construct of coping self-efficacy especially in relation to anxiety and depression. This could be potentially very effectively applied by training programs or as a part of the disease management programs. Such programs might prepare the patients to deal better with problems and stress that increase the burden of RA. Finally, intervention programs based on the concept of self-efficacy might be useful not only for managing concrete symptoms such as pain but also applied to improve general coping skills and this way improve the adaptation to the disease and psychological well-being as an important aspect of HRQoL.

Thirdly, more data regarding social participation are needed for monitoring program planning and interventions so they can be aimed at specific aspects of the disease. As this study shows the level of the perceived restriction in participation reflects the level of depression and pain, fatigue, functional disability and depression and was also found to be related to both components of HRQoL. This is, however, too specific for rheumatologists only and should involve the broader spectrum of public health researchers and occupational therapists familiar with this field.

Implications for future research

The findings presented in this thesis could be developed in future research especially regarding three aspects. Firstly, the complexity of relationships between personal and social variables that affect the pathway of disability well being requires sophisticated statistical models (e.g. multilevel analysis, structural equation modeling) to find support for the direction and partial pathways. This study provided results about significant associations between studied personal and social resources and was able to control for relevant variables. However, the findings are limited in terms of direction of the explored relationships.

Secondly, the measurement and the operationalization of social participation requires further exploration in the context of RA but also across various incapacitating diseases to improve the criterion validity. RA differs from other progressive chronic diseases mainly in its erratic pattern of progression which imposes great specificity in how it affects restriction in social participation. While this thesis provided support for the relevance of peer comparisons approach it requires further exploration.

Thirdly, it would be most valuable to include patients in a follow up study very early after the diagnosis. Most of the studies exploring early or recent RA patients including this thesis analyze patients with disease duration

of one, two, four years finding very few differences between the patients with shorter and longer disease duration [2,42]. Our findings showed very small differences at the group level. Further exploration of the course of RA from the moment of diagnosis or ideally from the onset of first symptoms could provide more insight into the changes that occur and are not detected on the level of group comparisons.

8.5 Conclusion

This thesis has addressed three topics regarding social and personal resources of RA patients especially in relation to Health Related Quality of Life and also specifically to psychological distress and its course.

The course of psychological distress was observed to be relatively stable with significant cross-sectional correlations with disease activity, joint tenderness, pain, functional disability. The best predictor of psychological distress was found to be the initial level of psychological distress along with pain and emotional support. Emotional support was found to be significantly negatively associated with psychological distress and certain evidence for moderating the impact of RA on depressive feelings was found.

Further, it was found that patients reporting higher self-efficacy to carry out coping behavior reported lower anxiety and depression levels. This was valid regardless of the disease activity and personality differences. However, in patients with shorter disease duration a large amount of anxiety could be attributed to high neuroticism and low coping self-efficacy. Weaker associations were observed among patients with longer duration of RA.

Lastly, our study showed that patients with different levels of perceived restrictions in social participation differed in experience of pain, fatigue and functional disability. Generally patients who reported more restrictions regarding opportunities to participate in life situations in comparison to their healthy peers had a tendency to report more pain, higher fatigue and worse functioning. Patients with higher personal mastery and self-esteem reported less restriction in social participation. In addition social participation was also found to be associated with the broader measure of health related quality of life and its both physical and mental components.

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