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Self-Rated Health and Quality of Life in Slovak Rheumatoid Arthritis Patients

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General introduction

The focus of this thesis is on the perception of health and quality of life in patients with rheumatoid arthritis. In this introductory chapter a general description of rheumatoid arthritis is given, followed by information on its consequences for patients' quality of life – physical, social and psychological. The theoretical model and conceptual framework used in this study is introduced and research questions are formulated. Additionally, the research context of the study - the EURIDISS project and the Slovak framework - are delineated. This chapter ends with a summary of the contents of the thesis.

1.1 Rheumatoid arthritis

Rheumatoid Arthritis (RA) is a chronic progressive autoimmune disease with unknown aetiology. In RA the joints' synovial membranes become thickened and inflamed, often resulting in degeneration of the cartilage and finally the joints. The joint involvement is typically polyarticular and tends to have bilateral and symmetrical distribution. Characteristic symptoms of RA are stiffness and swelling of joints, pain and fatigue (Kantor 1988, Schumacher 1988). The course and prognosis of disease, on the individual level, are uncertain and highly variable, particularly in recent-onset cohorts (Wolfe et al. 1991, Young 1995).

Prevalence and incidence

RA affects approximately 1% of the adult population in general, but this percentage increases with age. After the 55th year the prevalence rises to 5% in females and 2% in males. The incidence of this chronic disease ranges between 0.1 and 0.3/1000. RA usually manifests between the ages 20 and 50, and is more prevalent amongst females, with a sex ratio ranging from 2:1 to 4:1 (Schumacher 1988, Kelley et al. 1997).

Criteria for diagnosis

For diagnosis of RA no specific test is available. Even if several laboratory tests are useful in both diagnosis and pathophysiology of the disease, such as rheumatoid factor (RF) or presence of anti-IgG, none of them is specific for RA. The diagnosis of RA is therefore primarily based on clinical grounds. In 1956 the American Rheumatism Association (ARA)

formulated diagnostic criteria for RA classification. These have been applied world-wide, but after almost 30 years of use the criteria were criticised, mainly because of their lack of specificity. In 1987 the American College of Rheumatology (ACR; formerly the American Rheumatism Association) introduced revised criteria whose specificity was calculated to be 89% and sensitivity 91%. For classification purposes, a patient can be regarded as a real RA if he or she fulfils four out of the seven criteria described below (Arnett et al. 1988).

1987 ACR criteria:

- 1 Morning stiffness in and around the joints lasting at least one hour before maximal improvement, and present for at least six weeks
- 2 Swelling of three or more joint areas simultaneously for at least six weeks
- 3 Swelling of wrist, metacarpophalangeal or proximal interphalangeal joints for at least six weeks
- 4 Symmetric joint swelling
- 5 Rheumatoid nodules
- 6 Serum rheumatoid factor detected by a method positive in less the 5% of normal population
- 7 RA typical changes in hand roentgenogram including erosions or unequivocal bony decalcification

Course of the disease

The course of RA on the individual level is uncertain, but nonetheless it usually follows one of 3 patterns: intermittent, long clinical remissions or progressive.

- *Intermittent course* is reported to be present in 15-20% of patients. In this pattern the phases of elevated disease activity are regularly succeeded by remission phases. Remissions usually last longer than flare-ups.
- *Long clinical remissions* are present in approximately 10% of patients. For this pattern it is typical that after the acute onset phase accompanied by fever, severe joint pain and inflammation there follows a phase of remission lasting for several years.
- *Progressive course* is present in 65-70% of RA patients. These patients experience unpredictable exacerbations and remissions of disease activity with progressive deformity and disability. The onset can be explosive, with many peripheral joints involved, high fever and severe inflammation. However, it can also be subtle, with the disease taking a year or more to become fully present in the joints involved (Kelley et al. 1997).

In general, both clinical and health status measures demonstrate a progressive decline over time in patients with RA. This decline appears to be fairly rapid in the first 5 years of disease, by which time erosive joint changes have developed and a substantial portion of patients are work disabled. After 5 years, the rate of decline may be considerably slower (Meenan et al. 1991).

Risk factors related to unfavourable course of RA

Attempts at early diagnosis of RA are based on the knowledge that RA is a progressive disease leading to joint deterioration. Early diagnosis and treatment is essential in RA in order to prevent irreversible joint damage (Harris 1990). Many studies have demonstrated that in active polyarticular impairment with positive rheumatoid factor the impairment of joint or erosions may develop already in first 2 years after the beginning of disease (Heide van der et al. 1994, Leeuwen van 1994, Heide van der et al. 1996). Even in the first months of the disease the process of irreversible joint damage may start (Guillemin et al. 1992). However, in early stages of the disease it is not possible to predict the progressive course of RA with common clinical and laboratory measures. For this reason the search for other associated factors started. Several authors have provided a survey of the risk factors associated with more severe RA (Hochberg 1993, Heide van der et al. 1994, Heide van der et al. 1996). These factors are listed as follows:

Sociodemographic factors

- older age at the beginning of disease
- female sex
- lower level of education
- occupation involving physically hard work

Clinical parameters

- slow onset of disease
- longer disease duration before establishment of diagnosis
- more joints involved
- presence of rheumatoid nodules
- more severe disability or bad health

Laboratory findings

- rheumatoid factor (in high titre)
- elevated erythrocyte sedimentation rate (ESR),
C-reactive protein (CRP)
- bone erosions
- human leukocyte antigen positivity (HLA-DR4 , HLA-DR1)

Treatment

Because no rational curative treatment is available, management of RA is empiric. It is largely focused on medical management of pain and inflammation with the aim of modifying the disease process. The traditional drug therapy follows the so-called 'pyramid model'. This therapy starts with non-steroidal anti-inflammatory drugs (NSAIDs), and in the event that NSAIDs are insufficiently effective, they are replaced or supplemented with second-line antirheumatic drugs (slow-acting antirheumatic drugs – SAARDs or disease-modifying antirheumatic drugs – DMARDs). The 'pyramid model' was set-up because of potential toxicity of SAARDs. SAARDs should be given to patients only after 'milder' therapies have failed. However, recently the beneficial effects of the 'pyramid model' have been questioned because several studies have shown that later administering SAARDs delays the suppression of inflammation and, as earlier stated, radiological abnormalities (related to the extent of inflammation) appear in the joint early in the course of disease. Moreover, toxicity indices for NSAIDs were found to be similar to those of SAARDs. Thus, current clinical practice is shifting toward earlier introduction of SAARDs in patients with recently diagnosed RA, with the aim of controlling the disease process as soon as possible (Leeuwen van et al. 1994, Heide van der et al. 1996, Guillemin et al. 2003).

However, in spite of great advancements in medical treatment the disease remains incurable, so additional interventions (rehabilitation, psychotherapy, patient education) also appear to be highly relevant. Rehabilitation treatment methods include physical modalities, physical therapy and therapeutic exercises, but they also involve functional occupation therapy, splinting, energy conservation, joint protection and work simplification methods (Lanyi 1988). Patient education and psychotherapy focus on informing patients about the nature of RA, its symptoms and concomitants (chronic pain, disfigurement and diminished physical performance), planing vocational and avocational activities and helping patients feel and function better in their environment.

1.2 The impact of RA on patients' lives

RA has a severe impact on the individual's life in general. Several studies indicate that patients with RA have increased mortality - they die some 10-15 years prematurely as a result of the disease (Rasker and Cosh 1989, Wolfe et al. 1994). In addition, apart from life expectancy this disease has far-reaching consequences for various aspects of patients' quality of life – the physical, social and psychological aspects.

Physical

In RA pathological changes in joints leading to their destruction or deformity are accompanied by pain, stiffness and swelling of joints. These symptoms are usually of greatest concern to RA patients, and their reduction is the primary goal of medical treatment seeking (Young 1992). Due to joint destruction or deformity, dysfunctions in body systems, or in other words impairments, occur. These are for example weak grip or restricted finger flexion. Impairments cause difficulties in carrying out simple tasks of daily living. Activities of personal care (activities of daily living - ADL), such as ability to eat, dress, use the toilet or bath, transfer, get in and out of bed or chair become frustrating and burdensome. Activities that were done without thought yesterday, today become conscious acts of deliberation. Also instrumental activities of daily living (IADL) encompassing abilities to prepare own meals, do light household activities, manage own money, use the telephone or shop for personal items are impaired (Bury 1985, Krol et al. 1993).

Social

As a result of suffering from a chronic disease, patients' social functioning deteriorates as well. Sooner or later, RA patients lose the ability to perform adequately the tasks and roles they used to perform routinely, including occupational tasks, household activities or leisure activities. Physical limitations, fatigue and pain may restrain patients from social interaction. Patients' social integration and social relationships are threatened. RA usually has serious impact on patients' social networks - their relatives, friends and acquaintances. When important social relations are lost, sources of social support are threatened too (Bury 1985, Krol et al. 1993).

Ability to work is one of the most important areas of role activities affected by RA. Several studies have demonstrated that 50-60% of RA patients had to discontinue their employment within 10 years after the onset of disease (Meenan et al. 1981, Pincus et al. 1984, Yelin et al. 1987). Later studies report similar percentages in patients with early RA, i.e. with disease duration of less or equal to 4 years (Doeglas et al. 1995). Changes in ability to perform one's occupation can lead to great psychological distress and to changes of identity (Doeglas et al. 1995, Krol 1996). To be employed supplies individuals with a number of significant values, it creates an opportunity to gain satisfaction and self-esteem and contributes to the person's independence. Moreover, people losing their jobs may be confronted with a decline in their financial situation, and this decline may in turn have an impact on a number of other areas of life, e.g. social participation or leisure activities.

The onset of a chronic disabling disease is bound to disrupt not only the individual's life but also family relationships. In fact, the physical limitations and especially the presence of pain inevitably threaten the

psychological integrity of the individual and his or her social world. Disability in one family member restricts the functioning of others. The 'normal' become disabled too. The development of RA changes the routine ways in which family life was formerly conducted. Isolation and a tendency to withdraw from social contacts are therefore not just a matter of individual motivation or personality, but a logical expression of disruption and disadvantage brought about by chronic disease (Bury 1985).

Psychological

Chronic disease poses high demands on the individual's mechanisms of psychological adaptation. Due to the unpredictable course of RA and its physical implications, patients are perpetually confronted with uncertainty, threat and ambiguity. All this associated with uncertainty about the near future with respect to work position, income position, family responsibilities, social roles and activities can cause many psychological problems to occur in addition to the physical and social difficulties. Problems with self-care, household tasks, occupation, social engagements raise questions about the person's psychological identity. Individuals feel urged to redefine their perception of themselves. This may lead to changes in self-concept and in particular to decrease in self-esteem (Charmaz 1983).

Chronic illness creates dependency on others, which is a source of worry and fear for the individual. Fear of loss of independence, a lack of understanding of the disease, fear of being crippled and chair-bound is common among those with rheumatoid arthritis (Newman and Mulligan 2000). Pincus et al. (1996) found that RA patients are four times more likely to be anxious than controls. Suffering from a chronic disease is commonly associated with increased levels of depressed mood. Patients with RA may find themselves in a disadvantaged position with respect to the availability of resources for achievement of valued goals and interests. They often experience failure in fulfilling expectations of themselves or their partners. These expectations range from sexual activity to household tasks, self-care and companionship. The inability to control one's self and life in ways that has been hoped for, anticipated or assumed results in 'loss of self'. Former self-images crumble away without simultaneous development in valued new ones (Charmaz 1983). Previous research has clearly demonstrated that a negative attitude toward the self makes people vulnerable to depression (Brown et al. 1990). Importantly, the rate of depression among those with a rheumatological disorder is similar to that found in individuals with other chronic disease. Numerous studies have demonstrated that RA patients are vulnerable to increased levels of depressive symptoms with prevalence rates of approximately 20% (Pincus et al. 1996, Barlow et al. 1999, Newman and Mulligan 2000). In addition, elevated rates of depression are equally present in recently diagnosed

patients and those with more established disease (Meenan et al. 1991, Smedstad et al. 1997).

RA is a chronic disease that undoubtedly affects the lives of patients in many respects - physically, socially and psychologically. However, another recurrent finding is that two patients of the same age who are completely comparable on the level of the disease characteristics may show considerable differences in the course of disease and quality of life. Some patients are able to maintain performance of their activities of daily living and social roles, whereas others lose their independence in performing daily activities and need the help of others. If medical parameters only partly explain the variance in the course of the disease and quality of life, other factors, in addition to medical parameters, seem to be responsible for this variance. In this respect an interesting area is formed by socio-psychological phenomena explaining individual differences via individual dispositions such as personality-bound variables (self-esteem, coping, adjustment to disease) and the person's social environment (social support). Because the disease cannot be cured, and the prospects for chronically ill patients are rather poor, social sciences try help to find factors that counterbalance or break the negative spiral of the disease and its consequences.

1.3 Conceptual framework

The conceptual framework of this study follows 3 models: the model of chronic disease and rehabilitation - the so-called Disease-Handicap Model (DHM) (Verbrugge and Jette 1994, WHO 2001, WHO 2002), supplemented by Spilker's Quality of Life (QoL) model (Spilker 1990) and Lazarus and Folkman's Stress-Coping Theory (Lazarus and Folkman 1984). The DHM is applied in this study to describe the chronological order of the groups of variables, Spilker's QoL model is used to more explicitly describe which QoL domains should be distinguished and to characterise the place of the several variables within these domains, and Lazarus and Foklman's Stress-Coping Theory is applied in order to explain the mediating mechanisms of person-bound variables in the stressor (RA pain) – outcome (psychological well-being, self-rated health) relationship.

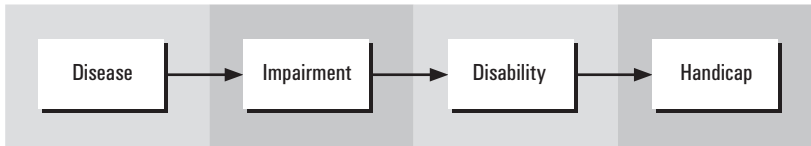
1.3.1 Disease-handicap model

The Disease-Handicap Model (DHM; see Figure 1) on which the International Classification of Functioning, Disability and Health (ICF)¹ is

¹ ICF is the revision of International Classification of Impairments, Disabilities, and Handicaps (ICIDH), first published by the World Health Organisation for trial purposes in 1980

based, was proposed by the WHO with the aim of providing a framework to organise information about the consequences of diseases, or in more detail, to clarify the consequences of diseases in terms of resulting impairments, disabilities and handicaps (Verbrugge and Jette 1994, WHO 2001, WHO 2002). The central focus of the DHM is to delineate the pathway from pathology to various kinds of functional outcomes.

Figure 1 Disease-Handicap Model (DHM)



The DHM has four main concepts: disease, impairment, disability and handicap.

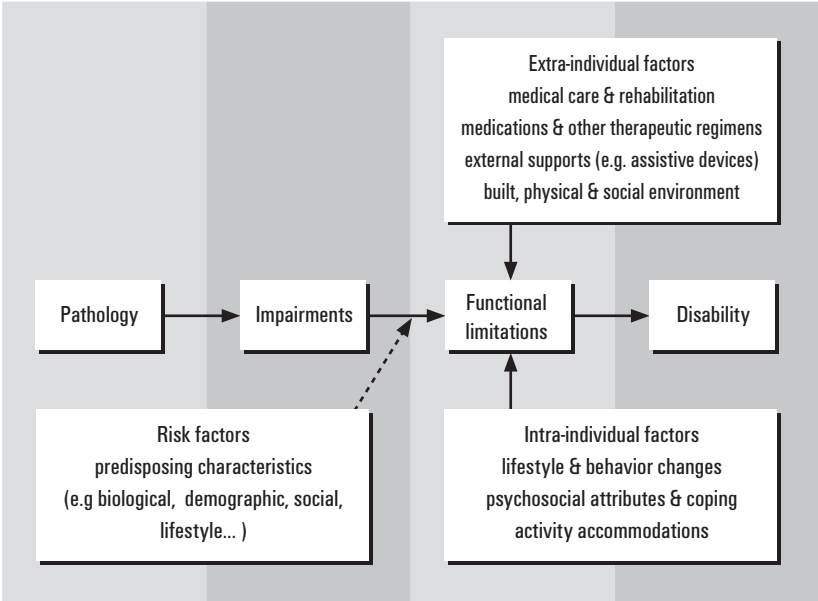
- According to this model, *disease* encompasses the intrinsic pathology or disorder. Pathology refers to biochemical and physiological abnormalities that are medically labelled as disease, injury, or congenital/developmental conditions. Chronic pathology includes progressive diseases, injuries with long-term consequences and enduring structural or sensory abnormalities.
- *Impairments* are dysfunctions and significant structural abnormalities in specific body systems. Impairments include anomalies, defects or losses and relate to the specific functioning of an organ or organ system but not to the organism as a whole. Examples of impairments in RA are mechanical problems with joints, joints hypomobility, stiffness, pain or numbness.
- *Disability* is defined as any lack or restriction (resulting from an impairment) of ability to perform a certain activity in a normal manner.
- *Handicap* is understood as a disadvantage for given individuals due to impairment or disability that limits or prevents fulfilment of their normal roles depending on age, gender or sociocultural factors (Verbrugge and Jette 1994, Doeglas 2000).

The DHM is based on the perception that every complaint caused by a disease interferes with daily life and therefore has social consequences. In this respect the model is too static. The more elaborate version of this model entitled 'The Disablement Process' was proposed by Verbrugge and Jette (1994). The aim of this later model was to contribute to conceptual clarity, internal consistency and measurement feasibility of the DHM.

The Verbrugge and Jette's model (Figure 2) describes the 'dynamics of disablement', i.e. the main pathway that links pathology, impairment, functional limitations and disability. The model incorporates the influence of intervening variables (personal and environmental factors) that speed up or slow down the disablement. The model also takes into account the 'feedback loops' in this process, i.e. dysfunction spirals and secondary conditions, that is to say new pathologies triggered by a given disablement process (Verbrugge and Jette 1994).

The main ideas of 'the disablement process' can also be found in the ICF, which differs significantly from the 1980 version of the ICIDH in the depiction of the interrelations between functioning and disability. The ICF takes into account contextual factors as well, i.e. environmental factors (the physical, social and attitudinal environment in which people live) and personal factors (features of individuals that are not part of their health condition or health status - e.g. gender, age, fitness, habits, coping styles, individual psychological assets). Contextual factors are not classified in ICF, but they are included in the model in order to show their contribution, since they may have a significant impact on individuals, their health and health-related states, or the outcome of various interventions. ICF provides a multi-perspective approach to the classification of functioning and disability as an interactive and evolutionary process. It is important to mention, however, that as a classification ICF does not model the "process" of functioning and disability. In this sense, the ICF and Verbrugge and Jette's 'disablement process' are complementary and they can serve as a frame for empirical studies. The ICF provides an inventory of specific disability-related concepts and their code numbers, whereas the 'disablement process' models the pace and direction of the trajectory from pathology to various kinds of functional outcomes over time.

Figure 2 Simplified model of the Disablement Process



1.3.2 Quality of life

The field of Quality of Life (QoL), or to be more precise the Health-Related Quality of Life (HRQoL) research has expanded exponentially in the past two decades, and the inclusion of QoL measures in medical research has become common (Sprangers 2002). As already stated, the impact of a chronic disease on the patient’s life is manifold. It affects the patient’s self-concept, psychological well-being, occupation, family life and social interactions in general. The QoL construct was introduced to more comprehensively evaluate the outcomes of a chronic disease or effects of treatment interventions (Spilker 1990, Suurmeijer et al. 2001).

The World Health Organization Quality of Life Group (WHOQOL Group) defines QoL as “individuals’ perception of their position in life in the context of the culture and the value system in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by person’s physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment” (Kuyken et al. 1995). QoL is considered to be a double-sided concept, incorporating positive as well as negative aspects of well-being and life. In this definition the patient’s perspective is emphasised, as it focuses on the impact of a perceived health state on the ability to live a fulfilling life. Nonetheless,

according to Suurmeijer et al. (2001) this definition excludes the use of so-called 'objective health-related indicators' (e.g. comorbidity, health-care utilisation) as well as 'objective social indicators' (e.g. employment, socio-economic status, recreational facilities), which can be considered necessary conditions for satisfaction and happiness. Moreover, in view of theoretical modeling it should be possible to deconstruct the QoL concept into its component parts (which should be hypothetically related to each other), so that interrelations between the various aspects of QoL might be examined. This is essentially implicated in the DHM, which describes the chronological order of variables. It seems useful, however, to supplement the DHM with a QoL model that more explicitly describes the QoL domains. Spilker's (1990) QoL model is a good candidate in this respect (Suurmeijer et al. 2001).

In 1990 Spilker introduced his 3-level hierarchical model of QoL. This model runs from highly general to more specific, and the three QoL levels are described as follows:

- The **first level**, the overall QoL level is defined as 'an individual's overall satisfaction with life and one's general sense of personal well-being' (Spilker 1990). In this sense this level reflects the global impression of QoL and corresponds with the WHOQOL Group definition of QoL.
- The **second level** comprises broad domains of QoL. Even though several authors report more domains, the physical, social and psychological domains are generally agreed upon and they are assumed to reflect QoL rather well. The three broad domains are usually understood as follows: The *physical dimension* refers to the patient's physical condition, performance or physical symptoms resulting from the disease or treatment. The *social dimension* reflects the quantitative and qualitative aspects of participation in social relationships, roles and activities. The *psychological dimension* incorporates individual's mood in a global sense resulting from an emotional evaluation of a specific situation, psychological well-being (anxiety and depression) and may include also cognitive functioning (Krol et al. 1993, Sprangers 2002).
- The **third level** of Spilker's model covers specific aspects of the broad domains. Accordingly, measures of anxiety and depression are specific aspects of the domain of psychological functioning.

In addition, Spilker's model assumes that different levels and different aspects of QoL are interrelated. This means for example that the physical restrictions caused by chronic disease play an important role in the decline of the psychological as well as the social domain of quality of life (Spilker 1990, Suurmeijer et al. 2001, Arnold et al. 2004)

According to several authors both the DHM and the QoL models are closely related and complement each other (Verbrugge and Jette 1994,

Ebrahim 1995, Suurmeijer et al. 2001). The DHM describes the chronological order of the groups of variables, whereas the QoL model is used to describe more explicitly which QoL domain should be distinguished - physical, social or psychological. QoL can be considered as the top layer of the Disease-Handicap Model presented above (Figure 2) and it reflects the ultimate outcome of the disablement process. Alternatively, QoL may be seen as the final common pathway of impairments, disabilities and handicaps.

1.3.3 Stress-coping theory

In the present thesis both the DHM and QoL models are supplemented by the Lazarus and Folkman's Stress-Coping Theory (1984) in order to explain the mechanisms by which person-bound or intra-individual variables may influence the disablement process and patients' well-being.

According to Stress-Coping Theory the interaction between the environment and the individual defines stress. *Stress* is experienced when demands from the environment exceed available resources. By *stressor* enduring problems that have the potential for arousing threat are understood. Various life events, such as loss of a spouse, divorce, severe illness, but also daily hassles can lead to severe stress. However, not the stressor itself, but how people perceive it and manage to cope with it determine the stress that is experienced. The mediating processes of *appraisal* and *coping* are therefore pivotal for occurrence of stress. Within this framework *appraisal* refers to the "process of categorising an encounter, and its various facets, with respect to its significance for well-being" (Lazarus and Folkman 1984, p.31). Two kinds of appraisals are distinguished: primary and secondary. During the phase of primary appraisal the person evaluates the implications of the stressor, and estimates the consequences of an event for his or her own well-being. During the phase of secondary appraisal, the evaluation entails what can be done to deal with the situation, and personal and social resources as well as coping options are evaluated. *Coping* refers to strategies for dealing with stress. Lazarus and Folkman (1984) define coping as follows: "constantly changing cognitive and behavioural effort to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person" (Lazarus and Folkman 1984, p.141). Thus, coping is understood as a stabilising factor that may help maintain psychosocial adaptation during stressful periods. In line with this, *adjustment to disease* can be viewed as a result of the coping process.

The way a person manages to deal with a stressful situation depends also on social and personal resources that the individual has access to. Stress-Coping Theory defines resources as what an individual "draws on in order to cope," arguing that resources "precede and influence coping,

which in turn mediates stress" (Lazarus and Folkman 1984, p. 158). *Social resources* are represented in interpersonal networks of which people are a part: family, friends, fellow workers and voluntary organisations. These may be a potential source of crucial support. *Personal resources* are personality characteristics that people draw upon to help them withstand threats posed by a stressor. One of these resources residing within the self is *self-esteem* (Pearlin and Schooler 1978). Presumably, people who have positive views of themselves should be less likely to feel overwhelmed when confronted with stressful demands than should people who do not have positive views. As an element of the self-concept, self-esteem - usually described as self-acceptance or overall affective evaluation of one's worth - has been found to be associated with both physical and psychological health (Brown et al. 1990, Krol et al. 1994).

1.4 Aims, theoretical model, research questions

In this section the theoretical model of this thesis is presented (Figure 3) and research questions are formulated.

Self-rated health and *quality of life* (QoL) are central concepts within the present thesis. Self-rated health is considered to be one of the global measures of QoL, and using Spilker's terminology it refers to 'general perceptions of health and well-being' (Spilker 1990, Suurmeijer et al. 2001). In the past two decades, patients' self-assessments on health-related quality of life (HRQoL) have become accepted as important measures for evaluation and comparison of treatments as well as for the assessment and management of individual patients. Since QoL is generally accepted as a multidimensional, multilevel construct incorporating at least three broad domains (physical, social and psychological), most QoL questionnaires provide a summary score for overall QoL or health status in addition to the assessment of the detailed aspects of QoL. Nevertheless, various definitions describe QoL as a uniquely personal perception, representing the way that individuals feel about their health status, and therefore it is recommended that QoL questionnaires should incorporate at least one simple global question about overall health. Such a global question allows patients to decide how to combine various QoL domains (Fayers and Sprangers 2002). In addition, the study of Arnold et al. (2004) demonstrates that separate QoL domains have only a limited contribution to overall QoL, and assessing QoL domains and overall QoL seem to be two different ways of measuring the impact of a disease on patients' lives.

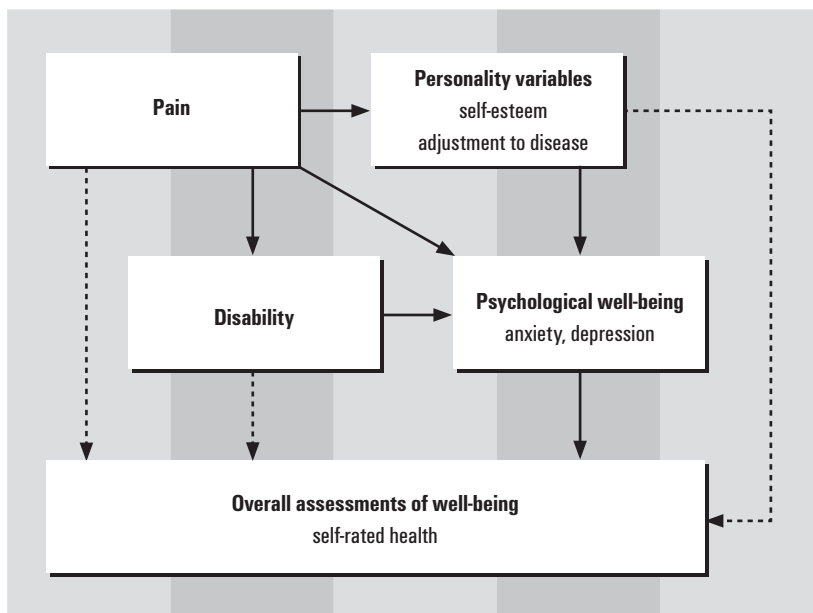
One of the most frequently used measures of overall health is self-rated health. Each answer to the simple question "How would you rate your health - excellent, good, fair, poor?" is a significant variable in studies

of health outcomes. A large number of studies have consistently shown, in a wide range of disease areas, that self-rated health is a powerful predictor of mortality, morbidity, utilisation of health care services, hospitalisation or health protective behaviour (Linn and Linn 1980, Mossey and Shapiro 1982, Idler et al. 1990, Idler and Kasl 1991, Johnson and Wolinsky 1993, Idler and Kasl 1995, Andresen and Lobel 1995). Self-rated health has been shown to be strongly related to such factors as medical diagnosis, functional ability, and physical and mental symptoms (Hays et al. 1996). Nonetheless, there still remain questions concerning the mechanisms underlying the process of evaluation of health as well as the associations between self-rated health and its possible determinants. Self-rated health appears to be more than a simple reflection of physical health status. It underlies a variety of factors – physiological, social and psychological, objective and subjective.

The **aim** of the present thesis is to determine the dynamics of relationships between various QoL domains – physical (pain, disability), psychological (anxiety, depression) and global (self-rated health) within the framework of ‘The Disablement Process’ delineating the pathway from impairment to quality of life. It is hypothesised that impairments resulting from disease (pain) lead to changes in functional ability (disability); these changes influence patients’ psychological well-being (anxiety, depression), which subsequently influences their global self-ratings of health (Figure 3). However, since little is yet known about the causal relationships between self-rated health and its determinants, the alternative pathways are also examined. This is also in line with the ideas of ‘The Disablement Process’, which assumes feedback loops in the disablement process. Another aim of this study is to examine the mediating role of coping-related variables (self-esteem and adjustment to disease) in the association between pain and psychological well-being. We expect high self-esteem and better adjustment to disease to have a positive effect on psychological well-being. We further expect improvements in psychological well-being to be reflected in improvements in self-rated health. This positive change in self-rated health might possibly have a positive effect also on mortality, morbidity and other health outcomes. However, these ideas are already beyond the scope of the present study.

Based on the preceding discussion, the main **research questions** have been formulated. However, before the relationships between the concepts were tested, some psychometric studies were first performed in order to test the psychometric qualities of the instruments that were intended for use in the study. In the present thesis, instruments measuring pain, disability and psychological variables are central. The psychometric properties of the Slovak version of the Groningen Activity Restriction Scale (GARS) (Suurmeijer et al. 1994), measuring disability were evaluated by Szilasiova et al. (1998). In this thesis, the psychometric

Figure 3 Design of the thesis



studies of the Nottingham Health Profile (NHP) (Hunt et al. 1980, Hunt et al. 1981), Ritchie Articular Index (RAI) (Ritchie et al. 1968) and McGill Pain Questionnaire (MPQ) (Melzack 1975) as well as the 28-item version of the General Health Questionnaire (GHQ-28) (Goldberg and Hillier 1978) are included.

- 1a *What are the psychometric properties of the Slovak version of the General Health Questionnaire-28 as a measure of psychological well-being?*
- 1b *What are the psychometric properties of the Nottingham Health Profile (NHP), the Ritchie Articular Index (RAI) and the McGill Pain Questionnaire (MPQ) as measures of pain?*
- 2a *What is the impact of disease duration, disability and psychological well-being on self-rated health?*
- 2b *Do changes in pain, disability and psychological well-being predict changes in self-rated health over time?*
- 3 *What are the direct and indirect effects of coping-related variables (self-esteem and adjustment to disease) on the relationship between pain and psychological well-being?*

1.5 Study design

1.5.1 Research context of the study - the EURIDISS project

Towards the end of 1990, the European Research on Incapacitating Diseases and Social Support (EURIDISS) started. EURIDISS is a multi-centre, multi-disciplinary, longitudinal project focusing on patients with rheumatoid arthritis. The countries involved were France, the Netherlands, Norway, Sweden, the United Kingdom (Northern Ireland) and Slovakia. The EURIDISS project had several objectives. Firstly, the aim of the research project was to understand the role of formal and informal care systems in the process of coping with incapacitating disease. In particular, the role of social support and social networks on the course of the chronic disease are investigated. Another aim of the project was to explore the intervening (mediating and moderating) effect of person-related variables on daily functioning. During the last decades the following variables that may influence the impact of rheumatoid illness on the individual have received special attention: self-esteem, locus of control, neuroticism, extraversion, self-efficacy and coping (Krol 1996, Doeglas 2000, Newman and Mulligan 2000). The third major aim of the EURIDISS project was to develop and test reliable and valid instruments that could be used for international comparisons (EURIDISS 1990).

1.5.2 Patient selection

Sampling procedure

Patient selection in Slovakia followed the regulae of the EURIDISS protocol (EURIDISS 1990). In order to sample a comparable group of patients in each of the participating countries, patients were included in the study only if they fulfilled four out of seven ACR criteria (Arnett et al. 1988). In the international research protocol additional inclusion and exclusion criteria described below were formulated in order to optimise the comparability between the cohorts in each participating country.

Inclusion criteria

- 1 both sexes
- 2 20 to 70 years old at the onset of the study
- 3 delay between time of establishing the RA diagnosis and inclusion in the cohort less or equal to four years
- 4 at least four out of seven ACR criteria for diagnosis of RA are to be fulfilled upon entry into the cohort
- 5 signed informed consent

Exclusion criteria

- 1 existence of another physical handicap prior to RA onset
- 2 association with other severe chronic disease (comorbidity)
- 3 malignant RA with systemic vasculitis
- 4 very disabling RA, e.g. stage IV of Steinbrocker's classification
- 5 any identified reason for becoming lost to follow-up

For the assessment of the ACR as well as the exclusion criteria, the rheumatologist was responsible. For the evaluation of other than medical aspects the research team was responsible.

The incidence cases of October 1990 and later were registered retrospectively. The data collection in Slovakia was carried out from October 1994 to November 1998 and followed the procedure described below. The researcher screened patients' files in the rheumatology practices in the Kosice and Presov regions (Eastern Slovakia). All the patients selected were assessed by the rheumatologist for treatment on the seven 1987 ACR criteria and the exclusion criteria. The assessment of patients was carried out by one rheumatologist, and the same rheumatologist assessed the patients during the whole sampling procedure. After the patients were evaluated by the rheumatologist and found to be eligible, they were informed about the study orally by the rheumatologist. The four-year period of the study was stressed and it was explained that co-operation in the research would include a medical check-up by the rheumatologist and an interview once a year. In addition, the patients were given a written informed consent form to sign.

Subjects

According to the sampling procedure described above, 176 patients were found to be eligible for inclusion in the research project. Out of these 176 patients 16 (9.1%) refused to participate. No particular reasons were given for the non-response. No significant differences were found between the responders and non-responders on sex and age characteristics.

The first wave of data collection (T1) started with 160 respondents. At T2 a total cohort of 151 RA patients remained; 5.6% of the initial sample had been lost for various reasons. At T3 another 18 patients (11.3%) were lost, leaving 133 patients of the original sample. The total number of patients completing the fourth wave of data collection (T4) was 124 patients (77.5% of the original sample). During the four-year period a total number of 36 patients dropped out; of these 2 patients died and 34 dropped out for other reasons. No significant differences were found regarding study variables between the drop-outs and patients who remained in the study.

Data collection

The data collection itself consisted of two parts: medical data collection and personal interview. Health status data were collected by the rheumatologist during a medical check-up of about 30 minutes. The rheumatologist arranged appointments with the patients in the rheumatology outpatient department. Within a fortnight after the medical check-up another appointment with each patient was made in order to collect data from an interview. A personal interview lasting about one and a half hours was conducted by a trained interviewer in non-hospital surroundings. As part of the interview each patient completed a number of structured scales administered verbally by the interviewer, and also filled in several self-reports.

The follow-up of the patients was 3 years, with data collected annually:

- T1 – baseline (first measurement)
- T2 – 12 months after T1
- T3 – 24 months after T1
- T4 – 36 months after T1

1.6 Slovak framework

Because Slovakia is the only Central European country within the EURIDISS project, a description of the Slovak healthcare system appears to be relevant due to potential dissimilarities with Western European systems and their influence on health and quality of life in patients with chronic disease.

Historical background

From the historical point of view the Slovak health care system has its roots in the Bismarck type of health care based on insurance. However, after 1948 the transformation of the health care system into a soviet-type system started. All health care facilities in Czechoslovakia were nationalised and became the property of the state; outpatient and inpatient services were integrated into hospitals with polyclinics and the insurance system was replaced by general taxation. The state took over responsibility for financing and managing the provision of health care. All health services, including drugs and medical aids, became free-of-charge for all citizens. The organisation and structure of the health system was unified, the integrated three-tier hierarchical organisational structure consisting of local, district and regional institutions was introduced. In November 1989 the so-called “velvet revolution” triggered radical political, social and economic changes in Czechoslovakia which also brought about reforms in the health sector. There was a strong political decision to replace the

socialist health system with the regulated market-like system based on health insurance. The organisational structure of the health care system radically changed, and the three-tier hierarchical structure was abolished. The provision of health care became fragmented, based on separated health care providers operating alone. The links between primary health care providers and secondary health care became weakened. In September 1992 the constitutional division of the Czech and Slovak Federal Republic into two independent successor countries started. After division, on 1 January 1993, the Constitution of the Slovak Republic that came into force guaranteed universal coverage of comprehensive free-of-charge health care services based on compulsory health insurance. The organisation of the current health care system is a mixture of state and non-state health care providers.

Health care delivery system

Primary health care

Primary health care includes all first contact ambulatory care, both preventive and curative, including home visits. The four types of first contact doctors have been preserved from the socialist health system: general practitioners (for adults), paediatricians (for children and adolescents), gynaecologist-obstetricians and dentists. Primary health care physicians carry out basic examinations, diagnosis, interventions and treatment. All four types of physicians act as gatekeepers, making referrals to specialist outpatient and inpatient care. Despite the gatekeeping role of primary care doctors, patients may self-refer to an ophthalmologist and, in some cases, may directly see psychiatrists, geneticists and specialists for sexually transmitted diseases. In addition, those with chronic illnesses who are registered in a specialist's clinic have direct access to appropriate specialist physicians, including rheumatologists. In 1998, there were 6341 primary health care doctors in Slovakia. Physicians in primary health care usually work in single-handed practices and are almost always private. Private doctors are paid directly through contracts with health insurance companies.

Secondary and tertiary care

In Slovakia secondary health care is categorised as inpatient and outpatient specialist care due to different kinds of reimbursement. Many specialists, private or state, still have their offices in the outpatient clinics owned by the regional state administration offices. In 1998, 4025 specialists worked in secondary outpatient care. Approximately 44% of them were private, with contracts with the health insurance companies, while 56% were state specialists, employed by the health facility and salaried through a national pay scale. The proportion reached between private and state outpatient

specialists is considered as well balanced. Outpatient secondary care accounts for about 5% of all health care expenditure.

Social care

Social care services include long-term inpatient care, day care centres and social services for the chronically ill, the elderly and other groups with special needs, such as the mentally ill, mentally handicapped and the physically handicapped. According to legislation in the Slovak Republic, such care is defined as subsequent care (which includes nursing, rehabilitation, psychological and spa care²), special care and community care. Subsequent and special care are financed by health insurance companies, while community care is financed by the state budget or through direct payments.

Public health services

As a result of the health care reforms of the 1990s, primary health care services have become separated from the public health services. Public health services are carried out by the network of 36 regional public health institutes (formerly state health institutes). The public health services comprise prevention and control of communicable diseases, environmental hygiene, child and youth hygiene, nutritional hygiene, preventive occupational medicine, protection against ionising radiation, epidemiology and medical microbiology. The public health institutes also monitor and analyse the health status of the population. Their management, organisation and financing is centralised and is headed by the chief hygienist. Activities and tasks carried out by the regional public health institutes are financed from the state budget.

Health care finance and expenditure

The financing of health care is based on compulsory health insurance. Health insurance companies are responsible for collecting health insurance contributions and for reimbursing health care services. Health insurance contributions are strongly individualised; coverage by the health insurance plan does not include family members. Contribution rates are defined by law and relate to income. At the present time contributions take up 13.7% of personal income. Since health insurance is compulsory, all permanent residents in Slovakia are covered. The state pays a contribution of 13.7% of the minimum wage on behalf of children, pensioners, persons caring for children or disabled persons, soldiers in military service, prisoners, refugees and other inactive persons.

² Treatment provided in spas; it is based on the use of natural sources (e.g. thermal springs, mud baths) in combination with most modern medical and rehabilitative methods.

Concerning payment of physicians, state-employed physicians are salaried according to national pay scales. This applies to those in hospitals and outpatient clinics. Private physicians in primary and secondary care have direct contracts with health insurance companies. During the last few years, the system for paying the primary care physicians has changed several times. In 1993, the German approach of fees for services based on a “points” system was introduced for outpatient care as well as for inpatient care. It was replaced with a 100% capitation system in October 1994. In 1998, based on the Act No 98/1995 on the Therapeutic Order, a “combined system” was introduced – a combination of 60% of payments by capitation and 40% by the points-based fees-for-services system.

When considering health care expenditure, the proportion of GDP spent on health varied between the lowest level of 5.25 % in 1903 and the highest level of 7.6 % in 1996. It is more than the central and eastern European countries average of 5.1% of GDP and less than the western European Union countries average of 8.4% (European Observatory on Health Care Systems 2000).

1.7 Summary of contents

Chapter 1 provides general description of RA and its consequences for patients’ lives. It also introduces the conceptual framework and research questions. In addition, it gives information regarding the research context of the study and the Slovak framework.

Chapter 2 deals with the reliability and validity of the Slovak version of the General Health Questionnaire-28 (GHQ) - an instrument measuring the psychological aspect of QoL. The scaled, 28-item version of this instrument is a standardised research tool with satisfactory psychometric qualities, well-documented in Western European countries; however, questions emerged whether the psychometric properties of this instrument are appropriate in order to measure the psychological component of QoL also in a Central European country, in particular in Slovakia.

Chapter 3 is devoted to comparison of three frequently used pain measures, the Nottingham Health Profile (NHP), the Ritchie Articular Index (RAI), and the McGill Pain Questionnaire (MPQ) with regard to their construct validity as well as their utility for both research and practice. Pain is one of the most important concomitants of RA, therefore maximum objectivity in assessment of pain is necessary for reliable clinical evaluation and effective treatment planning.

The aim of *Chapters 4 and 5* is to examine the relationships between self-rated health and its possible determinants - pain, disability and psychological well-being. On the basis of empirical findings a linear Structural Equation Model (SEM) is proposed and subsequently tested using LISREL. Data from all four measurement points are used.

Chapter 6 focuses on the impact of pain on patients' psychological well-being. Special attention is given to the possible mediating role of coping-related variables (self-esteem and adjustment to disease) in this relationship with the aim of bringing more clarity into the controversy in literature regarding the degree and causal direction of the associations between pain and psychological well-being in patients with a chronic disease.

Finally, in *Chapter 7*, a survey of the main findings is given and the results are discussed at a more general level. In addition, implications for future research and recommendations for health policy are delineated.

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