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

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Conclusions, discussion and recommendations

7.1 Introduction

Chronic diseases pose a heavy burden on both individuals and their families as well as society as a whole, because of their far-reaching consequences. The majority of chronic diseases are non-fatal, so people mostly live with chronic conditions rather than die from them. In the short and long run, symptoms and disability are the principal outcomes, and they become the focus of protracted personal and medical care. During the last decades a relative shift from 'cure' to 'care' can be recognised. According to health policy, attempts should be made to render the lives of people suffering from chronic diseases worth living in spite of their illness. As a result, a great deal of attention is given to the concept of 'Quality of Life' (QoL) in patients with chronic diseases. This research has grown exponentially in the past two decades and the inclusion of QoL measures in medical research has become common. QoL is a broad concept including aspects like psychological well-being, self-rated health and feeling happy. There is a growing recognition of the existence of feedback effects between the somatic, social and psychological levels of the disease process. Nevertheless, little is yet known about the pathways from impairment to disability, handicap and overall QoL. In this context, the concept of self-rated health, considered as a general aspect of QoL, attracts particular attention because of its power to predict important health outcomes.

This study is the result of a multicentre, multidisciplinary, longitudinal project that was set up to survey and specify the number of factors determining the course of disease and the QoL in patients with recent-onset rheumatoid arthritis (EURIDISS 1990). Three general questions were studied. The first question was whether the psychometric properties of the instruments used in this study to measure the physical and psychological components of QoL are satisfactory also in the Slovak context. In particular, instruments measuring pain and psychological well-being were examined, since these instruments occupy central positions in the models under study. The second question examined the

pathways between self-rated health and its determinants - pain, disability and psychological well-being. The third research question focused on the possible mediating role of self-esteem and adjustment to disease in the relationship between pain and psychological well-being.

In this final chapter the main findings of this study will be summarised and discussed. Attention will be paid to the methodological limitations, possible directions of future research as well as recommendations for practice implications.

7.2 Main findings

Research question 1a:

What are the psychometric properties of the Slovak version of the General Health Questionnaire-28 as a measure of psychological well-being?

The General Health Questionnaire (GHQ) is frequently used in Western European countries as a measure of the psychological component of quality of life. However, the number of studies from Central Europe using this instrument is remarkably small. Questions emerged therefore concerning the appropriacy of the psychometric properties of this instrument in Slovak conditions, as the only Central European country within the EURIDISS project.

When considering the reliability figures and the intercorrelations of the scales, the results indicate that the psychometric qualities of the GHQ-28 in Slovakia are satisfactory. The results of Principal Component Analysis (PCA) however reveal some discrepancies of the scale factor structure in comparison with the original scale. The 28-item version of the GHQ incorporates four subscales: somatic symptoms, anxiety/insomnia, social dysfunction and severe depression. According to our findings the subscale 'somatic symptoms' requires more attention in patients with RA because of its tendency to break down into two dimensions. General health ratings included in this scale (e.g. 'felt recently ill', items 1-4) appear to be more closely related to the subscale 'anxiety/insomnia' than to the original 'somatic symptoms' subscale, whereas items focusing on specific symptoms (e.g. 'having hot or cold spells', items 4-7) create an independent subscale. One of the most probable explanations of this tendency of the subscale 'somatic symptoms' to break down into two dimensions lies in criterion contamination; i.e. the fact that the scale is used in RA-patients with a higher level of somatic symptoms because of the disease. Also the findings of Sanderman and Stewart (1990) with the Dutch version of the GHQ-28 are in line with these considerations. However, the criterion contamination explanation seems to be not satisfactory since, interestingly, similar results were found when the Turkish version of the GHQ-28 in

a community sample of Turkish speaking emigrants in Melbourne was evaluated (Stuart et al. 1993).

In general the results of the analyses gave us satisfactory answers concerning the applicability of the 28-item version of the General Health Questionnaire as a measure of psychological well-being in patients with a chronic disease in Slovakia. Nevertheless, due to the possibility of criterion contamination more research on GHQ-28 in RA patients is still recommended.

Research question 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?

In line with expectations, the results of the analyses provided support for the construct validity of the three pain instruments. Significant factors accounted for between 45% to 64% of the total variance explained, as disclosed by Principal Component Analysis (PCA). In the NHP the PCA results show that the items form a strong unidimensional scale. In the RAI the symmetrical clustering of the items is in line with existing knowledge about the character of rheumatoid arthritis, i.e. symmetrical joint involvement. The factor structure of the MPQ is less clear, and questions remain about how closely the MPQ items reflect Melzack's theory of pain. However, this result is not surprising and is in accordance with previous findings, since most psychometric studies on MPQ failed to demonstrate the original MPQ structure (McDowell and Newell 1987, Melzack and Togerson 1971).

In addition, the outcomes of this study shed more light on specific qualities of these instruments, indicating that each of the three measures pain from a different perspective. Pain as assessed by the NHP is closely related to psychological well-being, whereas pain as measured by the RAI is associated with disease activity. The MPQ, despite some queries as to its factor structure, is a very important measure of pain as well, since it meets the need for measuring the qualitative aspect of pain. Therefore, for creating a complete picture about pain as a multidimensional phenomenon, the pain instruments should be used conjointly.

Research question 2a:

What is the impact of disease duration, disability and psychological well-being on self-rated health?

Functional disability and psychological well-being are variables that have been identified as strongly associated with self-rated health. Nevertheless,

the mechanisms underlying the process of evaluation of health were not entirely clear. Within a cross-sectional study the structural equation modeling technique was used in order to explore the relationships between self-rated health and its determinants and to see how the process of evaluation of health may operate over time.

The results of the study provided support for the expectation that functional disability and psychological well-being are important determinants of self-rated health. More activity restrictions and poorer psychological well-being are clearly associated with poorer health evaluations. Moreover, results from structural equation modeling indicate the following sequel to these associations: longer disease duration is initially associated with increase of disability, followed by a decrease in psychological well-being, and subsequently by poorer evaluations of subjective health. Nevertheless, apart from a clear path relationship between psychological well-being and self-rated health, the results also suggest that a strong correlation exists between self-rated health and psychological well-being. This indicates the presence of feedback loops in the process of health evaluation.

Research question 2b:

Do changes in pain, disability and psychological well-being predict changes in self-rated health over time?

Using a repeated cross-sectional design with four measurement points, the results support the findings of previous cross-sectional studies. In particular, pain, disability and psychological well-being were confirmed to be important determinants of self-rated health at all measurement points. On average, the combination of these variables explained approximately 40% of the self-rated health total variance explained. When the time perspective is taken into account the best predictors of change in self-rated health are prior health evaluations, and an even better predictor is change in psychological well-being. This finding is consistent for all time intervals.

Research question 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?

Chronic pain and decrease in psychological well-being have consistently been found to be associated with RA. However, the great variability in the strength as well as the causal direction of the relationship between pain and psychological well-being suggests that there are factors which may mediate the impact of chronic disease on patients' psychological

well-being. The results of the present study support the idea that patients' psychological well-being is significantly influenced by pain. At the four measurement points, pain explains from 20 to 40% variance in psychological well-being. But also self-esteem and adjustment to disease significantly contributed to the total variance explained, with an additional 10 to 25% of variance explained. The results of structural equation modeling further support our expectation that the impact of pain on psychological well-being is mediated by self-esteem and adjustment to disease. Moreover, the results suggest the increasing importance of coping-related variables in mediating the relationship between pain and psychological well-being as the disease advances

7.3 Discussion of main findings

7.3.1 Disablement process – the main pathway

The concept of self-rated health attracts particular attention in health-related quality of life research because of its great power to predict important health outcomes such as mortality, morbidity, utilisation of health care services or health protective behaviour. However, little is yet known about the mechanisms underlying the process of evaluation of health. Much of the earlier research on self-rated health was based on cross-sectional correlations between self-rated health and other measures of health status, in particular functional ability and disability. This research was insightful, but also revealed that self-rated health is not related exclusively to physical health status variables but also to socio-demographic and psychological variables. Poorer self-rated health was found to be correlated with depressive symptomatology, poorer cognitive functioning, being unmarried, having lower income, lower education and current smoking habits (Hays et al. 1996). Yet, considerable inconsistency can be found in the literature on correlates of self-rated health. Variables that have been shown to be most predictive of self-rated health in some studies have not been included in others. Hays et al. (1996) carried out an extensive survey of factors associated with poor self-rated health and they found that three factors proved to be most predictive, in particular physical health status variables (pain), disability (functional status), and psycho-physiological symptoms (depression, anxiety). Another inconsistency in literature can be found regarding the causal relationships between the variables. For example, several studies show that disability predicts poorer self-rated health (Johnson and Wolinsky 1993), while conversely other studies show that poor self-rated health leads to more disability (Idler and Kasl 1995). This thesis seeks to address this gap in the

literature, by considering the dynamic relationships between self-rated health and its correlates, using the conceptual frameworks of the theory of Verbrugge and Jette's (1994) 'Disablement Process' supplemented by Spilker's Quality of Life (QoL) model and Lazarus and Folkman's Stress-Coping Theory (Lazarus and Folkman 1984, Spilker 1990).

The results of the present study shed more light on the pathway that leads from pathology to global quality of life outcomes in patients with RA. The disablement process starts with pathology, which refers to biochemical and psychological abnormalities that are detected and medically labelled as disease (rheumatoid arthritis). The next stage is impairment, i.e. dysfunctions and significant structural abnormalities in specific body systems. RA symptoms such as stiffness and swelling of joints, restricted finger flexion, fatigue and pain can serve as examples of impairment. Of these symptoms pain is seen as the most significant health problem, and as one of the primary reasons of seeking medical treatment. Pain is often stated to be the most universal form of stress. Throughout history pain has been the object of extensive efforts to understand, control and alleviate it. The results of this thesis clearly show pain to be associated with disability, reduced psychological well-being as well as poorer self-rated health. Regarding these variables the strongest relationship was found between pain and disability, suggesting the next stages of the 'disablement process' – functional limitations and disability. Functional limitations are restrictions in performing fundamental physical and mental actions used in daily life. Examples of functional limitations in RA patients are problems with walking, lifting objects, climbing stairs, difficulties in grasping and rotating fixed objects etc. Functional limitations lead to disability, which can be defined as experienced difficulty doing activities in any domain of life. The focus is especially on the following 3 domains: personal care (ADL – activities of daily living), household management (IADL - instrumental activities of daily living), and labour (paid employment). On the other hand disability includes difficulties in other domains as well, e.g. socialising with friends and kin, hobbies, active recreation and so forth. Disability refers to the expression of a functional limitation in a social context. According to Verbrugge and Jette (1994) disability has a powerful effect on global quality of life indicators, but they do not specify this effect in more detail. Self-rated health can be considered as a global quality of life indicator (Suurmeijer et al. 2001). It was decided therefore, within the framework of this study, to examine what might be the possible causal pathway between disability, psychological well-being and self-rated health, since this relationship was so far not clear from the literature. Our findings suggest that in spite of a frequently reported rather strong correlation between disability and self-rated health, this association seem to be substantially influenced by the level of psychological well-being. In other words, changes in

disability lead to changes in psychological well-being and these lead in turn to changes in self-rated health. Nevertheless, this pathway is not one-directional, i.e. leading simply from pathology to disability or global well-being indicators, because feedback loops can be identified within the disablement process. Verbrugge and Jette (1994) describe vicious spirals on the disability - impairment level, and in addition to this the results of our study suggest a similar feedback effect between psychological well-being and self-rated health.

7.3.2 Disablement process – the effect of intra-individual factors

The above-mentioned main pathway from pathology to disability postulates a 'natural' sequence of events in chronic disease. One may think of the main pathway as a set of probabilities, or effects that occur if a chronic condition operates in a social vacuum, with only medical factors operating. This is of course seldom true. The model of the 'Disablement Process' was therefore extended so that it attains full socio-medical scope; the possible effects of risk factors, intra-individual and extra-individual factors have also been taken into account (Verbrugge and Jette 1994).

Of these additional factors, within the framework of the present thesis we have restricted ourselves to intra-individual factors. In particular the role of person/coping-related variables, namely self-esteem and adjustment to disease, were studied in more detail as possible intervening variables that may mediate the impact of pain on psychological well-being and subsequently on self-rated health.

According to its multidimensional model, pain is characterised by four components that are present in every type of pain: nociception, pain perception, pain experience and pain behaviour. Pain starts with *nociception*, i.e. the process of detecting tissue damage developing after injury to tissue, whether induced by disease, inflammation, accidental injury, or provoked by surgical operation. Nociception leads to the *perception* of pain. Pain perception refers to awareness of a noxious sensation, appreciation of negative emotion, interpretation and attribution of meaning to the experience. Processes associated with perception of pain may be significantly influenced by other psychological factors, such as anxiety, controllability and predictability of the pain stimulus. Perception of pain results in *pain experience*, which is understood as cognitive and emotional responses associated with perception of pain. The experience of pain usually disrupts ongoing activities and can result in *pain behaviour*, such as verbal or non-verbal behaviour (reflexive withdrawal reactions, posturing, bracing, grimacing), but also withdrawal from normal activities, inactivity, drug misuse, or curative action (Reitsma 1994).

According to the International Association for the Study of Pain (IASP) definition, pain is always accompanied by emotional disturbances

and distress (IASP 1979). Emotional distress may also be identified as a consequence, but also as a cause of pain. Fear, anxiety and depression can amplify pain, since they may provoke activity in biological systems, autonomic, visceral or skeletal, as a response to noxious stimulation. However, in chronic diseases emotional distress is more frequently referred to as a consequence of pain. In RA tissue damage, deformities and fatigue tend to provoke fear and anxious concern for oneself. If the inflammation and damage persist, pain can be perceived as unbearable and uncontrollable, and may lead to very high levels of anxiety and depression. According to Vlaeyen (1991) an emotion can be defined as a chain of events that has certain loosely coupled elements in a complex feedback loop system. This chain involves three response-systems, in particular autonomic responses, cognitive reactions and behavioural reactions. The traditional concept of cognition refers to thought processes, information processing, judging, reasoning, imaging, attitudes, beliefs and expectations. Following Lazarus and Folkman's terminology (1984), chronic pain is a permanent stressor which provokes the processes of cognitive appraisal and coping. When an individual becomes aware of pain, a process of *'primary appraisal'* may be elicited (Lazarus and Folkman 1984). This process refers to the analysis of pain in order to further assess its relevance or potential danger. These interpretations can be labelled as *'causal attributions'* and can be characterised by three dimensions: locus (whether the cause is located inside or outside the person), stability (whether the cause is lasting or not) and controllability (whether the cause is subject to volitional control or not) (Wiener and Graham 1984). Causal attributions in processes may modify significantly the pain experience. For example, it is assumed that controllability can affect predictability and permits more adequate preparation for pain (Weisenberg 1984). The process of *'primary appraisal'* is followed by a process of *'secondary appraisal'*. Based upon causal inferences, the individual will consider which of the possibilities of dealing with the present situation (coping resources) will be evaluated. It is assumed that the process between stress and coping is influenced substantially by psychological resources, and one of these resources residing within the self is self-esteem (Pearlin and Schooler 1978, Lazarus and Folkman 1984, Reitsma 1994). The results of the present study provide support for these considerations, since they clearly show that self-esteem is an important intervening variable in the relationship between pain and psychological distress. This finding is in line with several previous studies demonstrating that positive self-concepts have salutary and therapeutic consequences for individuals, while negative self-concepts are associated with poor coping abilities and negative health outcomes (O'Leary 1985). Furthermore, high self-esteem has been found to alleviate feelings of stress and low self-esteem to increase stress (Pearlin et al. 1981, Menaghan 1983). In addition, positive

self-concepts have been found to mediate the impact of pain on depression (Seff et al. 1992, Penninx et al. 1998). Similarly, the outcomes of this thesis provide support for the important mediating role of adjustment to disease, and they show that adjustment to the natural course of arthritis is beneficial to patients' psychological well-being. A recent study by Sprangers et al. (2002) demonstrates that patients who have learned to adapt to their conditions may in fact have learned to use coping strategies more effectively. As a result, their overall QoL may not be impaired despite possible physical and psychosocial restrictions.

To sum up, the results of the present research provide support for the idea of the important intervening role of intra-individual factors on the main pathway of the 'disablement process', and they bring more clarity to the understanding of the mechanisms by which coping-related variables, in particular self-esteem (personal resources) and adjustment to disease (result of the coping process), influence the impact of pain on psychological well-being.

7.4 Discussion on methodological issues

7.4.1 Research sample and generalisability of results

In the present study, RA patients were included who fulfilled several inclusion and exclusion criteria as defined by the EURIDISS protocol (EURIDISS 1990). Among other things, patients needed to meet four out of the seven 1987 ACR criteria. This requirement was used in order to obtain comparable patient samples in the participating countries within the EURIDISS project. Consequently, the results obtained may not be representative for the entire RA population as found in clinical practice. On the other hand, following this well-defined selection procedure resulted in a sample of patients with clear-cut rheumatoid arthritis, so the findings do apply to a well-defined group of RA patients.

7.4.2 Study design and data collection

Although the EURIDISS protocol was followed and the data were collected carefully, some caveats need mentioning. From our results, but also the results of other EURIDISS studies, it appears that only minor changes in mean scores in the physical, social and psychological domains of QoL could be detected in the longitudinal analysis over the first four years of disease, although quite large individual differences did exist (Smedstad et al. 1997, Doeglas 2000). This phenomenon is called 'erratic pattern' of disease. Diseases with erratic clinical courses are more difficult to study than chronic illnesses with a clear beginning and clear evolution. Several

analysis procedures have been developed for handling this type of disease process, e.g. the area under the curve (AUC) approach. Composite scores as obtained by AUC fluctuate less, and could subsequently yield clearer results. Another possibility is to apply multilevel analysis for longitudinal data. Doeglas (2000) tried to demonstrate this variety in disease process as well as its consequences for QoL. The relationship between disease process and QoL was not found however. This means that the data collection has to cover a longer period to find larger changes in the disease process for the whole sample and stronger effects of these changes on outcome variables.

7.4.3 Measurement instruments

A frequently addressed issue in patients with RA is the measurement of the psychological component of quality of life. More specifically, it is argued that illness-related aspects such as pain and fatigue possibly contaminate the answers on depression scales and personality questionnaires. In this study the GHQ-28 was used as an outcome measure, assessing the psychological component of quality of life. Of the four subscales of the GHQ-28, the items of the subscales 'somatic symptoms' might be contaminated by illness-related aspects.

7.5 Recommendations for future research

The results of this study highlight only some of the interesting relationships between different aspects of QoL in patients with recent-onset RA. In order to trace particular factors contributing to the disablement process and QoL in general, it would be interesting to differentiate between patients with early RA and patients with more established disease. By replicating parts of this study among patients with longer disease duration it may be found that other factors have a more profound influence on the pathway from pathology to disability and general QoL. It might be considered worthwhile, therefore, to expand this study with a tenth assessment. Similarly, in order to trace particular disease-specific factors contributing to changes in QoL, it would be interesting to differentiate between other chronic diseases as well. By replicating parts of this study among patients with other chronic diseases, it may be found that disease-specific factors have a more significant influence on quality of life of chronically-ill patients.

The data on which the results of this thesis are based are mainly cross-sectional in nature. However, only longitudinal analyses can satisfactorily provide us with answers concerning the causal relations between the variables. It would be interesting to follow the development

of personality-related characteristics shortly after the disease has been established. If changes in personality occur, results of longitudinal data may point to periods of vulnerability. To answer questions like this, one way would be through prospective studies in which individuals are followed for several years. Another way would be to have more frequent measures, directly related to experienced changes, as may be done through patients' diaries. Moreover, results of intervention studies that focus on enhancement of self-esteem, better ways of coping or cognitive-behavioural pain management programs would additionally contribute to answering questions concerning the causality of the associations.

In RA changes in disease activity and functional ability are associated with uncertainty and unpredictability of the future course of disease, performance in everyday activities and fulfilling the expectations of others. This can lead to feelings of helplessness, which have in turn been found to be related to pain and depression and changes in global health status (Stein et al. 1988a, Stein et al. 1988b). In addition, as pointed out by Doeglas (2000), uncertainty constitutes a restriction on the realisation of valued objectives, which leads to decrease of the patient's social network and ultimately to decrease of the patient's quality of life. As a result, patients with 'erratic pattern' of disease feel more depressive compared with patients who experience a rather stable course of disease. On the other hand, individuals' perception of the degree of control over their disease has been found to be an important predictor of psychological well-being (Newman and Mulligan 2000). More attention to the level of uncertainty in RA is therefore recommended, but as mentioned before, this will probably need a longer time for follow up.

7.6 Implications for practice

Using instruments

The outcomes of this study may be used for improvements in practice. The psychometric properties of the Slovak version of the GHQ-28 were shown to be similar to those in Western European countries. We would recommend therefore that researchers from Slovakia (and probably also those from other Central European countries) use this instrument in their studies to measure the psychological component of quality of life. Similarly, pain instruments applied within this study, namely the Nottingham Health Profile (NHP), the Ritchie Articular Index (RAI) and the McGill Pain Questionnaire (MPQ), proved to have good psychometric properties. When comparing the three instruments for usefulness in clinical situations, the NHP is a convenient self-report measure that does not require the presence of a specially trained person and moreover in comparison with the RAI it does not cause discomfort to the patient. When

speaking about the advantage of the RAI, it has been found to be sensitive enough to indicate the activity of the disease and has been shown to reflect exacerbations and improvement induced by antirheumatic drugs. The third pain measure, the MPQ, provides a great deal of information regarding the qualitative aspect of pain. For both researchers and clinicians it is recommended to use measures of pain jointly, because together they can better reflect the multidimensional picture of pain.

Information

Suffering from a chronic disease requires major psychological adaptation as individuals have to learn to come to terms with a painful, disabling condition that is unpredictable in its course. Some understanding of this process is needed in order to educate patients and their families about the nature and stages of disease, planning vocational and avocational activities and to help patients feel and function better in the environment. In chronic diseases, the patient is the principal caregiver. This is readily seen when one considers the tasks the patients must perform, alone or with the family: using medications properly, changing behaviours to improve symptoms or slow disease progression, interpreting and reporting symptoms accurately, adjusting to new social and economic circumstances, coping with emotional consequences and participating in decisions concerning treatment. It is the responsibility of the health care system to prepare patients for those tasks. The benefits of patients' education fall into many categories. One is symptom improvement (e.g. proper medication use, but also cognitive distraction that can reduce pain), another area is physical activity (regular exercise helping to prevent mobility limitation), a third area is reducing psychological distress.

Education

Educational programmes could be developed to teach patients how to cope effectively with the chronic disease. Adequate information about possible symptoms of the disease during its course and how and where to get help if needed may be beneficial for patients in the sense of having control and better adjustment to disease.

Intervention

Recognition of the importance of psychological factors in adapting to rheumatological disorders should lead to the development of psychosocial interventions that attempt to modify patients' beliefs, coping strategies and social support in order to enhance their psychological well-being and health status. As a result of the shift in health policy from cure to care, nowadays more patients are offered educational programs in which they are provided with information about the disease as such and the possible consequences of the chronic condition.

Attention to patients' self-esteem merits a place in these programmes. High self-esteem goes along with their ability to emphasise the remaining possibilities rather than the impossibilities, and as a consequence may result in better quality of life. In the treatment of RA health professionals should emphasise those possibilities which are still left in the patient's life. Treatment directed not only at medical status but also towards the patient as an individual in his or her unique environment may meet the needs of the patient more accurately and be beneficial for the treatment programme as a whole. Restoring self-esteem by the satisfaction derived from newly developed goals may contribute to a renewed equilibrium in the lives of patients with RA.

Planning of education and intervention

It seems recommendable that these programmes should be offered to patients shortly after the diagnosis has been established. Psychoeducational, or self-management treatment interventions diminish costs of health care, since they have been found to yield reduced need for medication, less frequent visits to physicians and reduced hospital use. Effective patient education, therefore, especially for self-management practices should be an integral part of health care.

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