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Living with Rheumatoid Arthritis

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Data sources

The empirical support for the findings of this thesis is based on longitudinal and cross-sectional data originating from three samples of rheumatoid arthritis patients attending rheumatology clinics in the Eastern part of Slovakia. In this Chapter a brief description of the context of the study, patient selection and procedure is provided.

2.1 The context of the study

In the 1990s a multicentre, multi disciplinary longitudinal project EURIDISS (European Research on Incapacitating Diseases and Social Support) was launched in France, the Netherlands, Norway, Sweden, UK and four years later in Slovakia. The project had several aims among which the most important was the exploration of the role of social support when facing an incapacitating disease or, in this case rheumatoid arthritis [1]. Many studies have been published from the EURIDISS project based on longitudinal data [2-5] and the aim of this thesis is to contribute to this knowledge by providing results based on the Slovak sample of RA patients focusing on the role of personal and social resources. In addition, this thesis is also based on findings from further empirical research based on additional cross-sectional data consisting of two samples of early and established RA patients inspired by the original EURIDISS project.

2.2 Patient selection and inclusion criteria

A description of the patient selection and inclusion criteria is provided in the following paragraphs and a general overview of the basic characteristics of the samples is provided below in Table 2.1.

2.2.1 Longitudinal data

The longitudinal analyses (Chapters 3 and 4) in this thesis are based on the Slovak part of the EURIDISS (European Research on Incapacitating Diseases and Social Support) project. Four waves of data collection conducted on an annual basis were carried out during the years 1994-1998 in rheumatology clinics in Eastern Slovakia [5].

The inclusion criteria for participating in the study were: age from 20 to 70 years at the beginning of the study, RA diagnosed no more than four years prior to the beginning of the study, fulfillment of at least 4 criteria of the

American College of Rheumatology (ACR) and the willingness to sign the informed consent form. The exclusion criteria were: existence of another physical handicap prior to RA, association with another severe chronic disease (comorbidity), malignant RA, very disabling RA assessed by the IV stage of Steinbrocker's classification [1,6].

According to the above mentioned criteria 176 patients from Eastern Slovakia were found to be eligible from which 16 patients refused to participate. Thus the first wave (T1) consisted of 160 patients (90%). In the second wave (T2) 9 patients were lost and in the third wave (T3) an additional 18 patients ceased the participation. An additional 9 patients were lost in the fourth wave (T4). The overall response rate of the study was thus 77.5% with 124 patients participating at the fourth wave. The dropouts from the study and the patients participating in the fourth wave were compared to ascertain whether they differed in characteristics obtained at the beginning of the study; gender, age, disease duration in months were compared and no significant differences were found.

The data were collected in annual intervals via the administration of the same set of questionnaires during a semi-structured interview conducted by a trained interviewer lasting about ninety minutes. The medical information of the patients was retrieved from their medical files.

2.2.2 Cross-sectional data

The cross-sectional analyses (Chapters 5-7) in this thesis are based on the data collected between January 2006 and July 2010 in rheumatology clinics in Eastern Slovakia, covering the same area as the EURIDISS project. The inclusion and exclusion criteria remained the same as presented above except the restriction of age was omitted and the disease duration was specifically defined: four years or less for the early RA (same as in EURIDISS) and twelve years or more for the sample of the established RA patients.

For the established group 222 patients were identified and approached from which 157 (response rate 71%) agreed to participate. For the early patient group 143 patients were identified and approached by the research team. Out of the approached patients 112 agreed to participate in the study. One patient did not attend the interview and was excluded from the study leaving 111 participants (response rate 78%). Gender and age of the responders and non responders were compared. No significant differences were found in either of the samples.

Patients were contacted and meetings were arranged at their rheumatologists where they were informed about the project and asked to participate. Upon the agreement to participate in the project the patients underwent a clinical examination and participated in a semi-structured interview conducted by a trained interviewer lasting for approximately ninety minutes. They were also asked to fill in self report questionnaires. Additional medical information of the patients was retrieved from their medical files. After the interview the patients were debriefed about the purpose of the project.

Table 2.1 Overview of the study samples (longitudinal sample 1 is shown at the baseline)

		Sample 1 (baseline)	Sample 2	Sample 3
Design		(early; RA ≤ 4years) Longitudinal*	(early; RA ≤ 4years) Cross-sectional	(established; RA ≥ 12 years) Cross-sectional
Chapters		3, 4	5, 6, 7	5, 6, 7
Data collection	years	1994-1998	2006-2010	2006-2010
Sample size	n	160	111	157
Age	years (SD)	48.1 (12)	53.4 (12.3)	58.2 (10.6)
Gender	female	84%	76%	86%
Disease duration	years (SD)	1.8 (1.3)	2.8 (1.2)	16 (3.5)
Response rate	%	90	78	71

Note 1: *4 annual measurement intervals

2.2.3 Measures and statistical analysis

Generally measures applied in this thesis correspond with the measures of EURIDISS [1]. For the purposes of a better understanding of social and personal resources additional measures were added to the questionnaires in the cross-sectional exploration. Those include especially social participation and coping self-efficacy measures, recently constructed and validated among chronically ill populations. A detailed description of the measures and the statistical procedures used to explore the research questions are addressed in the individual chapters of this thesis.

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