Study of the Quality of Life and Social Status of Patients Suffering of Chronic Musculoskeletal Diseases Treated on Rheumatology Rehabilitation In-patient Departments

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Introduction

For all of the people with disability – independently from the origin, degree and type of their disability – the possible best reintegration should be provided in the society, promoting the personal development and carrier of the disabled persons.

The principles of the European Union and the statements of the European Council aim to improve the quality of life and the participation in the society of the disabled and their families. The backbone of the action of EU for the disabled is to provide equal possibilities regarding education carrier and work for them.

The social and economic changes in Hungary cause a heavy burden for the whole society, but certainly put even more burden onto the social groups being in worse position, threatening them with poverty and social isolation.

Hungary, as member of the European Union is obliged to prepare an annual announcement about her occupational politics and developments according to the Founding Document of the European Union Hungary submitted her first National Occupation-political Plan in 2004.

The strategy of the Hungarian Occupational Political Plan is to ascertain full occupancy, improvement of the quality of work, increase of productivity, strengthening of social cohesion.

In the Action Plan the improvement of chances of the disabled on the work market, and their return to employment was outlined as a priority.

The most common obstacle of the disableds' return to work is the lack of upthein to date occupational knowledge and skills.

The chances of employment are decreased by the low level of free environment, the negativity of employers toward employing disabled, the lack of part-time jobs, and telework. The lack of tolerance and prejudices contributes to the present situation.

The number of patients suffering from musculoskeletal diseases has been increasing in the last 20 years as a result of civilization life styles and aging of the population. Further increase can be expected especially in people of working age.

The musculoskeletal diseases not only decrease the quality of life, but also cause significant mortality, although this is rarely mirrored in mortality statistics, it mostly remains hidden.

The musculoskeletal diseases significantly decrease the health related quality of life. It can be explained by the fact, that these diseases cause visible impairment, loss of locomotor functions and visible disability hindering social participation a great deal. All these are very expensive both for the patient and the society. Pain is a very important factor of decreased function, quality of life and social participation.

Aims and research hypotheses.

Hungary firstly joined The Bone and Joint Decade 2000-2010, and its extension, The Bone and Joint Decade 2010-2020. One of the main aims of the Decade is the improvement of rehabilitation of musculoskeletal diseases.

The study of the dissertant included patients treated at rheumatology rehabilitation departments as in-patients, and analyses their demographic data, social status and disability. The status, the clinical and outcome parameters of the included patients were not analysed, these were not aimed by the study.

The dissertant decided to assess:

- the age
- gender
- occupation
- social status
- the duration of disease
- the health related quality of life
- the degree of depression of patients treated at rheumatology rehabilitation wards.

Hypotheses.

It was supposed that the parameters and data mentioned above – especially the social status of the patients - are very important factors in their medical and also social rehabilitation. It is a well-known fact that the social and psychological status, the quality of life is very important to the patients' medical and social rehabilitation, but may be successful if the disabled thrives with all of his/her mind to be integrated in the society.

The dissertant wished to know whether patients with decreased quality of life, really needing medical rehabilitation had been treated at rheumatology rehabilitation wards, or not.

The dissertant – based on her previous experiences – supposed that the patients taking part in medical rehabilitation are not fully informed about the causes of their disability, about their diseases and the legislation supporting them. The dissertant wished to assess the patients' knowledge and information of the above mentioned topics, because this makes the patients more motivated, and their medical and social rehabilitation more effective.

Being no physician, the dissertant collected only the most important medical data about the patients with the assistance of the medical teams.

The following medical data were collected: rheumatology diagnosis, diagnosis of the accompanying diseases and whether the patients had been rehabilitated in optimal time after operations characteristic of their disease.

Only cross-section study was performed, the affectivity of medical and social rehabilitation was not studied. The study was not representative because of the poor financial resources.

In spite of these weaknesses this study hopefully provides basis and initiatives for further studies.

Patients material.

The cross-sectional study included rheumatoid arthritis, osteoarthritis, osteoporosis and chronic low back patients of four Hungarian hospitals.

The four hospitals with rheumatology rehabilitation in-patient units were chosen to represent: West Hungary (Cholnoky Ferenc Hospital – Veszprém), East Hungary (Józsa András Hospital – Nyíregyháza), the National Institute of Rheumatology and Physiotherapy, Budapest and the Hungarian rehabilitation spa hospital (Szent András Spa and Rehabilitation Hospital, Hévíz).

At all of the rheumatology rehabilitation wards of the four hospitals 300 numbered questionnaires were distributed among patients rehabilitated for the four diseases chosen. The data collection was completed at the rheumatology rehabilitation ward (41 beds) of Cholnoky Ferenc Hospital, Veszprém, rheumatology rehabilitation ward (15 beds) of Józsa András Hospital, Nyíregyháza, 1st Rheumatology Rehabilitation department (70 beds) 2nd Rheumatology Rehabilitation Department (67 beds), 3rd Rheumatology Rehabilitation Departments (70 beds) of the National Institute of Rheumatology and Physiotherapy, Budapest and at the rheumatology rehabilitation wards (225 beds) of the Szent András Spaand Rehabilitation Hospital, Hévíz. 1024 patients were included in the study. In all of the four hospitals 256-256 patients were recruited. The inclusion of patients was completed between the beginning of March and the end of July in 2009; with the exception of the Józsa András Hospital Nyíregyháza, where – because of the small number of inpatients' beds (15 beds) - the inclusion of patients lasted until the end of October.

Methods.

Questionnaires have been developed by the dissertant and filled out by the patients, anonymously after they had given their written consent.

I. The social status of chronic rheumatic patients was assessed by questionnaire developed by the dissertant.

The patients were inquired about their demographic data: age, gender, address, family status, social parameters: level of education, present and previous occupations, living conditions, sources of income and per capita income of their family.

a. Social status of patients.

The questionnaire inquired about the following:

- ✤ Address
- ✤ Family status
- Housing, standards of living
- Present and previous job, occupation
- Sources of family income
- ✤ Level of education
- ✤ Per capita income in the family

b. Data about the disease of the patients

- How long you have your rheumatic disease?
- Having seen by your family doctor when were you consulted by the specialist?
- Do you have any accompanying diseases? If yes, please specify.
- Was your knee, hip or spine operated on?
- After operation when was your medical rehabilitation started?

c. Evaluation of the patients' knowledge and information level about their diseases. The questionnaire put six questions for the patients:

• Have you been fully informed how can you avoid worsening and flare up of your disease?

- Have you been fully informed about the drugs you need?
- Have you been fully informed about other treatments you need, and the regular check-ups required?
- Have you been fully informed about the physiotherapy and exercises you need?
- Have you been fully informed about dietary changes you may do?
- Have you been fully informed about the necessity and form of changing your lifestyle?

d. The patients' knowledge about help and assistance they may apply for.

Four questions were formed about this topic:

- Are you aware of the forms of assistance you may apply as a part of your citizen's rights?
- Are you aware how to apply, and the way to use the assistance?
- Are you aware of financial part of the assistance you have the right to apply for?
- Are you aware of the postoperative care and rehabilitation possibilities?

What kinds of help or assistance you need first of all?

Six questions were developed to inquire about this topic:

- ✓ Do you need help in your official administration?
- ✓ Do you need help in receiving information about prevention and healthy lifestyle?
- ✓ Do you need help in receiving medical aids for your rehabilitation?
- ✓ Do you need help getting information how can you receive financial support?
- ✓ Do you need psychological support?
- ✓ Do you need home care?

II. Measuring the Quality of Life of patients: SF-36 Questionnaire

For measuring the quality of life the generic questionnaire SF-36 was applied. The SF-36 was filled out by 863 patients of the 1024 patients originally included in the study. Using generic questionnaire the burden of different diseases are comparable. The questions of different health domains can be answered and scored with a maximum of 100 scores. The maximum score of SF-36 is also 100, meaning the ideal health status, not approached even by the healthy population. The mean values of SF-36 of the Hungarian population measured by Czimbalmos et al are between 70 and 90, with the highest mean scores in the domain of physical function (90) and the lowest in general health (70).

II. <u>Beck's scale</u>

For assessing depression of the patients the validated Hungarian version of Beck's scale was used. Beck's scale itself is not suitable for diagnosing depression, however it strongly supports this diagnosis.

Statistical analysis

The MedCalc statistical program package was applied for statistical analysis. For controlling normality the Kolmogorov-Smirnov test was used. For analysing some results F-test, t-test, Wech-test, Kruskal-Wallis test, chi-square test, Mann-Whitney test and one-tailed test was applied if required.

Results

The proportion of the 1024 patients included in the study according to the four diseases chosen is shown on Table One.

City	Osteoporosis	Low back pain	RA	OA	Altogether
Hévíz	63	91	59	43	256 (25.0%)
Nyíregyháza	87	73	69	27	256 (25.0%)
Budapest	52	54	88	62	256 (25.0%)
Veszprém	51	93	77	35	256 (25.0%)
	253	311	293	167	1024
	(24,7%)	(30,4%)	(28,6%)	(16,3%)	100.0%)

Table One

Number and percentage of patients recruited in the four chosen hospitals

Out of the patients 863 filled out all of the questionnaires. The data of these patients were worked up (Table 2).

		Age					
Disease	20-30 yrs	31-40 yrs	41-50 yrs	51-60 yrs	>60 yrs	Altogether	
OSTEOPOROSIS	4	16	30	77	84	211(24,4%)	
LOW BACK PAIN	6	17	40	94	110	267(30,9%)	
RA	0	12	35	90	102	239(27,7%	
OA	2	9	37	51	47	146(16,9%)	
Altogether	12	54	142	312	343	863	
	(1,4%)	(6,3%)	(16,5%)	(36,2%)	(39,7%)	(100.0%)	

Table Two

The age of different patient's groups.

Diagnostic distribution.

The percentage of patients with the four chosen diseases was very similar in the four hospitals. The chronic low back patients were - not surprisingly - in the highest number, followed by RA, OP and OA patients. More than 70% of patients were females, and 7,7% of all patients was in the 20-40 years age group.

Gender	Age				
	20-30 yrs	31-40 yrs	41-50 yrs	51-60 yrs	Altogether
MALE	4	25	54	108	261
					(30.2%)
FEMALE	8	29	88	204	602
					(69.8%)
Altogether	12	54	142	312	863
	(1,4%)	(6,3%)	(16,5%)	(36,2%)	(100.0%)

Table Three

Distribution of gender and age of the studied patients.

More than 60% of patients were above 60 years. In this age group occupation rehabilitation is out of question. Surprisingly only 7,7 % of patients was 20-40 years old. Certainly RA nowadays starts later, most often between 50 and 60 years, Osteoporosis and OA are diseases of the older age groups, but chronic low back pain is common also in younger age groups, also below 40 years.

How long do you suffer from rheumatic disease? Duration of disease.

Out of the 239 patients with RA 146 (60,9%) had duration of their disease shorter, than 5 years; 98 (38,9%) longer, than 5 years.

The disease duration was shorter than 5 years in 106 (72,58%), longer in 40 (27,39%) of the 146 OA patients.

The osteoporotic patients' (267) disease duration was shorter than 5 year in 72,97% (154 pts), and longer in 21,1% (57 pts).

The number of low back pain patients taking part in the study was 267 altogether. Their disease duration was one year in 51 patients (19,1%) 1-2 years in 62 (23,22%), 2-5 years in 95 (35,58%) over 5 years in 59 (22,09%).

How long after attending their family doctor were the patients consulted with the specialist?

Out of the 239 patients with RA 25 (10,4%) were consulted with the specialist within 3 months, between 3-6 month 34 (14,2%) between 6 and 9 months 48 (20,8), more than 9 months 132 (55,2%).

In the OA group within 3 months 29 patients (19,86%) between 3-6 months 35 patients (23,97%) between 6-9,months 27 patients (18,49%) longer than 9 months 55 patients (37,67%) were consulted with the specialist, altogether 146 patients.

The distribution of osteoporotic patients according to their first visit at the specialist was: 39 (18,66%) within 3 months 46 (22%) between 3-6 months 50 (23,9%) between 6 and 9 months, and 74 (35,4%) longer than 9 months after first seen by their family doctor.

Out of the 263 patients with low back pain 94 (35,74%) were seen by the specialist within 3 months, 80 (30,41%) between 3 and 6 months, 60 (22,8%) between 6-9 months, and 29 (11,02%) longer than 9 months.

Have you any accompanying diseases?

Out of the more frequently registered accompanying diseases 166 RA patients at had least one of them: 37 patients (22,2%) hypertension, 15 (9,83%) congestive heart failure, 11 (6,62%) diabetes, 12 (7,32%) depression or panic disorder, 10 (6,02%) bronchial asthma, 10 (6,02%) irritable bowel syndrome, 15 (9,03%) peptic ulcer, 46 (27,7%) osteoporosis.

115 OA patients had accompanying diseases: 32 (27,8%) hypertension, 11 (9,56%) congestive heart failure, 11 (9,56%) diabetes, 10 (8,69%) depression and/or panic disease, 10 (8,69%) bronchial asthma, 10 (8,69%) irritable bowel syndrome, 10 (8,69%) peptic ulcer, 11 (9,56%) osteoporosis.

155 osteoporosis patients reported major accompanying diseases: 43 (27,74%) had

hypertension, 25 (16,12%) congestive heart failure, 26 (16,77%) diabetes, 16 (10,21%) depression and/or panic disease, 14 (9,03%) bronchial asthma, 15 (9,67%) irritable bowel syndrome, 16 (10,32%) peptic ulcer.

Out of the low back patients 118 reported having accompanying diseases: 24 (20,33%) hypertension, 9 (7,62%) congestive heert failure, 12 (10,16%) diabetes, 18 (15,25%) depression and/or panic disease, 15 (12,71%) bronchial asthma, 13 (11,01%) irritable bowel syndrome, 15 (12,71%) peptic ulcer and 12 (10,16%) osteoporosis.

Have you had operation of your knee, hip or spine?

Out of the RA patients answered this question. The RA patients were asked only about knee operation: 32 patients (13,4%) had knee operation, 7 was rehabilitated at Hévíz, 5 at Nyíregyháza, 11 at the Natl. Inst. of Rheumatology, Budapest, and 9 at Veszprém.

The OA patients were inquired about knee and hip operations: 24 OA patients had knee operation, 6 rehabilitated at Hévíz, 2 at Nyíregyháza, 9 at the Natl. Inst. of Rheumatology, Budapest, 7 at Veszprém.

24 (11,4%) OA patients had hip joint operation: 8 patients were rehabilitated at Hévíz, 9 at Nyíregyháza, 2 at the Natl. Inst. of Rheumatology, Budapest, 5 at Veszprém.

Out of the 267 patients with low back pain 57 (21,3%) had spinal operation: 23 were rehabilitated at Hévíz, 11 at Nyíregyháza, 8 at the Natl. Inst. of Rheumatology, Budapest, 15 at Veszprém.

When did the patients receive medical rehabilitation after knee, hip and spinal operations? Out of the 32 RA patients having knee joint surgery 23 (71,8%) were admitted for rehabilitation within four weeks, 9 (28,1%) between one and two months after surgery.

24 OA patients had knee joint surgery, 19 (79,1%) within 4 weeks, 8 (36,3%) between 4 weeks and two months after operation were admitted for rehabilitation.

The 22 OA patients having hip joint surgery, 14 (63,3%) were admitted for medical rehabilitation, 8 (36,3%) between 4 weeks and two months.

24 osteoporosis patients had hip operation out of them 15 (62,5%) were admitted for medical rehabilitation, 9 (37,5%) between 4 weeks and 2 months.

57 low back pain patients underwent spinal operation. 35 (61,4%) were admitted for medical rehabilitation within 4 weeks, 17 (29,8%) between 4 weeks and two months, 5 (8,7%) between 2 and 3 months postoperatively.

Age, family and social state of the patients:

Altogether 142 patients (16,5%) were between 41-50 years of age what seems to be low. Out of them 35 had RA, 30 suffered from osteoporosis, the remaining patients had OA or low back pain. That means that the younger age group, for which occupational rehabilitation would have been most important, was underrepresented. 66% of patients lived in family 5,6% were single, 8,1% divorced living alone, 17,4% widowed, living alone.

It was advantageous that majority of patients lived in a traditional family, because their social problems could have been solved within the family due to the principle of subsidiarity.

The family income of patients was the lowest (<100.000 HUF/month) at Nyíregyháza, the highest at Hévíz. The family income of patients rehabilitated at Hévíz was significantly higher (p=0,0138) than those rehabilitated at the National Institute of Rheumatology, Budapest.

The patients rehabilitated at Nyíregyháza had a significantly lower income (p=0,0083) than the patients rehabilitated at the National Institute of Rheumatology Budapest. Between the family incomes of patients rehabilitated at Hévíz and Veszprém there was no significant difference. 13,5% of patients the income below the poverty limit.

Out of the patients 64,1% were inactive, non-occupied, 28,8% were employed 0,7% lived on maternity care, 1,1% were students.

35,8% of patients were originally heavy physical, 22,9% light physical workers. Altogether 58,7% were physical workers originally. Out of the low back pain patients 154, of the osteoporosis patients 122 were originally physical worker. The highest percentage of

originally heavy physical workers was rehabilitated at Nyíregyháza.

The education level of the patients was the following:

- less than the 8 class primary school: 2,3%
- primary school: 18,7%
- secondary school: 18,8%
- high school or university: 17,9%

The percentage of patients receiving only primary school education or less was the highest at Nyíregyháza. Out of the 861 patients 181 had no job or work qualifications. No analphabetics were found among the patients.

The accommodation of patients was satisfactory, most of them had also bathroom.

According to the location of the patients biggest numbers of village-dwellers (97) were rehabilitated at Veszprém. At Hévíz and Nyíregyháza the majority of patients were town-dwellers, while most of the patients rehabilitated at the National Institute of Rheumatology, Budapest (66) lived in the capital city of Hungary. People living at scattered farms at the countryside were most numerous (20) at Nyíregyháza. According to the data of the Hungarian National Office of Statistics the ratio of town dwellers and village dwellers is 2,27 in Hungary (17).

The quality of life of patients admitted for rehabilitation.

The highest scores of SF-36 were found in the social function domain (65) while the lowest in the domain of physical role (27). The total of SF 36 scores were 35, less than half of the Hungarian average, what mirrors a very low quality of life.

In the physical health domain Nyíregyháza had significantly smaller score (p=0,0114) than Veszprém (p<0,05)..

The physical health of osteoporosis patients was significantly lower, than that of RA and low back patients (p=0,0143, p=0,021 resp.) The domain of emotional role was scored significantly lower (p=0,0021) than that of RA patients.

According to our results more than half of the inquired patients would have had more information about their disease, treatment alternatives, prevention, and healthy life style. About the importance and availability of physiotherapy the patients had satisfactory level of information.

Four fifth (80%) of the patients required information about the possibilities of financial support. In arranging official affairs 44,9% of the patients needed help.

The highest number of patients with 60.000-100.000 HUF per capita in their families was treated at Hévíz.

Psychological support was needed by 25% of patients, what seemed to be low compared to the high level of depression and the low scores in the emotional role domain.

Regarding help in receiving supportive medical aid was asked by 34,6% of patients, showing difficulties in medical aids support. Only 11,4% of patients answered, that home care may be important for them.

	Héviz	Nyiregyháza	ORFI	Veszprém	Összesen
NORMAL	18	29	51	44	142 (16,5%)
MILD	104	103	82	83	372 (43,1%)
MODERATE	71	59	46	40	216 (25.0%)
SEVERE	24	45	27	37	133 (15.4%)
Total	217	236	206	204	863
	(25.1%)	(27.3%)	(23,9%)	(23.6%)	(100.0%)

Table Four

Distribution of patients with depression among the four hospitals.

Out of the patients 16,5% had no depression, 43,1% suffered from mild, 25% of moderate and 15,4% of severe depression. There was no difference between the patients rehabilitated at Veszprém, Nyíregyháza and the National Institute of Rheumatology, Budapest. At Hévíz was found lowest percentage of normals and also of patients suffering from severe depression, but the highest number of patients with mild and moderate depression. This might be explained by the higher age, and better financial status of the patients rehabilitated at Hévíz.

Summary of the results. New findings and their practical importance.

Conclusions drown assessing the results of social status, quality of life measured by SF 36, depression, measured by Beck scale of chronic musculoskeletal patients.

The quality of life (measured by SF 36) of patients admitted to the rheumatology rehabilitation departments of the hospitals selected for the study was only 50% of the Hungarian average.

The decrease of the quality of life was biggest in the domain of physical health, despite most of the patients suffered from depression according to the Beck scale assessment.

The patients were admitted for rehabilitation in due course, with only a few exceptions. Only 24,2% of the patients were 50 years or younger, 28,8% was working.

70% of patients were female, 58,7% of them was originally physical worker. 18,7% of the 863

patients (161 patients) had primary school education, 20 patients (2,3%) had not finished even their primary school education. 181 patients had no classifications for any jobs.

More than half of the patients questioned would have had more information about their disease, tha treatment alternatives, also about prevention and healthy lifestyle. About the financial supports to be claimed 67,4% required more information.

In official administration 36,9%, on psychological field 25%, in receiving of rehabilitation aids 35%, in home care 11,9% required help and assistance. The number of patients with family income of >100.000 HUF/month was the smallest at Nyíregyháza, the biggest at Hévíz. The family income of patients rehabilitated at Hévíz was significantly higher than of the patients rehabilitated at the Natl. Inst. of Rheumatology, Budapest (p=0,0138), but not different from the patients treated at Veszprém. The patients rehabilitated at Nyíregyháza had significantly lower family income, than that of treated at the Natl. Inst. of Rheumatology, Budapest (p=0,001)

The 13,5% of patients had income lower than the poverty limit. The most patients who had been heavy physical worker previously lived at farms, had the lowest quality of life and family income was found at Nyíregyháza.

The practical usefulness of the study.

This study first provided data about rheumatology patients admitted for rehabilitation to different types of rheumatology rehabilitation wards of different types of hospitals at different regions of Hungary; about their demographic and social data, about their disease characteristics regarding admission for rehabilitation, their quality of life, their information needs regarding healthy life style, their disease and its treatment, what kind of financial support might they claim. First was studied what kind of support these patients might require.

New findings.

The patients studied at different rheumatology rehabilitation wards really needed medical rehabilitation. The quality of life of the patients was less than half of the Hungarian average, with lowest scores in the physical health domain, despite most of the patients suffered from depression assessed by the Beck scale. The timing of the patients' medical rehabilitation was correct. The number of patients under 50 years of age (21,2%) and that of being employed (28%) was low, although the occupational rehabilitation of this age group and return to work would be most important for the society.

The patients need more information about their disease and its treatment, the healthy life style (50%), nearly 80% about the possible financial supports to be claimed. The patients may require assistance in official administrative issues (36,6%), psychological help (25%) in receiving rehabilitation aids (35,5%) and home care (11,4%).

Professional recommendations regarding information and education of rheumatology patients requiring rehabilitation is urgently needed. Such recommendations certainly improve the rehabilitation of rheumatology patients.