Original research article:

Rehabilitation needs approached by health professionals at a rheumatism hospital

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Abstract

Objective. The aim of the present study was to examine the characteristics of patients referred to OTs, PTs, and SWs at a rehabilitation unit in a hospital specialized in rheumatology, and the rehabilitation needs clinicians and patients agreed should be approached in the encounters with the particular health professional groups.

Method. Consecutive hospitalized patients at a rheumatism hospital were recruited by the health professionals. Questions about patient characteristics and rehabilitation needs were posed. Free-text responses of rehabilitation needs were coded by the International Classification of Functioning, Disability, and Health (ICF).

Results. The patients varied considerably in age distribution, disease duration, disability level, and diagnoses, and several patients had comorbidities. The rehabilitation needs classified under the component Body function fell into the chapters: Sensory functions and pain (PTs), Functions of Cardiovascular system (PTs), Neuromusculoskeletal and movement-related functions (OTs, PTs), under the Activity and Participation component: General tasks and demands (OTs), Mobility (OTs), Self care (PTs), Interpersonal interactions and relationships (SWs), Major life stress (SWs), and under Environmental Factors component: Products and technology (OTs) and Services, systems and politics (SWs).

Conclusion. The patients were fairly heterogeneous. The needs identified in the encounters with the different professional groups fell into all three components of the ICF, and there was only a minor overlap between the health professionals at the chapter level of the ICF.

Keywords

Rheumatic diseases, rehabilitation needs, occupational therapy, physiotherapy, social work

Introduction

Over the last few decades, there have been significant advances in pharmacological approaches for treating patients with rheumatic autoimmune diseases. For example, early aggressive use of disease-modifying anti-rheumatic drugs has minimized joint destruction (Gramling and O'Dell, 2012). However, several patients still experience limitations in performing daily life activities and participating in social life (Vliet Vlieland, 2003). To address such limitations, drugs are often complemented with non-pharmacological approaches like patient education, life-style modifications, therapeutic exercise, and vocational rehabilitation (Keefe et al., 2008; Vliet Vlieland, 2003; Vliet Vlieland et al., 2009). As multiple approaches can be needed in rehabilitation of rheumatic diseases, the best clinical practice is assumed to be delivered by a multidisciplinary team including physicians and health care professionals with different specialized skills and expertise (Crossland et al., 2015).

In Norway, a multidisciplinary rehabilitation approach to people with rheumatic diseases are delivered by interdisciplinary teams at hospitals specialized within rheumatology and teams at rehabilitation centers outside the hospitals which are broadly specialized within rehabilitation (Klokke et al., 2012). In addition, non-pharmacological services can be offered in the municipalities, and then mostly delivered by physiotherapists working monodisciplinary (Løchting et al., 2009). In 2009, the Interaction Act for the Health Care and Social Security System (The Norwegian Government 2009) was passed by our Parliament. An important issue underpinning this act is the effort to increase the capacity of hospitals and lower health service costs by transferring the responsibility of care and rehabilitation to the municipalities. Accordingly, health professionals in rehabilitation units at rheumatism hospitals are required to appraise their present practice and decide what should be transferred

to primary health care and what services should be offered in hospitals in the future. Informing such a process, it became valuable for us to find out what type of patients are receiving rehabilitation services from a team specialized in rheumatology, and what kind of needs the patients may have. This would give us ideas about the particular health professionals' roles within a multidisciplinary team, and what can be lost when the work of a multidisciplinary team specialized within rheumatology is replaced by monodisciplinary services in the municipalities.

Several arguments forwarded by health professionals and members of patient associations have supported specialized interdisciplinary rehabilitation at rheumatism hospitals. One is that patient problems and needs are complex and multifaceted, so they are best handled by an interdisciplinary team. Moreover, a team at a rheumatism hospital is expected to have in-depth and updated professional knowledge within rheumatology to provide the best therapies available. On the other side, critics of such practice by health economists and politicians address that such services are expensive, patients may claim specialized services even if they could be treated properly in primary health care, and rehabilitation is most efficient when delivered where the patients live. Several studies have been performed to improve our understanding of how it is like to live with rheumatic diseases from a patient perspective (Hewlett et al., 2005; Mattson et al., 2012; Mengshoel, 2008), what the patients themselves want to improve (Carr et al., 2003; Munters et al., 2014; Stamm et al., 2011), and what treatment goals they may have (Carr et al., 2003; Meerkens et al., 2013). However, we have not found any literature reporting which rehabilitation needs are approached by the different health professional groups in an interdisciplinary team specialized within rheumatology.

In a recent systematic review, the included papers showed that the three most frequently health professional groups reported to be required for a multidisciplinary approach

were physiotherapists (PTs), rheumatologists, and occupational therapists (OTs), and less frequently referenced were social workers (SWs) and psychologists (Crossland et al., 2015). PTs and OTs are educated to address a patient's physical functioning, whereas PTs, OTs and SWs may all be concerned about vocational participation. Although the education and the curriculum of these health professionals differ, the specialization within rheumatology may have lead to some or considerable overlap between these health professional groups. Our assumptions of overlap between these health professionals and a possible future scenario that specialized rehabilitation addressing physical functioning can be transferred to a non-specialized, monodisciplinary service within the municipalities, motivated us to explore what kind of needs the OTs, the PTs, and the SWs in a specialized rehabilitation unit at a rheumatism hospital tended to emphasize.

The present aim is to examine the characteristics of patients referred to OTs, PTs, and SWs at a rehabilitation unit in a hospital specialized in rheumatology, as well as the rehabilitation needs the clinicians and the patients agreed should be approached in the encounters with the particular health professional groups.

Methods

The rehabilitation context

The Hospital for Rheumatic Diseases at Lillehammer, Norway, runs a rehabilitation unit offering services for hospitalized and ambulatory patients. The services include medical diagnostics and pharmacological therapies, as well as comprehensive assessments of functioning and non-pharmacological approaches aimed at preventing future disability, and improving or maintaining physical functioning in patients with autoimmune or degenerative joint diseases. Thus, an overall aim for the health professionals is to enhance the patients' abilities to manage their disease and continue to live an independent and active life. Individual therapies are offered by different health professionals, and intensive self-management courses are run by the interdisciplinary team. At the time of the present study, the interdisciplinary team comprised rheumatologists, OTs, PTs, SWs, and nurses. The OTs, PTs, SWs and the nurses were invited to participate in the study. The OTs, PTs, and the SWs agreed, but the nurses refused the invitation as they were occupied in carrying out another project.

Design and ethics

Hospitalized patients were approached for inclusion in the present study. A survey of all hospitalized patients receiving services from OTs, PTs, and SWs was conducted during February and March 2013. All health professionals working with in-patients participated. The patients were included consecutively at the first encounter with the health professionals. All patients were informed about the study and asked about their willingness to participate and for their permission to register information about them for the study. The registered information was anonymized before handed over to the first author for data analysis. The study was

conducted in accordance with the Helsinki Declaration of Research Ethics. The Regional Committee of Research Ethics was contacted, but this study was not found to be applicable for board evaluation.

Data collection

The OTs, PTs, and SWs were given forms to fill out at their first encounter with each new patient. The questionnaire comprised standardized questions about the patient's age, sex, marital status, professional background, employment status, diagnosis, and disease duration. The health professionals had to evaluate the patients' disability level in four categories according to the ACR Classification of Functioning (Hochberg et al., 1992). In addition, three questions were answered by free texts: 1. what problem does the patient want you (each particular health professional) to address? 2. what do you consider essential to focus on to address the problem? 3. what kind of therapeutic approach do you find relevant? In the data analysis, responses to the second question were classified to find out what specific needs were considered essential by the health professionals.

Data analysis

The characteristics of patients were analyzed by descriptive statistics and given as number, percentage, mean, and standard deviation (SD). The differences in age and disease duration of patients seeking the different health professionals were analyzed by one-way ANOVA and chi-square tests. The free text responses were classified according to the WHO's International Classification of Functioning, Disability, and Health (ICF). The classification is based on a biopsychosocial model to describe human functioning in a detailed way (WHO, 2001;

Fransen et al., 2002; Heerkens et al., 2003). The classification system comprises two parts, each with two components. Part I covers Functioning and Disability and comprises the following components: 1. Body Functions and Structures and 2. Activities and Participation. Part II covers Contextual Factors and comprises the components: 1. Environmental Factors and 2. Personal Factors (which lacks a classification scheme).

According to the ICF, impairments are defined as problems related to significant deviation or loss in the Body Functions and Structures (indicated by the letters b or s), while activity limitations are difficulties an individual has in executing Activities and Participation in life situations (indicated by d). Environmental factors are external to individuals and make up the physical, social, and attitudinal environment in which people live and conduct their lives (indicated by e). Presently, coding of the text by the ICF follows the linking rules by Cieza et al. (Cieza et al., 2009). The concepts of the texts were first sorted under the components. Afterwards, the concepts were linked to the first chapter level (corresponding to the first digit), and thereafter to the second level under each chapter (corresponding to the second and third digits). An overview of the ICF classification is shown in Figure 1. The identified codes were counted and calculated as a percentage of the total number of codes given by each professional group to give an overview of the main needs being emphasized by the OTs, PTs, and SWs.

Results

Patient characteristics

During the two-month observation period, data was obtained for 81 patients from the OTs, 72 from the PTs, and 60 from the SWs; in total 213 completed questionnaires. Most patients were seen by several professionals of the interdisciplinary team, but individual patients presenting different needs for the various health professionals cannot be traced because of the anonymized data. The patients' demographic characteristics are shown in Table I. The patients of the SWs were younger than those of the OTs ($p=0.01$) and the PTs ($p=0.002$). Most of the patients were blue-collar workers, and they varied greatly in age and employment status. Table II shows a great variability among the patients with respect to disease duration, diagnoses, and disability levels. Several patients had different comorbidities, which most frequently were fibromyalgia, heart diseases, and neurological disorders. There were both newly diagnosed patients and patients with long disease duration within all age groups of patients.

Patient rehabilitation needs *(for details see Table III)*

Occupational therapists. The information given by the OTs about 81 patients was coded into 132 categories. Of those, 27% codes fell into the Body Function and Structure component, 54% into the Activity and Participation component, and 19% into the Environmental Factors component. The most frequent codes applied in the Body Function and Structure component were assigned to Chapter 7: Neuromusculoskeletal and Movement-Related Functions within the category Muscle Functions (b730). The most frequent codes within the Activity and Participation component fell into Chapter 2: General Tasks and Demands, and its categories:

Carrying Out Daily Routines (d230), as well as Chapter 4: Mobility, Fine Hand Use (d440). In the Environmental Factors component, all codes fell into Chapter 4: Products and Technology, under the category of Products and Technology for Personal Use in Daily Living (e115).

Physiotherapists. From the 72 records developed by the PTs, the texts were coded into 154 categories, whereas 74% of the codes fell into the component of Body Functions and Structure, and 25% fell into the Activity and Participation component. The most frequent codes under the component of Body Functions and Structure were classified under Chapter 7, all of which were under the Functions of Joints and Bones category (b710) and the Muscle Functions category (b730, b735, b740), along with Chapter 2: Sensory Functions and Pain, all under the Pain category (b280). Within Activity and Participation, codes most frequently fell into Chapter 5: Self-Care under the category Looking After One's Health (d570).

Social workers. The information given from the first encounters of 60 patients with the SWs was coded into 74 codes. No codes fell into the Body Function and Structure component, 58% of the codes fell into the Activity and Participation component, and 42% of the codes fell into the Environmental Factors component. Most frequently, the codes under the Activity and Participation component fell under Chapter 8: Major Life Areas, and of those, mostly coded under Acquiring, Keeping, and Terminating a Job (d845) and under Chapter 7 Interpersonal interactions and relationships, all under the code Family Relationships (d760). Under Environmental Factors, the codes most frequently fell into Chapter 5: Services, Systems, and Politics, all under the category of Social Security Services, Systems, and Politics (e570).

Discussion

There was a great variety in patients' age, disease duration, and disability level, and they had various rheumatic diseases, often with comorbidities. The rehabilitation needs were classified within all three components of the ICF, but within quite definite chapters. Mostly, the professional groups differed in their focus on patient needs classified at the Chapter level of the ICF.

Rheumatic autoimmune diseases may have various impacts on patient functioning related to diagnoses, disease duration, and disability levels, but these are also related to personal characteristics like age, sex, education levels, and employment status. The patients referred to the rehabilitation unit specialized in rheumatology varied considerably in all these variables. Several patients had relatively rare rheumatic diseases, such as different connective tissue diseases. The patients could also be newly diagnosed, and presumably they had other concerns and needs than those having lived with a chronic, progressive disease for years. These newly diagnosed patients were distributed in the whole spectrum of age range, which also implied that to get a chronic disease might have different impact on their lives. For example from a patient perspective to get a diagnosis in adolescence will raise different concerns than when they reach old age. They are in different life situations with different expectancies for their functioning at the present and for their anticipated future. The disability level among the patients who had had diagnoses for years also differed greatly with respect to disability levels of the ACR classification, signifying that they also had different prerequisites for functioning that required to be met in different ways. Overall, these factors indicate that the health professionals presently met a great variety of patients with various needs and prerequisites for improving their functioning. Accordingly, it is likely that the health professionals had to take this variety into consideration and adapt their approaches to meet it.

The needs emphasized by the OTs, PTs, and SWs covered all components of the ICF classification scheme. Looking across the health professional groups, the most prominent concerns met were pain, joint and muscle function, self-care in carrying out daily routines and health promotion, as well as work-related issues. This fits well with what is emphasized in international meetings of allied health professionals, for example themes covered in the EULAR conference meetings. All health professional groups emphasized needs that were coded under the Activity and Participation component, while both the OTs and the PTs had codes under the component of Body function, and the OTs and the SWs had codes classified under the Environmental Factors. However, when looking into the categories at the chapter and the second category level of the classification, there was surprisingly little overlap. Some particular chapters and categories covered most classified needs, showing an explicit similarity within the particular health professional group, as well as clear distinctions between the groups. The OTs focused on carrying out daily routines, fine hand use, and muscle power. The PTs targeted pain, joint mobility, muscle power, exercise tolerance, and looking after one's health which is in line with what is reported by a Dutch survey of physiotherapists' management (Hurkmans et al., 2012). The SWs focused on family relationships, acquiring, keeping or terminating a job, and social security services, systems, and politics. The only overlap discovered was actually the category muscle power that was addressed by both the OTs and PTs. Thus, the analysis at both the chapter and category level revealed that there were rather distinctive similarities within the particular health professional groups, as well as clear diversities between the groups. Accordingly, the health professionals seem to maintain a clear professional mandate within the interdisciplinary team. According to Constrand and MacDermid (2014), the ICF may clarify this and support the communication between different professions. For example, Dalen et al. (2013) developed a tailored core set for goal setting based on their ICF analysis, which they argue will facilitate collaboration between

team members. Thus, it is likely that our findings can be applied to develop a shared language within the particular health professional groups that promotes communication and clarify professionals' roles and efforts within an interdisciplinary rehabilitation team.

The reason for conducting this study was also to obtain information for the discussion on the future organization of rehabilitation services within rheumatology. Our findings illuminate that the hospitalized patients at the rheumatological rehabilitation unit are heterogeneous in personal and social characteristics, diagnoses, as well as in functioning and rehabilitation needs. It is easy to conclude that such heterogeneity can best be met by an interdisciplinary team with in-depth and broad knowledge within rheumatology. However, it is not necessarily that simple. The findings can also be considered as possibly portraying the complexity of the present rehabilitation unit's practice and what is valued there rather than expressing the importance that these needs have to be met by future health services. This means that in deciding the future organization of rehabilitation for patients with rheumatic diseases, discussion is needed about which individuals and needs should be given priority, at which organizational level should services be delivered, and how they should best be organized. For example, the PTs in a monodisciplinary rehabilitation context in primary health care probably to some extent may cover what the PTs do in an interdisciplinary rehabilitation team, and thus, the needs addressed by the OTs and SWs will be unmet. Hence, the findings of this study invite a debate about what rehabilitation needs should be prioritized and addressed by health services in the future.

Prior studies have been performed to provide suggestions for developing future instruments in rheumatology by examining how instruments frequently applied within the field cover relevant aspects of functioning in the ICF (Munters et al, 2014; Stamm et al., 2004). For example, Stamm et al. (2004) reported that present instruments covered a great variety regarding aspects of functioning, but the instruments also missed essential aspects. For

the purpose of obtaining a broad overview of patients' functioning, this is certainly a relevant issue. In contrast, if the aim is to document or evaluate the specific health professional groups' practice, our findings suggest that instruments tailored to specific aspects could be appropriate, for example to survey challenges within family and job and evaluate the efficiency of the SWs' work to deal with the challenges. An important question for qualitative studies could be what kind of barriers is hindering the SWs in their work to support a patient's efforts to continue working.

The use of the ICF classification tool was found to be both appropriate and valuable for classifying the free text data of our study. Of course, this analysis would have been easier for the researcher if the clinicians had interpreted and decided themselves which codes of the ICF were most suitable. Presently, the coding was not a problem at the component and chapter levels, but in accord with prior studies, there could sometimes be challenges in deciding which codes are appropriate at the second level (Heiberg et al., 2013). The codes were then discussed with others who are familiar with the classification tool, and a consensus was reached regarding which particular code to which the texts could best be linked. Nevertheless, in spite of some uncertainty with some coding at the second levels, we consider the validity of our results to be robust. Another question is whether our findings can be generalized to other interdisciplinary rehabilitation units. Importantly, referral practices to rehabilitation units may vary between countries and even within Norway. Nevertheless, our patient sample seems to be much in line with patients participating in surveys of specialized rehabilitation units in Norway (Klokkeud et al., 2012) and in other countries (Meerkens et al., 2013; Verhoef et al., 2007; Sinclair et al., 2009). The professionals who participated in the present study are active in sharing their knowledge with colleagues in Norway, attending conferences abroad, and reading international literature, which may shape their practices and what they focus on. Accordingly, it is reasonable to believe that our study also mirrors what

OTs, PTs, and SWs are likely to emphasize in an interdisciplinary rehabilitation context specialized in rheumatology elsewhere.

In conclusion, the patients seen by OTs, PTs, and SWs were rather heterogeneous with respect to personal characteristics, diagnoses, and disability levels. The needs identified by the health professionals covered all components of the ICF. Most prominent were concerns about pain, joint and muscle function, self-care in terms of carrying out daily routines, health promoting activities, and work-related issues. There were great similarities within the particular health professional groups, as well as distinctive differences between the groups.

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Table 1. Demographic characteristics of patients seeing occupational therapists (OTs), physiotherapists (PTs) and social workers (SWs) in a rehabilitation unit at a rheumatism hospital.

Demographic characteristics	Seeing OTs n= 81	Seeing PTs n=72	Seeing SWs n=60
Mean age (min-max)	60 (20-89)	62 (34-89)	54 (20-88)*
Females in %	61	60	62
Living alone in %	26	21	12
No white/blue collar professionals in %	19/72	26/69	27/73
Whole/parttime employed without compensation in %	12	7	9
Whole/part-time sick-leave in %	24	15	45
Rehabilitation compensation in %	5	5	14
Disability pension in %	27	35	15
Age pensioners in %	32	38	17

* $p \leq 0.01$

Table 2. Disease characteristics of patients seeing occupational therapists (OTs), physiotherapists (PTs) and social workers (SWs) in a rehabilitation unit at a rheumatism hospital.

Disease characteristics	Seeing OTs n= 81	Seeing PTs n=72	Seeing SWs n=60
Disease duration in years mean (min-max)	11 (0-54)	14 (0-48)	13 (0-47)
Rheumatic disease categories			
• Spondyloarthropathies	35%	44%	52%
• Rheumatoid arthritis	43%	41%	33%
• Connctive tissue diseases	5%	7%	5%
• Degenerative diseases	2%	3%	0%
• Fibromyalgia/myalgia	0%	3%	0%
• No explicit diagnosis	14%	2%	10%
Disability level¹			
No problems in performing physical functioning	15%	10%	15%
No problems in performing personal care and work, but restricted leisure activities	20%	29%	10%
No problems in performing personal care, but restricted in work and leisure activities	35%	49%	68%
Limited in performing personal care, work and leisure activities	30%	12%	7%

¹Assessed by the ACR Classification of Functioning

Table 3. Rehabilitation needs identified by occupational therapists (OTs), physiotherapists (PTs) and social workers (SWs) reported when occurring $\geq 10\%$ of the total numbers.

	Needs identified by OTs n (% of 132)	Needs identified by PTs n (% of 154)	Needs identified by SWs n (% of 74)
BODY FUNCTION			
Chapter 2 Sensory functions and pain b280 Pain		28 (19)	
Chapter 4.Functions of cardiovascular etc b455 Exercise tolerance functions		22 (14)	
Chapter 7 Neuromusculoskeletal and movement-related functions b710 Mobility of joint functions b730 Muscle power functions	28 (21)	21 (14) 30 (20)	
ACTIVITY AND PARTICIPATION			
Chapter 2 General tasks and demands d230 Carrying out daily routine	27 (21)		
Chapter 4 Mobility d440 Find hand use	16 (12)		
Chapter 5. Self care d570 Looking after one's health		23 (15)	
Chapter 7. Interpersonal interactions and relationships d760 Family relationships			7 (10)
Chapter 8 Major life areas d845 Acquiring, keeping and terminating a job			27 (37)
ENVIRONMENTAL FACTORS			
Chapter 1 Products and technology e115 Products and technology for personal use in daily living	25 (19)		
Chapter 5 Services, systems and politics e570 Social security services, systems and politics			22 (30)

Fig. 1. An overview of the ICF classification applied in the present analysis