Vocational rehabilitation of patients with prolonged fatigue

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Citation for published version (APA):

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Chapter 1

General Introduction
We all feel tired at times, usually after physical activity, mental exertion or when feeling ill. In most people, feelings of fatigue abate after a change in task or a period of rest. However, 10-20% of the general population suffers from severe fatigue that persists and does not abate after rest. In the Dutch working population, the prevalence of prolonged fatigue is estimated to be 22%. Fatigue is a prominent symptom in chronic diseases like rheumatoid arthritis, cancer, and depression. Fatigue itself can also be a discrete disorder (i.e., chronic fatigue syndrome (CFS)) or can occur as a common health problem that is not related to a specific chronic disease or disorder. In fact, fatigue that becomes prolonged can cause considerable suffering. Not only does prolonged fatigue affect personal well-being, but it also has negative impact on individual, social, and occupational functioning. For example, fatigued patients might experience problems performing domestic activities, have limited social contacts, and face difficulties meeting mental, physical, and psychosocial demands at work. These functional impairments may become serious enough that workers call in sick. Therefore, apart from the physical and mental impairments it causes, fatigue can have negative consequences concerning one’s ability to optimally perform at work and result in sickness absence.

Sickness absence and work disability constitute a great problem in Western society. In the Netherlands, 30% of sick-listed workers are on sick leave due to mental health problems, which include prolonged fatigue as a major symptom. Moreover, mental health complaints accounted for almost 38% of permanent work disability claims in the Netherlands in 2006. More specific to the topic of this thesis, fatigue has been associated with sickness absence, ranging from more than one month to permanent work disability. Recently, Sabes-Figuera and colleagues found that prolonged fatigue is associated with high economic costs in Great Britain (£3878 per six months). Productivity loss due to absence from work and the care from family members or friends (i.e., informal care), were the main contributors to these costs. Sick leave and work disability are not only an economic burden due to productivity loss, health care, and disability pension costs, but they can also negatively affect one’s quality of life. Therefore, options for improving work participation and preventing work disability in patients with prolonged fatigue should be further explored and evaluated.

For the purpose of this thesis, fatigue is considered as a continuum of complaints ranging from mild complaints of tiredness to severe, disabling fatigue that is neither
task-specific nor easily reversible (e.g., CFS). At any point on this continuum, fatigue can occur as a symptom of a known or unknown disease. When fatigue complaints are sustained for a long period of time and are minimally abated with rest, the condition is referred to as prolonged fatigue. The study population in this thesis comprises patients with self-reported prolonged fatigue as a main or important symptom that causes functional impairments. The latter concept encompasses constraints in everyday life that cause role functioning limitations and participation restrictions.

**Prolonged fatigue, participation problems and perpetuating factors**

The origin of fatigue complaints remains elusive, even after decades of research. In many cases of fatigue complaints, there is limited evidence for underlying disease or permanent damage, and the pathophysiology remains unclear. However, it is questionable if knowledge of the exact cause of this condition (predisposing and precipitating factors) is necessary to provide effective care aiming to improve daily life functioning and participation. Health care is traditionally based on the medical model of disease: recognise patterns of symptoms, apply therapy to the underlying pathology, and expect the patient to recover. This medical model was originally developed for medical conditions with a clear-cut pathology and still functions well for these conditions. The model also assumes that work disability is a consequence of disease. However in more complex conditions, especially with long-lasting health problems, the traditional medical model is insufficient to explain underlying causes and to plan treatment that influences work participation. A biopsychosocial model is more useful than the traditional medical model in complex situations, like that of prolonged fatigue. The biopsychosocial model states that health and sickness result from complex interactions between biological, psychological, and social factors. In prolonged fatigue, several biological, psychological, and social mechanisms are known to be associated with the development and persistence of fatigue complaints and disability. From a (neuro)biological point of view, prolonged exposure to stress and the inability to terminate stress responses, with associated fatigue, may lead to an overuse and damage of physiological stress systems. Relationships between the dysregulation of stress systems (i.e., autonomic nervous system) and the hypothalamic-pituitary-adrenal (HPA) axis hypofunction in cases of prolonged fatigue complaints have been reported. In addition, cognitive and behavioural factors (e.g., causal attribution, low self-efficacy, dysfunctional beliefs about activity and
fatigue) are also believed to be involved in the persistence of fatigue complaints.\textsuperscript{31-33} Furthermore, a lack of social support can be a perpetuating factor in fatigued patients\textsuperscript{34}, and psychosocial factors, like attitudes towards work, can play roles in function limitations and long-term sick leave.

In conclusion, although predisposing factors (e.g., family-genetic, early trauma) and precipitating factors (e.g., physical or psychological stressors) are involved in the development and triggering of fatigue, perpetuating factors may reinforce and maintain fatigue symptoms and disability (often via vicious circles), even after the original factors causing fatigue have been terminated.

\textbf{Vocational rehabilitation in patients with prolonged fatigue}

The previous section suggests that perpetuating factors involved in fatigue complaints and participation restrictions are important to the design and content of an appropriate intervention for these patients.\textsuperscript{35} To stimulate effective, functional recovery in fatigued patients, treatments should consider individual, perpetuating factors.\textsuperscript{36,37} As Waddel & Burton\textsuperscript{38} stated, “biopsychosocial problems need biopsychosocial solutions.” In medical rehabilitation, this approach is well-known and is used for both somatic and mental disorders.\textsuperscript{39-41} However, one limitation of these rehabilitation programmes is the lack of focus on work participation. Another limitation is the lack of accessibility for impaired workers that have disorders that cannot be unambiguously diagnosed.

Vocational rehabilitation (VR) is an approach that does focus on work participation and aims to facilitate return-to-work (RTW) and work retention in addition to preventing work disability.\textsuperscript{42,43} Due to diverse legislations, differences exist in the organisation of VR in numerous countries. In the Netherlands, employers are obliged to continue paying the salary of their sick-listed workers during the first two years of sickness absence or temporary work disability. During these two years, both the employer and worker are obliged to cooperate in the VR process of the sick-listed worker. An occupational physician (OP) is involved in this process, providing general occupational health care to workers and advice to employers. Specifically, the physician provides an assessment of ability to work, social-medical guidance, recommendations for adjusting working conditions and specialised treatment.\textsuperscript{44} Therefore, in addition to influencing work participation, the OP has the potential to
identify a worker who is at-risk for sick leave or for developing functional impairments.\textsuperscript{45}

Also as a part of this social system, Dutch VR treatments are offered to impaired workers and those who are on sick leave.\textsuperscript{46} These treatments are designed by outpatient institutions and are conducted by experienced trainers and caregivers from different disciplines. VR treatments aim to improve physical, mental, and occupational functioning; they consist of several components like physical training, mental coaching, behavioural treatment, and work-directed intervention. Although these multi-component VR treatments are provided in the Netherlands, the number and specific content of these treatments are unknown. Moreover, there is a lack of evidence of the effects of these practiced treatments, especially as it relates to work participation. A better understanding of the content, underlying concepts and outcomes of VR treatment may contribute to a better understanding of the working mechanisms of the treatment and may lead to the development of more effective treatments.

**Evaluating VR treatments**

In Figure 1, a conceptual model describes the process and aims of multi-component VR treatment in patients with prolonged fatigue with work participation problems. This model is used in this thesis to evaluate existing VR treatments. It indicates, as mentioned above, that biological, psychological, and social factors can be involved in the perpetuating character of prolonged fatigue complaints and disability. Factors like somatic attribution, physical deconditioning, and psychosocial factors at work, can negatively affect patients’ beliefs and perceptions about the condition and subsequently affect their behaviour. These mechanisms reinforce each other and the fatigue symptoms, leading to the preservation of complaints and its related disability. To improve daily life functioning and work participation, intervening on those factors that hinder recovery in an individual should be part of VR treatment. In addition, by using a combination of intervening mechanisms at different levels like influencing physiological stress systems, changing dysfunctional beliefs and improve adequate coping strategies in daily life and at work, we expect to influence those factors that obstruct recovery. This will allow patients to change their attitude and behaviour involving their daily and working life in a favourable direction. Moreover, we expect this multi-component strategy to break the vicious circle of sustained complaints and
participation restrictions (see dotted line in Figure 1), leading to improved daily life functioning, work participation and less fatigue complaints (see black arrow in Figure 1).

From the model, we hypothesise that multi-component VR treatment is an effective strategy for treating patients with prolonged fatigue complaints with participation problems. It is assumed that multi-component treatment will increase mental and physical functioning, improve work ability and work participation, and decrease fatigue complaints by intervening on individual factors that obstruct recovery using a biopsychosocial perspective. This hypothesis is tested by evaluating existing VR treatments.

![Figure 1. Model of multi-component vocational rehabilitation for prolonged fatigue](image-url)
When evaluating existing treatments, special attention is needed with respect to the research design. In cases of complex health interventions with a long causal pathway from intervention to outcome, it is difficult to conduct research in tightly controlled circumstances. Thus, organizing a randomised controlled trial (RCT) may easily fail.47,48 More suitable for evaluating multi-component treatments in real-life settings are studies with a pre/post-test design, using practice-based research.49 This type of research includes assessments of patients treated in routine practice and addresses individual problems in a real-life setting, thus giving the research high external validity.50-52 Staying as close as possible to the real-life situation, and monitoring the process during and after the treatment will increase internal validity as well. In this thesis, practice-based research is used to investigate the content and the short- and long-term effects of existing VR treatment in the Netherlands.

Treatments like multi-component VR treatments regard patients as active partners who are involved in treatment decision making. To be successful, these treatments require active collaboration of the patient, and the treatment prescribed must match the patients’ needs.53 In addition, patients should not be considered as an object of treatment but should instead play a key role in their treatment. In practice and clinical research, this approach is receiving growing attention. Conducting research from a patient’s perspective can provide a better understanding of the problems that patients actually face, including their health-related needs and what they gain from treatments. Such knowledge has the potential to improve the quality of VR care and better meet patients’ needs. Therefore, patients’ perspectives are also included in this thesis.

Thesis objectives and research questions

The main objective of this thesis is to generate knowledge about the role that existing VR treatments play with respect to daily life functioning and work participation of patients with prolonged fatigue complaints. The research questions of this thesis are as follows:

1) Which VR treatments are practiced in the Netherlands, and what is their content?
2) Can VR treatments improve daily functioning and work participation of patients with prolonged fatigue on the short- and the long-term?
3) What are fatigued patients’ perspectives regarding work experiences before and after receiving VR treatment?
Thesis outline
The study presented in Chapter 2 offers an inventory of the VR treatments available in the Netherlands for workers with prolonged fatigue complaints (research question 1). The content of existing VR treatments is the focus of this chapter. The following chapters address an evaluation of existing VR treatment programmes for patients with prolonged fatigue complaints (research question 2). Chapter 3 first explores the changes in physiological parameters and fatigue complaints after a six-week physical training programme. In Chapter 4, the outcomes of an outpatient, multidisciplinary treatment programme were studied using retrospective data on fatigue, daily life functioning and work participation. Chapter 5 elaborates on Chapters 2 and 3 and presents a longitudinal study in which the process and outcomes of three existing outpatient VR treatments were evaluated. This study describes the content and process of those treatments (research question 1), including information about patient recruitment, content completeness and patient satisfaction. Furthermore, the short-term outcomes at three months after treatment are explored as they relate to fatigue complaints, work participation, work ability, daily life functioning, and heart rate variability. Chapter 6 focuses on patients’ perspectives. Using a qualitative survey, work-related limitations that workers experienced before attending VR treatment and their RTW experiences after VR treatment are explored (research question 3). In Chapter 7, practice-based research of long-term outcomes after VR treatment is presented. Patients from the study presented in Chapter 5 were followed for 18 months after completing VR treatment. In this study, results from the three institutions were combined and outcomes on fatigue complaints, work participation, work ability, daily life functioning, and heart rate variability are presented. Finally, in Chapter 8, the main research findings of this thesis are summarised and discussed, and this is followed by a discussion of recommendations for research and its practical implications.

References