

Workplace problems and solutions for employees with chronic diseases

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Background	While many employees who have a chronic disease manage their jobs well, others are hampered in work performance, experience work-related problems and are at risk for job loss.
Aims	To identify the practical and psychosocial barriers recognized by employees with chronic disease who experience work-related problems and to examine preferred work accommodations.
Methods	A questionnaire was sent by mail and completed by current workers who have a chronic disease and experience serious problems at work.
Results	One hundred and twenty-two employees participated in this study. On average, they had been ill for 10 years and 44% had more than one disease. The most outstanding work-related problems were psychosocial, including work-home interference and a lack of acceptance of the chronic disease. Performing and finishing work tasks and social relationships with supervisors or colleagues were also felt to be slightly problematic. The most preferred work accommodations included fewer work hours, working from home, a slower work pace and more autonomy in planning work tasks. Almost three-quarters of the respondents were so fatigued that they were at risk of sickness absence or work disability.
Conclusions	A chronic physical disease may lead to both practical and psychosocial problems and serious fatigue. Managing psychosocial problems may decrease fatigue.
Key words	Chronic disease; fatigue; job satisfaction; occupational health; psychological distress; work-related problems.

Introduction

Chronic diseases are becoming more prevalent within the aging labour force of industrialized countries and new measures are needed to prevent work disability. Thirty-seven per cent of Dutch employees have a long-standing disease or handicap. While more than half of them state that they are not hampered in work performance, 41% are slightly hampered and 8% are severely hampered [1]. Employees with a chronic disease are more fatigued on average than healthy employees [2]. This may be troublesome in itself and is also a predictor of work disability [3]. Lerner *et al.* [4] studied a large sample of US employees who had a variety of chronic conditions. Depending on the condition, they found that 22–49% of the employees experienced difficulty in meeting physical work demands and 27–58% experienced difficulty in meeting psychosocial work demands.

Studies have found that physical limitations, physical work tasks, a higher age and a lower educational level are

predictors of work disability [5,6]. Recent studies pay special attention to the employees' perspectives on their employment situation. Support from and understanding of colleagues and line managers are found to be important to job retention [7–9]. A lack of family support for employment [10], demanding working conditions and interpersonal difficulties [11] are problematic. Psychological factors include a reluctance to disclose health information, a fear that others may see one as unfairly favoured [11], an inability to cope with the illness [7], an inability to set limits, a negative self-image and feelings of hopelessness related to employability [12]. Most of these studies are small, qualitative studies. They are relevant because they point to modifiable factors and identify possible interventions that may remove barriers and reduce the chance of job loss. Training employees to solve work-related problems and educating colleagues and line managers about disability and workplace accommodations may prevent unnecessary job loss.

We studied a group of current employees who had a variety of chronic physical conditions, experienced serious

work-related problems and feared either job loss or loss of job satisfaction. These employees were motivated to complete empowerment training. We investigated the following questions:

- What particular aspects of working life do these employees experience as problematic?
- What work accommodations do these workers prefer?
- How do their fatigue, burnout and perceived quality of work scores compare with those of other employees?

Methods

This study is part of a larger research project that includes a randomized controlled trial (RCT) evaluating the effectiveness of an intervention aimed at job retention [13]. The experiences of the participants in this RCT (both the experimental and the control groups) are discussed here.

We offered a group-training programme to help individuals solve problems they experienced at work due to their chronic conditions. Participants were recruited via outpatient clinics, occupational health services, patient organizations, employers and a yearly national conference on chronic disease. Participants were eligible for the study if they had a chronic physical medical condition, had a paid job, experienced problems at work and feared the loss of their job or job satisfaction. Workers were excluded if they were on long-term 100% sick leave that was expected to last for several months.

All participants received a baseline mail questionnaire about their health, employment situation, work accommodations, work performance, work-related problems and perceived quality of work.

Work-related problems were measured by examining eight areas: problems with specific work tasks, finishing work, arranging the workplace and equipment, commuting, communicating with colleagues, communicating with the supervisor or line manager, acceptance of the chronic disease and balancing work and life at home.

Work accommodations were measured with work accommodations list of Kremer *et al.* [14].

Fatigue was measured with the Checklist Individual Strength, a validated questionnaire for the working population [15]. A score of ≥ 76 is considered as a level of fatigue that puts the individual at risk for sick leave or work disability [16].

Burnout was measured with the Utrecht Burnout Scale [17].

Quality of life was measured with the SF-12.

Nine subscales of the Dutch Questionnaire on Perception and Judgement of Work [18] measured physical or mental task burdens, work pace, job autonomy, job satisfaction, social relationships with colleagues or supervisors, worry about work and uncertainty about the future.

Descriptive statistics such as frequencies, percentages, means and standard deviations were used to describe the study population and in order to answer the first two research questions. *T*-tests were used to compare differences of means of the study population with those of the Dutch working population.

The Medical Ethics Committee of the Academic Medical Centre in Amsterdam approved the study design and deemed ethical review unnecessary due to the non-medical nature of the research. All participants signed informed consent documents.

Results

Data of the 122 study participants were collected between September 2006 and February 2008. About two-thirds had musculoskeletal, nervous or digestive disorders; 44% had more than one chronic disease. The mean disease duration was 10 years (Table 1).

The mean age of the respondents was 46 years and most were women living with a family. Lower educational levels and persons working outside of service areas were underrepresented (Table 2). Almost all of the participants felt either slightly or severely hindered at work due to health problems. Physical or mental work capacity was bad or very bad only for a minority. Colleagues and supervisors were almost always aware that the employee had a chronic disease (Table 3).

Table 1. Chronic disease^a and other health characteristics of the study population ($n = 122$)

	<i>n</i> (%)
Diseases of the musculoskeletal system and connective tissue ^b	30 (25)
Diseases of the nervous system ^c	28 (23)
Diseases of the digestive system ^d	25 (21)
Endocrine, nutritional and metabolic diseases ^e	10 (8)
Neoplasms	6 (5)
Diseases of the respiratory system	5 (4)
Diseases of the circulatory system ^f	4 (3)
Other diseases ^g	14 (12)
One or more additional chronic disease	54 (44)
Disease duration in years, mean (SD)	10.2 (9.5)

^aICD, International Classification of Diseases.

^bIncluding rheumatoid arthritis 12×, fibromyalgia or other chronic pain 5×, systemic lupus erythematosus 4×, arthrosis 3× and Sjögren's disease 2×.

^cIncluding multiple sclerosis 13× and Parkinson's disease 9×.

^dIncluding Crohn's disease or *Colitis ulcerosa* 24×.

^eIncluding diabetes 5×, Graves' disease and other thyroid gland disorders 4×.

^fAll heart conditions (4×).

^gIncluding human immunodeficiency virus 3×, renal failure 2×, visual impairments 2× and other diseases 7×.

Table 2. Personal and work characteristics of the study population ($n = 122$)

	Mean (SD) or n (%)
Age	45.6 (8.7)
Women (%)	91 (75)
Living alone (no partner, children or parents) (%)	34 (28)
Education (%)	
Lower	4 (3)
Middle	52 (43)
Higher	66 (54)
Branch of industry (%)	
Agriculture and fishing	0 (0)
Industry and building industry	2 (2)
Commercial services	49 (40)
Non-commercial services	70 (58)
Temporary appointment (%)	12 (10)
Appointment	
Hours per week	30.9 (8.1)
Days per week	4.3 (0.8)

Work-related problems are presented in Table 4 and arranged from the lowest to the highest frequency of occurrence. The arrangement of the workplace or equipment was the least-reported issue. Commuting and contact with the supervisor or with colleagues was more often problematic, as was performing and finishing work tasks. The great majority (85%) of the respondents found it difficult to accept having a chronic disease. Finding a balance between work and life at home, i.e. work-home interference posed a problem for 90% of the participants and was a severe problem for more than half of them.

Table 5 presents the percentages of respondents who did or did not prefer each of 17 different work accommodations and the percentage who already received these accommodations. The large majority of respondents (84%) had experience with one or more accommodations; the average was 3.2 accommodations. The most common accommodations were the possibility of planning work oneself, alternative or fewer working hours, dropping tasks, a slower work pace, assistance from others and working at home. One out of every five respondents had a special desk or chair to accommodate their needs. Nearly a fifth had other aids at their disposal, often computer-related aids such as an ergonomic mouse, a special keyboard, speech recognition software and a headset telephone. Ninety per cent of the respondents stated that they preferred (more) work accommodations. Working fewer hours and working from home were preferred accommodations, as well as a slower work pace, control over the planning of tasks, alternative working hours, fewer tasks, extra training, assistance from others and a better workplace climate.

The study participants scored high on fatigue complaints, compared to Dutch employee reference figures;

Table 3. Work performance characteristics ($n = 122$)

	n (%)
On disability compensation (partially or 100%)	30 (25)
Sickness absence, no. of days in last 4 months, mean (SD)	17.0 (22.1)
Hindered at work due to health problems	
No	5 (4)
Yes, slightly	74 (61)
Yes, severely	42 (35)
Work capacity, physical	
(Very) bad	22 (18)
Moderate	62 (51)
(Very) good	38 (31)
Work capacity, mental	
(Very) bad	20 (16)
Moderate	53 (43)
(Very) good	49 (40)
Contact with occupational physician in last 4 months	55 (45)
Frequency in last 4 months, if yes, mean (SD)	3.1 (2.1)
Disclosure towards colleagues	113 (93)
Disclosure towards supervisor	117 (96)

73% had a score higher than the cut-off point of 76, which identifies them as at risk for sickness absence or work disability [16]. Individuals with one chronic disease had a mean fatigue score of 85.2 [standard deviation (SD) 22.8], whereas those with two or more diseases had an average fatigue score of 93.2 (SD 19.4). The burnout exhaustion and burnout distance subscales were significantly higher than in reference populations. According to the guidelines of Schaufeli [17], the burnout exhaustion and burnout distance scales showed that 78 and 34% of the study population, respectively, were burned out. The study participants had unfavourable scores on several scales measuring quality of work, compared to reference figures (Table 6).

Discussion

In our study, three-quarters of employees with chronic physical disorders were so fatigued that they were at risk for sickness absence or work disability. While practical arrangements at the workplace like desk and chair accommodations or computer aids were seldom an issue, the study participants more frequently identified problems with colleagues or supervisors. The largest issues were acceptance of the chronic disease and balancing work and life at home. The majority of participants preferred further work accommodations, particularly organizational accommodations like the ability to work at home, work fewer hours, work at a slower pace, receive extra training or have more autonomy in work planning.

The strengths of this study were that it examined a group of employees with various severe chronic diseases who had difficulties remaining at work and that we paid

Table 4. Work-related problems ($n = 122$)

Due to my disease, I experience problems with	No (%)	Yes, slightly (%)	Yes, severely (%)
Arrangement of workplace (equipment)	71	22	7
Commuting	61	23	16
Contact with supervisor or line manager	52	34	14
Contact with colleagues	53	41	7
Finishing my tasks	34	48	19
Performing work tasks	16	69	16
Acceptance of having a disease	15	39	46
Finding a balance between work and life at home	10	38	52

Table 5. Work accommodations, realized and/or preferred^a ($n = 122$)

Work accommodations	Realized . . . ,		Not realized . . . ,	
	and content (%)	preferred more (%)	but preferred (%)	not preferred (%)
Working less hours	26	13	29	32
Other working hours	29	11	20	39
Adjusted breaks arrangement	6	1	18	75
Lower work pace	16	6	28	50
Help of others	16	6	20	59
Dropping work tasks	24	7	22	47
Other work tasks	11	7	8	74
Possibility to plan tasks oneself	34	14	20	31
Acquisition of aids	17	2	12	69
Accommodated desk or chair	16	4	13	67
Utensils/equipment	2	0	7	91
Working at home	15	6	30	50
Climate (temperature, ventilation)	2	2	20	76
Dust-free workplace	2	0	11	87
Commuting	5	0	18	77
Extra training	4	2	27	67
Other work accommodations	9	5	5	81

^aThe first and second columns add to the total percentage that has realized the accommodations; the second and third columns add to the total percentage that does prefer these accommodations and the last column presents the percentage that neither has nor prefers the accommodation.

particular attention to modifiable factors. Many of our findings suggest that we selected 'severe cases'. The mean fatigue score was 89 and 44% reported having more than one chronic disease, whereas a representative group of employees with a chronic disease had a mean fatigue score of 68 and only 9% reported two or more chronic diseases [21]. Almost all of the respondents in this study had disclosed their disease to their colleagues or line managers, while Munir *et al.* [22] found that only half of the employees with a chronic disease did so. In addition, 84% of our respondents reported receiving work accommodations, which is a much higher percentage than has been reported

by others [23,24]. This study also has limitations. The study population was interested in following a vocational rehabilitation program that paid attention to communication at work in order to solve problems. The great majority of participants worked in the commercial or non-commercial service sector. This means that individuals who were not motivated to reflect on and discuss problems were underrepresented; in addition, individuals working in the industrial, transportation or agriculture sectors and employees who did not expect to get permission from their supervisors to follow the rehabilitation program were underrepresented.

Table 6. Quality of life, fatigue, burnout and quality of work of study population ($n = 122$) as compared to reference figures of the Dutch working population

	Study population, mean (SD)	Dutch working population, mean (SD)
Fatigue (20–140) ^a	88.7 (21.6)	57.2 (23.7)***
Burnout exhaustion (0–6) ^b	3.37 (1.4)	1.57 (1.1)***
Burnout distance (0–6)	2.02 (1.3)	1.54 (1.1)***
Burnout competence (0–6)	4.20 (0.9)	4.14 (1.0)
Social relationship, colleagues (0–100) ^c	27.0 (14.3)	22.2 (13.9)***
Social relationship, supervisor (0–100) ^c	25.2 (18.5)	23.0 (16.9)
Worrying about work (0–100) ^c	42.4 (39.2)	21.0 (30.0)***
Job satisfaction (0–100) ^c	22.0 (29.1)	12.7 (18.8)***
Work pace (0–100) ^c	51.9 (17.9)	44.0 (15.3)***
Mental task burden (0–100) ^c	78.2 (17.8)	79 (no fig.)
Physical task burden (0–100) ^c	21.4 (19.4)	17.1 (17.5)**
Job autonomy (0–100) ^c	44.1 (20.0)	41.7 (19.4)
Uncertainty about future (0–100) ^c	41.0 (30.2)	32.6 (34.3)**

^aFatigue scale: a higher score indicates more fatigue. Reference figures [19] (12,095 employees).

^bBurnout scales: higher scores indicate more exhausted, distanced or competent. Reference figures [17] (1,018 civil servants).

^cQuality of work scales: a higher score means a more unfavourable situation. Reference figures [20] (68,775 workers; 13,491 workers for mental task burden; no figure available for SD).

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

The results of this study largely correspond with those of other often qualitative studies on the importance of social support from colleagues and supervisors for employees with a chronic disease [7–9, 11], and the importance of factors like a negative self-image, feelings of hopelessness and the inability to set limits or cope with the disease [12, 7], which may be interpreted as problems with acceptance of having a chronic disease. As mentioned before, others [2, 19, 21] reported that employees with a chronic disease experience higher fatigue levels; Franssen *et al.* [21] found that having two or more chronic diseases raises the fatigue level substantially. They attributed fatigue among the chronically ill partly to the disease itself and partly to psychological distress.

This study has several important implications. This population wants to remain working. Yet many of them feel that they cannot continue to work much longer. The first challenge for this group is to deal with psychological problems. Chronic diseases are characterized by permanence, unpredictability over time, day-to-day variability and often invisibility [25]. To be confronted with an irreversible disease that may have an unpredictable course alters one's perspective and self-perception [26, 27] and may lead to feelings of depression, anger, guilt or shame about loss of health and loss of work capacity. Time and reflection are required for individuals to adapt to their limitations. Acceptance is the first step and many employees need help dealing with their changed perspectives. The second step is to openly and self-confidently discuss the consequences of a chronic disease for work, including decreased work capacity, day-to-day variability and the need for work accommodations. Although the majority of our respondents were on good

terms with their colleagues and line managers, a large minority found that contact was slightly or severely disrupted. This hampers discussions of work-related problems and the possibility of finding solutions. It is difficult for an employee to solve these problems alone. Health care professionals should be alert to psychosocial problems and occupational physicians, human resources managers and supervisors should be aware of issues that may affect an employee with a chronic disease. An understanding and flexible employer will help in decreasing distress and possibly fatigue.

Even when psychosocial issues are addressed, fatigue or other consequences of a chronic disease may continue to be a problem for a number of employees. They are simply unable to fully perform in a full-time appointment. This is why many study participants would like to work fewer hours or at a slower work pace. They know that continuing to work at a full level requires them to sacrifice their health, their family life, their leisure activities and their social relationships outside of work. Recent social policy in Europe aims at increasing the employment rate for chronically ill or handicapped persons. An argument for this is that paid labour increases quality of life and can be good for health [28]. This may be true for the general population and for individuals with common, manageable health problems like mild or moderate musculoskeletal or cardio-respiratory diseases [29], but it may not be true for everyone. Research shows that many people with a chronic disease and physical disability are dissatisfied with their work and that a large percentage is satisfied with not being employed [30].

In conclusion, employees with a chronic physical disease may experience not only physical limitations but

psychosocial problems and excessive fatigue as well. If so, they may benefit from work accommodations, especially organizational accommodations.

Key points

- Employees with a chronic physical disease who experience work-related problems face not only physical limitations but psychosocial challenges as well.
- About three-quarters of the employees who experience work-related problems are so fatigued that they are at risk for sickness absence or work disability.
- Employees with chronic diseases prefer work accommodations that offer them more flexibility in the organization of work tasks and allow them to work fewer hours.

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Conflicts of interest

None declared.

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