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How Persons with a Neuromuscular Disease Perceive Employment Participation: A Qualitative Study

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Abstract *Introduction* A qualitative study was carried out to understand how people with a slow progressive adult type neuromuscular disease (NMD) perceive employment participation. *Methods* 16 paid employed persons with NMD were interviewed in open, in-depth interviews. Data were analyzed using the constant comparison method. *Results* Four themes were identified in the analyses: (1) Experiences regarding the meaning of work; (2) Solving problems oneself; (3) Reaching a turning point; and (4) Taking into account environmental aspects. Persons with NMD highlighted benefits of staying at work as well as the tension they felt how to shape decisions to handle progressive physical hindrances in job retention. This study shows how participants at work with NMD were challenged to keep up appearances at work and at home, the tension felt around when and if to disclose, the effect of their condition on colleagues and work reorganisation

challenges. Participants experienced that disclosure did not always make things better. With increasing disability participants' focus shifted from the importance of assistive products towards considerate colleague, in particular superior's willingness in supporting job retention. *Conclusions* Implications for health professionals might include awareness of the significant impact of changes in physical condition on employment. Timely communication and if appropriate referral to a health or occupational professional may empower employees with NMD to handle employment issues at a for themselves appropriate way. Assistive products and a supportive superior might enhance employment participation.

Keywords Job retention · Neuromuscular Diseases · Employment · Participation · Qualitative research

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Introduction

The importance and meaning of paid employment has been studied over decades. Gainful employment is seen as a human right inclusive of people with a disability [1, 2]. Persons with slow progressive adult types of neuromuscular disease (NMD) experience few tangible hindrances because of their disease during their upbringing or education, however decreasing muscle strength, increasing functional problems and in some cases cognitive decline become apparent during adulthood [3]. As a result persons with NMD start employment in good health with a seemingly normal career potential. Although persons with a hereditary NMD might be aware of the impact of possible future physical deteriorations on activities of daily life, individual experiences differ as result of the clinical heterogeneity of NMD which varies even within families [4–6].

According to a Dutch report on Public Health Forecasting, the employment rate of chronically ill persons (35 %) is in sharp contrast with that of healthy persons (65 %) [7]. The employment rate did not differ from the normal population for persons with facioscapulohumeral dystrophy (FSHD) (64 %) and hereditary motor and sensory neuropathy (HMSN) (70 %). In a group of 591 persons with an adult type of NMD 57 % were found to be employed between the age of 35–65 [7, 8]. Thus, persons with NMD seemed less disadvantaged in this respect compared to chronically ill people in general. These percentages were more promising than in former Dutch studies in which an average of 40–50 % of persons with NMD were employed [9, 10]. Andries et al. [11] investigated employment rates for persons with NMD and found that labour participation tends to decrease around the age of 34 years onwards until middle-age. From the age of 34 the majority of employees with NMD require assistive products [12] in order to remain employed [11, 13]. Employment rates for men were better than for women. A 1995 study found that at age 54 years, an average of 60 % of the men with NMD were employed compared to 90 % of the overall male population; for females the percentage was 34 % after the age of 34 compared to 54 % of the overall female population [11]. Although comparison of studies is difficult due to different time frames and sample populations, a tendency towards a drop in employment rates seemed related to the diagnosis and in line with the deterioration process taking place in persons with NMD [10, 11].

A systematic review of employment factors in patients with NMD revealed a number of factors that seemed to influence the employment rate in persons with the three types of NMD. In addition to general factors, such as age, gender, and education, factors such as physical function, muscle strength, fatigue, type of NMD, interest in employment and type of job influenced the employment rate in persons with NMD [14]. However, according to a best evidence synthesis for

quantitative research [15], these studies were not based on rigorously measured evidence [13]. Although employed and not-employed persons with NMD reported severe fatigue (cut-off ≥ 35 on the CIS fatigue subscale) [8, 16] the employed group reported significantly less fatigue than their not-employed peers. Fatigue as an influencing symptom in employment participation is also found in persons with other slow progressive neurological diseases, such as multiple sclerosis (MS), Parkinson's disease and for persons who have experienced a cerebral vascular accident [17]. Persons with myotonic dystrophy (MD) were not only severely fatigued, but also had the least social participation, the most psychosocial problems and the poorest psychosocial well-being compared to persons with other types of NMD [18]. These social consequences are likely related to cognitive decline, a typical characteristic for this multi-system disorder. Besides a huge impact on daily life, this disease-related characteristic likely impacts their ability to work [8] although health care providers may not always have recognized this. For example, recently it was reported by couples, of which one had been diagnosed with MD, that health care providers lacked awareness of the consequences of MD for daily life [19]. Early identification of employment issues for persons with a disability is thus recommended so that timely support can be provided during the early stages of decline and before employees encounter the stress of deteriorating abilities [20, 21].

Although the above-mentioned studies provide some information about relevant factors influencing employment participation, the experiences of persons with NMD, i.e. the client perspective, regarding job retention is lacking. This client perspective can provide knowledge about the impact of the disease on employment capacity and employment performance and factors which can enable continuation of their participation in the work force. Information from employed persons with NMD in particular can give insight into the meaning of work for life fulfilment, individual capacities and environmental requirements for enhancement of employment participation.

The objective of this study was to explore how persons with NMD still at work perceive the impact of the slow process of NMD related deterioration on employment participation and the strategies used in maintaining their jobs.

Methodology

Design

In 2010 and 2011 a qualitative study was performed. Purposeful sampling was used to include currently employed adult persons in the age range of 18–65 years representing three different neuromuscular genetically well defined,

homogeneous, and large client populations with relatively common neuromuscular disorders: (1) FSHD [4], (2) HMSN [5], and (3) MD [6] and who experienced hindrances in employment participation. Included persons confirmed that employment participation and performance were influenced by their disease symptoms and that they were employed at least 12 h a week conforming to the definition of a working population defined by the Dutch government [22]. The intention was to include persons from different age groups, levels of education, types of jobs and stages of the disease in order to look at problems concerning work from a variety of perspectives. Recruitment was carried out using four methods; notices on the website of the Dutch Federation of Muscular Diseases [23]; in the periodical of the same organization; from the database of persons with NMD previously admitted to a neuromuscular center of a university hospital in the Netherlands; and via participants.

Data Collection and Participants

Data collection consisted of a single, open, in-depth interview (16 in total) at a location selected by the participant: 12 opted for an interview at home, two preferred to be interviewed at the university hospital and two invited the researcher to their work place. Some informal talk about the hospitality at their home or work place and their willingness to participate preceded the interview. Furthermore, the participant's understanding of the purpose and format of the interview was ascertained, and additional explanation was provided when necessary.

The first researcher (MM) began the session by showing interest in the interviewee's job and asking a few factual questions about education and training in order to understand the context of his/her work. The main question was "What does work mean to you?" Interview topics focused on an ordinary day at work, experiences, satisfaction, importance of working for remuneration and engagement with the current job. The researcher encouraged elaboration on topics such as the impact of the disease on the ability to work, the requirements or preconditions enabling job retention, and the possibilities for either job rotation or applying for another job within the company or with another employer.

Each interview proceeded in an informal conversational style, lasting 45 min–1 h. Based on the researcher's written memos on the impressions and reflections of one interview and first analysis, the interview guide was adapted in the consecutive interviews with probing questions if new themes showed up. This was done to deepen and expand the topics. For example: "What is your own contribution to keeping your job?"; "What is your relationship with your colleagues and your superior?"; "How does the state of the economy

influence your career opportunities?" After the interview with the 12th participant, saturation was reached, since the interviews with four additional persons did not produce any new themes.

The researcher checked eligibility, explained the objective of the interview to potential participants in a telephone conversation and sent written information about the study. All candidates confirmed participation in the study, and when contacted a week later, the researcher made an appointment for the interview. Participants were explicitly informed that participation was entirely voluntary and that withdrawing from the study was possible at any time. Written informed consent was obtained. Permission to audiotape the interview as well as reassurance of confidentiality was confirmed during the visit. Following the interview, participants were invited to reflect on their experiences and indicate potential need for formal after care but none of the participants needed this.

The Medical Ethics Committee of the Radboud University Nijmegen Medical Centre in the Netherlands CMO nr 30076, approved the research project in accordance with the Helsinki Declaration [24].

Data were gathered from 16 currently employed persons with three different types of NMD (5 women and 11 men). All participants resided in the Netherlands, were Caucasian, and aged 24–62 years. Seven persons contacted the researcher in response to the announcement on the aforementioned website. Seven persons from the database of persons with NMD previously admitted to a neuromuscular center of a university hospital in the Netherlands were approached by telephone and two persons were asked by other participants to enroll in the study. One participant lived with his parents, ten lived with a spouse or partner and five lived alone. Five persons were diagnosed with MD (type 1 or type 2), five participants with FSHD and six participants with HMSN. Severity of symptoms, educational level, socio-economic background and type of job varied. Fourteen participants were employed and two participants were entrepreneurs. Working experience varied between two and 40 years. All participants were breadwinners, of whom five were joint breadwinners. Five participants worked fulltime, the others worked part-time or were partially work disabled and received both a salary and disability pension. All participants used assistive products or had been facilitated, for example, working fewer hours or at a slower pace (Table 1). The order in the table was based on the type of diagnosis.

Data Analysis

The analysis was inspired by a hermeneutic approach involving a constant comparison method. Atlas.ti[®] computer software (www.atlasti.com, GmbH, Berlin[®])

Table 1 Demographic profile of participants

Participant	Gender	Age	NMD type and other conditions	Severity of symptoms	Marital state	Education level	Profession	Assistive products and adjustments at the work place or at home to facilitate employment
1	Female	43	FSHD	Moderate	Married	Intermediate	Residential counselor	Reduced working hours Wheeled office chair
2	Male	30	FSHD	Moderate	Co-habiting	Advanced	Builder website applications	Reduced pace at work
3	Male	62	FSHD	Severe	Married	Advanced	IT consultant	Wheeled office chair Computer facilities
4	Male	53	FSHD	Moderate	Married	Lower	Shovel operator	Adapted shovel Support from employer and colleagues
5	Male	45	FSHD	Moderate	Married	Advanced	Teacher primary school	Wheeled office chair. Printer, scanner, copy machine in the classroom
6	Male	24	HMSN	Little	Living with parents	Lower	Truck driver	Partner taking over home duties Adaptation in the truck present and needed
7	Male	49	HMSN and hernia	Severe	Living alone	Intermediate	Office job at the municipality	Adapted car to commute Powered office chair
8	Male	28	HMSN and hip dysplasia/arthropathy	Moderate	Married	Intermediate	Arborist	Voice controlled computer Support from employer and colleagues
9	Female	41	HMSN	Moderate	Married	Advanced	IT consultant Former head nurse	Extra pair of protection shoes Quad and quad transportation system Changed job with same employer Reduced working-hours and -pace at work
10	Female	42	HMSN	Moderate	Living alone	Advanced	Psychiatrist	Wheeled office chair Support from employer and colleagues
11	Male	42	HMSN	Severe	Married	Intermediate	Entrepreneur accountancy	Reduced working hours Assistance by secretary No night and weekend shifts Support from employer and colleagues
12	Male	46	MD	Little	Married	Intermediate	Entrepreneur director	Able to manage own pace at work Office at ground level Adapted computer mouse Able to manage own pace at work

Table 1 continued

Participant	Gender	Age	NMD type and other conditions	Severity of symptoms	Marital state	Education level	Profession	Assistive products and adjustments at the work place or at home to facilitate employment
13	Male	43	MD	Severe	Living alone	Intermediate	Buyer and manager of products at a food company	Reduced working hours Different job with same employer Office at ground level Home care Adapted car to commute
14	Male	51	MD	Severe	Living alone	Advanced	Accountant at major corporation	Changed type of job Reduced working hours Reduced pace at work
15	Female	46	MD	Moderate	Living alone	Intermediate	Former assistant accountancy Now musician	Reduced pace at work Reduced pace at work
16	Female	44	MD	Moderate	Married	Lower	Homecare	Reduced pace at work

NMD neuromuscular diseases, FSHD facioscapulohumeral dystrophy, HMSV hereditary motor and sensory neuropathy, MD myotonic dystrophy

1993-2013) version 6.2.27 was used to assist in organizing the data. After completing five interviews, in-depth analysis started following each additional interview. The researcher transcribed the audiotapes verbatim. The analysis of the data consisted of the following steps [25]:

1. Familiarization with the interviews, and understanding the experiences on the job by multiple readings of the transcripts, the production of summaries and reading the reflective memos and field notes.
2. Assignment of in vivo codes related to the research questions to meaningful units so as to stay close to the participants' original phrasing.
3. Categorization of meaningful units, reorganization and interpretation, resulting in the formulation of themes and subthemes.
4. Interpretation of relations between themes and sub-themes. Use of other sources, including literature, field notes and personal experiences, leading to new insights and better understanding of the meaning of work for participants with NMD.

The first researcher (MM) executed all these steps. During the analysis, a number of conceptual maps of the emerging themes were constructed and discussed by a small peer review group and experts in qualitative methodology (TS and AK). Text extracts that supported each theme were discussed for consensus on several occasions and over time with discussion. To capture the thoughts and insights, the first researcher wrote minutes and memos to assist and documented the development of the themes and subthemes. The findings were discussed five times within the whole research team which reached consensus on the themes and subthemes in a final meeting. Whenever necessary for the purpose of anonymity, the participant's wording was paraphrased (omitting dates and names) [19].

Interview Findings

Four themes were identified in the analyses: (1) *Experiences regarding the meaning of work*: "Work is belonging"; (2) *Solving problems oneself*: "I am not going to tell"; (3) *Reaching a turning point*: "I have to be realistic"; and (4) *Taking into account environmental aspects*: "I can understand both sides" (Table 2). Each of these themes and related subthemes are described in detail with quotes to illustrate the themes.

Experiences Regarding the Meaning of Work: "Work is Belonging"

The first theme dealt with the way participants with NMD at work experienced the meaning of work. Most participants

Table 2 Themes and subthemes identified through analysis of interviews with 16 employed participants with a neuromuscular disease

Experiences regarding the meaning of work: <i>“Work is belonging”</i>
Working for personal benefit
Working for economic and social benefits
Working as a burden
Solving problems oneself: <i>“I am not going to tell”</i>
Disguising limitations thus postponing disclosure at work
Contemplating job demands and other roles in life
Reaching a turning point: <i>“I have to be realistic”</i>
Struggling to let go
Accepting change: an emotional process
Using strategies to keep one’s job in the long run
Taking into account environmental aspects: <i>“I can understand both sides”</i>
Valuing assistive products
Considering colleagues’ positions
Considering employer’s position
Interfering macro-economic influences from society

indicated that work was an important activity throughout their lives, irrespective of the phase of the disease or severity of symptoms. Reasons why work was meaningful and what aspects were meaningful varied among the participants, but most of them felt that work connected them to the community. The following quote underlined the significance of work for participants with NMD.

Work is 80 % of my life fulfillment, yes (P14).

However, paid work seemed to become a burden when working with their disease related limitations was felt to be a necessity, i.e. when participants experienced that they had no other choice than staying at work.

Working for Personal Benefits

Aspects that participants mentioned to express the advantageousness of a paid job and what made work meaningful to them were the pleasure, status and self-esteem derived from work. Some participants stated that work justified their personal value, others who were single and experienced severe symptoms had chosen to put all their energy into their work at the cost of other social contacts and emphasized that work was important since work seemed to be their only remaining connection to society. Participant 4, diagnosed with FSHD, had the same view, and although he had a family and hobbies at home he expressed that he valued his paid job because filling time with hobbies that were difficult to perform due to physical deterioration seemed a poor alternative for his paid work.

At work I talk with my colleagues, there are stories to tell, I am busy. I like that... having colleagues, taking part in society, I am glad that I work ... Indeed, I can do a lot of chores at home, once I did, but this is getting increasingly difficult too (P4).

Working for Economic and Social Benefits

Analysis showed that the value of employment was evident in the economic and social benefits that participants experienced from working. Some participants mentioned that receiving a salary enabled them to pay for their children’s education, health care or hired assistance for physically demanding domestic activities. Obligations connected to personal roles in life positively influenced participants’ meaning of being gainfully employed. Participants who were breadwinners (men and women) indicated that for them this role was linked to a sense of full participation in society. It felt good to be able to provide the necessary income for oneself and the family.

I have many choices and a lot of freedom, due to the fact that I work. I do the work I can do, with which I earn money that allows me to hire people for physically demanding jobs at home (P10).

For me it is important to be useful for society, not just having to rely on support by society (P11).

Working as a Burden

Although participants preferred to work instead of having to rely on social benefits, analysis showed that having to work for economic reasons was experienced as a burden, especially when participants experienced symptoms such as fatigue, which affected their employment performance.

As head of the family and being responsible for my children, I must make sure that there is food on the table.... I also have responsibilities. I have my own house. I need to pay my mortgage every month (P5).

... and besides, it is currently a financial necessity. I must work now. I’m not a breadwinner, but my son wants to become an interior decorator. That training costs a lot of money. I want to give my child the opportunity to follow his preferred education (P1).

Solving Problems Oneself: “I Am Not Going to Tell”

Analysis showed that participants held on to the job and subsequently searched for solutions themselves to relieve their workload. Strategies for solving problems differed among participants and depended on the type of job, their

upbringing, and stages of deterioration. Most participants stated that their first reaction to physical signs of deterioration, such as reduced muscle strength or increased fatigue, was to avoid going on sick leave as it was against their values and norms. To them a reliable employee was someone who works hard, without complaints or periods of sick leave. The first reaction after diagnosis was to pretend that nothing was the matter. One participant stated that she feared losing her job from the moment she was diagnosed in 2003, so that she did not talk about her problems at work as long as she was able to hide the symptoms.

Colleagues pass by, now and then. What's up? Are you able to keep up? Yes, I'm fine. I carry on, even in bad periods. As long as it's not getting worse, I am not going to tell (P1).

Disguising Limitations thus Postponing Disclosure at Work

Physicians' unfamiliarity with early symptoms delayed the initiation of support in daily functioning or appropriate interventions on behalf of some participants. Moreover, after having been diagnosed, many participants tended to deny their condition and the challenges within their environment. Postponing disclosure at work could last for years as long as symptoms and consequences for employment participation could be hidden even when symptoms started hindering occupational performance.

The GP claimed that referral to a neurologist was unnecessary. After my insisting I was referred and then the diagnosis was confirmed (P1).

For years it troubled me, yes there was something wrong, but I didn't know what it was. When I was diagnosed in '87, I just kept going on and work went reasonably well (P4).

I denied my illness for 15 years. That is true for many persons with MD, indeed of 3,000 people in the Netherlands with MD; only 900 are members of the association (P14).

...and I've always thought as long as I do not have it, I have nothing; I mean so long as I did not notice anything (P15).

Examples of ways participants disguise their limitations, thus avoiding sick leave varied from voluntary reduction of working hours to asking for parental leave, even when this meant a lower income. Seeking a less strenuous job within the organization without mentioning the reason was found to be another solution. Other reasons mentioned by

participants for avoiding disclosure were the fear of being fired and repercussions by the organization.

At work I started doing things that fitted my physical condition...In 2002 I [nurse] applied for an office job... yes, at a certain moment in time, it was in 2007, I decided to ask for a period of parental leave. I wanted to work so badly, but was not able to continue anymore (P9).

As long as it does not really get worse, then I am not going to tell. If it gets worse, yes, I must tell, but as long.... Yes, he [employer] might as well fire me, when I am on sick leave. Indeed, I have just completed 1 year in this organization (P16).

Contemplating Job Demands and Other Roles in Life

Analysis indicated that participants became aware that the choice to continue to work had consequences for their private lives and family members. If one of the partners was diagnosed with NMD, couples shared the struggle. Indeed most participants with a partner did not start rebalancing job demands, but began by giving up responsibilities and duties in the private domain, in their roles as a parent or a spouse. Concerns about income, or the possible need to change roles within the family due to the disease could be emotional. For one couple, roles were changed: the woman quit her job because the combination of working and caring for her family without the support of her partner with NMD was no longer an option for her. He wanted to work fulltime and did not have enough energy to support his wife in domestic roles as he used to. The resulting dilemma was that because of his partial disability the current decisions might cause unexpected financial problems and need to be altered.

Two years ago my wife quit her job. At some point she could no longer sustain a busy family of four children. I work fulltime and therefore my energy is low and she had to do more at home. The balance we have now might have to be adapted again in the near future. Of course that makes me sad sometimes and this is where I start to have my doubts. Where will this lead? (P5).

Analysis showed that some participants made use of legislation and regulations in order to rebalance roles among partners. For example, after years of proving himself in paid jobs, one participant purposely chose to make temporary use of a disability pension in favor of his wife who wanted to work. Unfortunately in this latter situation the tension over how to shape decisions at home became apparent when she lost her job. In another case, the participants' partner became the health care provider for her

partner and got paid by health insurance, with the advantage of providing the care in a timely fashion.

Yes my wife worked in the field of health care. When we heard about the new legislation that provides financial compensation instead of home care, several years ago, we took the opportunity and now my wife is being paid for the care she provides to me. She has resigned her job and has started her own day-care business from home. So she is always at home for work, to take care of our and other people's children and she can help me any moment of the day when I work in my office next door (P11).

Consequences of keeping up appearances at work might have repercussions at home. To save energy, participants sacrificed familial obligations to fulfil work obligations, were not able to do anything at home after work or as another participant explained the intensity of social contacts was lowered.

My wife knows the other me, completely exhausted, physically and mentally burnt out, and now completely worn out in my chair (P12).

At the moment I'm not present [for music practice in the evening]; my friends know that today my energy level is low. Then I grab my moment of rest (P5).

Reaching a Turning Point: "I Have to be Realistic"

From the moment that symptoms became obvious and participants were no longer able to work in the same way in spite of measures they had taken, a turning point was reached. Some participants had reached this turning point long ago, for others it was a fresh reality. The most common reason to admit to themselves that continuation of work as before was no longer possible, was that symptoms disrupted job productivity. The participant that reached this stage of openness during the interview became emotional, however still referred to this turning point in the impersonal 'you' form, as though it was not yet his own concern, while some other participants at a later stage of the disease or close to retirement seemed to be beyond that stage of grief and showed an active coping attitude towards changes and lived day-to-day.

Of course that makes you feel miserable sometimes and you think where does this end. At what point, is it going to be a real problem.... Erm..., okay you're not present for a day,... it still feels very difficult. Then you wonder, is it worth continuing to work full time, if besides work, you have no energy for your family, hobbies or your social network (P5).

Struggling to Let Go

The participants' story showed a changing attitude about their ability to continue work or to change jobs, however it was clear that this change had an emotional effect with fear for the future, grief and feelings of insecurity. This changing attitude was caused by symptoms that started to impact employment participation as a result of severe physical hindrances and the inability to combine all roles in life. Many quotes began with the phrase: "*I had to be realistic...*" or "*I came to realize*" indicating being forced by their physical conditions to admit that going on in the old way was no longer an option. A changed attitude was seen in participants openly engaging in dialogue with colleagues about the disorder and the work-related consequences of their physical condition.

...then I came to realize, I must have been a problem for my colleagues, by not asking for help (P9).

Participants covertly indicated that sooner or later performing the way they were accustomed to was no longer possible, which made them struggle. In the process of letting go and changing, rational considerations alternated with emotional reactions. For several participants the struggle was prolonged, probably since no experts were consulted and they could not foresee the benefits of openness. Participants related that their fear of losing connection to society kept them from giving into symptoms and accepting change. Several participants blamed others, or mistrusted superiors who threatened job retention. Due to uncertainty these participants expressed openly fear of loneliness, knowing that being fired was inevitable.

When I applied for the job in 2006 I didn't report that I had a muscle disease. I had a bit of fear that I wouldn't be hired... and ... erm... now [2010], I think that there is a chance of losing my job. Don't think you're indispensable when you are not functioning. Now I still can manage those 2 days, but I think ultimately the disease will hinder me so much, that maybe a whole day will be too much anyway. Now I can do it, but whether it still works in 5 years I do not know (P1).

At an advanced stage of the disease, analysis revealed that changing jobs or finding another employer was no longer an option and it was obvious that work might even become impossible. The story of the participants showed a change in attitude to their own ability to continue work. One participant anticipated that the career would end earlier than under normal circumstances and that changing jobs in the future would be difficult.

Being mobile is the most important thing. I'm neither mobile nor presentable. Then one must be realistic,

with my handicap I will never ever get another job anymore (P14).

... but perhaps it will be more difficult to find work again somewhere else, when you carry your condition with you in your luggage. That is something that is going round in your head (P7).

Using Strategies to Keep One's Job in the Long Run

In order to maintain long-term employment, strategies were chosen from the beginning of the process of deterioration. Looking back into their past career, some participants emphasized that having been able to build goodwill turned out to be helpful in negotiating current job retention, although it was recognized that goodwill and personal strategies alone were not adequate to ensure employment participation.

Someone said to me: Your boss does not want to lose you, he wants to keep you. Indeed, I contributed a lot when I used to work fulltime. I don't know how to say it, but with my 12 h, I am still worthwhile for the company (P9).

After being diagnosed many years ago and anticipating future symptoms, some participants developed strategies such as doing work they knew that would make them indispensable, to guarantee job retention later on.

Your position partly depends on your indispensability. In fact, the better your position at work, doing work that needs to be done, the better it is of course (P8).

Taking into Account Environmental Aspects: "I Can Understand Both Sides"

However it should be noted that ultimately personal strategies for keeping one's job were no guarantee of success. Many aspects influenced the chances of job retention.

Valuing Assistive Products

All participants at all stages of the disease required adapted work environments to be able to work or to continue working when physical limitations hindered employment performance. Analysis revealed that participants who used assistive products and were provided with adapted work conditions did not experience these measures negatively. As a matter of fact these measures enabled them to continue their work and this was experienced as positive. The type of measures that had been taken at home and at work that facilitated ongoing employment varied greatly among

participants, depending on both the physical abilities of participants and job demands.

Now, they [homecare] come simply every day at 7.30 AM, so that I am at work on time of course (P14).

I have a battery powered office chair so that I don't have to walk so much and voice recognition on the computer. I chat to the computer and the computer does what I say (P7).

I am now at home on Wednesdays. The other days I work from 8:00 to about 15:30 pm. The load is nicely distributed over the week (P10).

One participant was explicit that one should not take these measures for granted and was aware of the need to be sufficiently productive, to make the firm's investments in these measures worthwhile.

If you want to have that kind of equipment, I think it is important to realize that this must be paid for. That's why you have to make money for your boss and provide quality at work. Yes, I think that way. It is important to have good relationship with your manager, and do your job so well that they like to keep you (P8).

Considering Colleagues' Positions

In addition to the importance of assistive products and facilities, analysis provided evidence on the importance of good work relationships. With increasing disability, relationships at work became crucial. Compassionate colleagues and, above all, good relationships with superiors willing to support participants' job retention became increasingly important as dependency due to physical deterioration progressed. Absence of this consideration negatively influenced employment status.

Having sympathetic colleagues was very much appreciated. Work enjoyment was boosted by colleagues' understanding and empathy. The importance of social contacts at work was emphasized especially by singles, for those who put work first and foremost at the cost of their private contacts and those who experienced more severe physical dysfunction at a later stage of the disease. Because they put all their energy into work, the work place provided the majority of social relationships, which in turn made work even more meaningful.

Yes, and colleagues, I have very nice colleagues, who understand my situation too. They help with everything, where they can help, and they are very considerate. During holidays my colleagues carry my bags, assist me from the room to the dining room, ... erm, from hotel to bus. They help me get on the bus,

when we get to the ski-hill then they lift me onto the ski lift, and once I am in the lift... then we can go... this makes me very emotional (P7).

Participants realized they had been unaware of how their condition had impacted colleagues. After disclosing their work problems, participants' found that their colleagues were relieved to have this in the open. Several participants then came to realize that trying to hide symptoms was a burden for their colleagues. It turned out that openness made it easier for their colleagues to provide support.

It seemed to be a relief for my colleagues. My colleagues took over my evening and weekend shifts immediately when I announced that I would like to quit these obligations in a few months (P10).

However openness about the disease did not guarantee empathy from colleagues. Some participants experienced disappointment that after having shared the grief of their progressive illness, misunderstandings concerning their inability to perform certain tasks remained or support from the superior was lacking. One participant was unpleasantly surprised by the negative attitude of his employer, in particular since his superior had experienced periods of severe fatigue himself recently. Several participants highlighted this emotional dimension in the process of change.

I am very open and I find it no problem to talk about my things; however it sometimes makes me tired, that I have to explain my disability over and over again. For instance why is it not obvious, that I won't be able to be present, if the meeting is on another floor? (P5).

He [superior] wants me to do this work anyway, even though he knows what it's like to be tired because he has experienced the same in recent months. He was very tired, could not work as much. This is why I was disappointed by him (P2).

Considering Employer's Position

Participants considered things from their employers' perspective including the challenges for the employer involved in supporting participants' employment retention in spite of potential or existing physical limitations. The policy of the organization and the way this policy was carried out by the superior also determined whether participants managed to keep their jobs. Overall the superior's attitude was experienced as particularly important. Participants working in firms with a policy mandating accommodations to facilitate employment for persons with reduced capacities had confidence in the future and dared to be open with their superior about the problems in employment performance that emerged.

Yes, yes it is a great employer here, who will never say you must go, because we cannot do anything for you anymore. That never happens here. That gives me a safe feeling. I have job security here (P4).

When companies were reorganized and new superiors were in charge, the former arrangements could easily fall apart. Lack of understanding and negative actions by the company caused decreased pleasure in work. Absence of a sense of security restrained these participants from daring to speak openly about their problems.

A colleague who had heart problems was advised by the occupational physician to work less. Then she was offered another position, less suitable, supposedly there was no other option. Eventually she decided to leave. Then they [employer] have you where they want to have you, because they want to get rid of you... (P1).

Although analysis revealed that for some participants their condition was taken into account by superiors, others were quite dissatisfied about the lack of understanding by their superiors. The way participants judged their employers' attitudes regarding the presence or absence of employment support depended on participants' own situation and disease severity. One young participant who had vague symptoms and two others with a severe condition were indignant about not getting or keeping their favourite job. One of them, although annoyed, and still able to hide her symptoms, understood the choice of her potential employer to not to award her the job after having heard the possible diagnosis.

As soon as my superior realised my condition, I could imagine that he would be afraid that something would soon go wrong, that I would be forced to work less and that the company would have to pay for my absence because I have a contract (P1).

The day after he [the future employer] phoned back. I immediately explained what was going on and that the diagnosis was not clear yet. Then he announced that he was not going to offer me a contract (P6).

I think, he [employer] thought I would be totally disabled very quickly. And this was what he really feared. It was a small company, that did not want to take that risk, just financially. And somehow, I can still understand it too. If I was an employer and I had 10 people and I wanted someone there and I would have to choose between someone who is ill and someone who is healthy, I would know what to choose (P15).

For participants with severe physical hindrances the impossibility of changing jobs was probably a good reason

to fight to keep their current job. During years of living and working with NMD, one participant became an expert in legislation and regulations for persons with a disability. He convinced his employer of his rights to work with his handicap, and overruled the employer's point of view that this employee was a potential danger to the firm with regard to accountability in case of an accident. This participant had firm opinions about employment participation and expectations for unconditional job retention and employers' responsibility in supporting this.

I said to my employer that I do not qualify for the disability law. My skills are in my head and those capabilities are not affected by my illness. For motor skill problems, there are other solutions" ... "That he [the employer] should be positive towards you, by saying: "You are disabled, okay, but we want to do everything to keep you at work so we will try to create opportunities" (P14).

The two entrepreneurs named the advantages of being able to make one's own choices, set one's own pace and working times fitting their capabilities. These entrepreneurs felt blessed by their independence and their ability to regulate working hours and to take other measures themselves.

... as an entrepreneur I am able to manage my work. I can judge for myself what is really important (P11).

Interfering Macro-Economic Influences from Society

Last but not least, analysis revealed that participants were fully aware of being in a more vulnerable position than healthy colleagues in the event of an imminent reorganization. The participants expressed that the risk of job loss due to economic crises or reorganization seemed to be larger for them than for healthy persons in their organization. From the participants' point of view reorganization could be improperly used to dismiss someone. Some participants with severe physical hindrances discussed with their employers ways to keep their jobs. Although some participants had been successful in surviving several reorganizations in the past the threat of dismissal remained. When companies were reorganized and other superiors were in charge, the former arrangements were at risk.

We need to reorganize, and this is the result. Except me, everyone is healthy. All personnel who lost their jobs because of the reorganization were offered another position and continue to work, except me. That is very strange. I worked hard for the firm and now they lay me off (P13).

In that sense, it is important that someone has a job where his boss is also nearby.... But our company was getting bigger and bigger.... And since May last year... erm... this empathetic boss has gone. I have seen no boss until March... and actually the first time I talked to my new boss in June, he called me to say that I was on the list of persons whose work went to India. So it is very important to have your boss close by so that in addition to your work at your workplace, your physical sight of the work, perhaps your psyche in relation to the work can be assessed. In the past that's always been perfect. These days arrangements can be easily discarded (P3).

The willingness to work was found throughout participants' lives, irrespective of disease severity. When macro-economic circumstances affect employment, participants tended to be in a disadvantaged position compared to healthy colleagues.

Discussion

This study explored the meaning of work for 16 employed persons with three slow progressive types of NMD and the experiences, challenges and strategies regarding job retention. Also the stages participants encountered in the process of physical deterioration which impacted employment participation were identified. Although the employment rate of persons with NMD was relatively high compared to persons with other chronic diseases [9, 11, 22], the findings of this study may be useful in helping professionals to empower persons with NMD to maintain employed.

Various Experiences Underpinning the Meaning of Work

Participants experienced work as an important activity throughout their lives irrespective of disease severity. At first glance, the reasons that work was meaningful to them did not differ from those of healthy people, namely deriving economic benefits from work, developing talent, self-realisation (self-esteem, social contacts, pleasure), and contributing to society [26].

The first theme, '*Experiences regarding the meaning of work: "Work is belonging"*' highlighted the meaning of work and was recognized as an overall theme throughout participants' lives. The way participants elaborated on the meaning of work in spite of the accompanying challenges emphasized the importance of work to them, a phenomenon recognized in another study on the meaning of work in the lives of people with disabilities [27]. Participants with a

severe condition highlighted the meaning of paid work and willingness to work even more euphorically, probably because for them work was the main link to society. Apparently participants valued the advantages of having a job as opposed to receiving wage replacement benefits as provided in the Netherlands [28]. However, it is a fact that they were aware that from an economic point of view this was a more beneficial choice.

The three subsequent themes: (2) *Solving problems oneself*: “I am not going to tell”; (3) *Reaching a turning point*: “I have to be realistic”; and (4) *Taking into account environmental aspects*: “I can understand both sides”, reflected participants’ shift from an internal towards an external focus by changing strategies to maintain their position at their jobs while adapting to physical decline. Comparison with the process of self-management tasks identified in persons with a chronic disease after being diagnosed (focusing on illness needs, activating resources, and living with a chronic disease) became apparent [29]. Participants’ goals of compensating for physical deterioration varied with the phase of the disease. Initially participants struggled and did not always recognize the significance of vague symptoms. In families with hereditary records it could be expected that persons with these symptoms were, to some extent, prepared for future challenges. However, there was no indication that this knowledge was used by the participants to choose an education or profession that could accommodate their subsequent physical deterioration.

The Moral Pressure at Work to ‘Keep Up Appearances’

As soon as participants were diagnosed, their first reaction was to solve problems themselves, which was identified as the second theme. Comparison with the first stage of the self-management process, namely focusing on illness needs, evolved [29]. Individual problem solving, disguising limitations and postponing disclosure might be a reflection of the tensions participants experienced about when and if to disclose their condition and might coincide with a stage of denial [30]. Disclosure was apparently experienced as ‘irreversible’ and therefore avoided. Reasons for the participants’ reluctance to complain and their decision to postpone disclosure was apparently related to fear of being put in an unfavorable position, fear of being dismissed and consequent financial instability. Risk of financial instability and loss of self-worth might have been reasons for delaying disclosure which was also found in persons with slow progressive neurological diseases such as early-onset MS [31] and for persons with a chronic disease in regards to job retention [32, 33]. The struggle with decisions regarding whether to disclose and discuss disabilities at work is seen in other studies [34]. This dilemma and the accompanying

fear of potentially negative consequences are actively debated on websites of client associations [35] and uncertainty seemingly caused pressure to keep up appearances at work.

How Keeping Up at Work and at Home Shapes Decisions About Remaining at Work

Problem solving or coping included pondering and negotiating first within personal relationships and later on in work relationships with the aim to maintain their job was strongly developed by participants of this study. Developing coping strategies as a way of adjusting to a chronic disease and activating resources was also an important finding in other studies [29, 36, 37]. They did not always recognize the impact of their condition and problem solving strategy on colleagues. Based on colleagues’ reactions after disclosure it became apparent that it might have been difficult for colleagues to notice participants’ work problems. However, these colleagues did not dare to start talking about it with them. It can be assumed that participants’ ignorance of symptoms and their reluctance to complain about their problems at work, possibly leading to less production, might make it difficult for colleagues, line managers (LM), human resource managers (HRMs), occupational physicians (OPs), physicians or health care workers to provide adequate assistance [38]. Only after disclosure some participants realized that it might have been wiser to communicate work issues at an earlier stage, instead of continuing working to the detriment of the family as some participants did. Haafkens et al. [38] found that according to LMs and HRMs, employees must accept their own share of responsibility for job retention.

This dilemma was apparently not experienced equally among participants. Some participants communicated openly with colleagues and superiors, and successfully bargained about necessary changes aimed at continuation of the job. In these cases communication and sharing the grief of future physical, personal and societal consequences seemed to be instrumental in their relief and resulted initially in compassion by some colleagues and superiors. However in other cases open communication failed when colleagues and superiors seemed to have forgotten participants’ needs and workload was increased again and again. This means that there were differences in environmental conditions which influence the vulnerability of the persons with NMD. This was confirmed by data of Jans et al. [39]. They discussed the complexity of decision making regarding whether, when, and how to discuss disability, which depended on workplace culture and personal choices [39]. Our findings that insufficient support from colleagues or LMs were felt as threatening are understandable. In some studies about work and the chronically ill it was

found that these factors were positively associated with withdrawal from the labour force [37].

When open communication at work was not effective, participants expressed being disillusioned or even angry. Thus communication and disclosure did not always make things better.

When physical deterioration could no longer be concealed, most participants reached a turning point, identified as theme three, in which the struggle of letting go and accepting change became apparent. Reaching a turning point was true for every participant although at different points of time or phases of disease and this seemed to be a moment to re-evaluate life [29]. Although wanting to be realistic, participants struggled with the process of letting go, changing and balancing private life and work needs. Some participants kept bargaining till the bitter end and seemed not to reach a turning point, seeking for normalcy at work [29] carrying out work tasks and responsibilities as long as possible.

Environmental Aspects Influencing Job Retention

Irrespective of the time line described in the findings, a variety of environmental aspects influencing job retention for participants were identified. First of all, the provision of assistive products, timely work adaptations, work adjustments and accommodation through adapted work conditions may enhance participants' employability. In other studies LMs, HRMs and OTs confirmed these preconditions for job retention of the chronically ill [38, 40–42]. As Andries et al. [40] stated "Where disabilities in daily life and job demands coincide, work handicaps may be the result. Work handicaps can be removed or their effect mitigated by work adjustments". Secondly, previous and current relationships at work with colleagues as well as superiors and the policy of the company were valued by participants. In the study by Haafkens et al. [38] good manager/employee cooperation and knowledge transfer within the company was identified as an important cluster by LMs and in the same study HRMs perceived organizational policy and culture as the most important mechanism. Superiors' willingness to support participants depended on their ability to manage company policies. However these policies could be overruled by reorganizations and macro-economic circumstances [43]. These issues might also influence opportunities for job retention or possibilities for alternate employment for participants. According to some participants these circumstances were covertly used for termination and they experienced being in a disadvantaged position compared to healthy colleagues with regard to job retention.

The Chain of Delay

The relative rarity and variety in the hereditary types of NMD [23] might explain the delay in physicians' recognition of early symptoms. This, along with the participants' lack of awareness of the seriousness of first symptoms, might create the first delay in receiving proper support related to job retention. The apparent delay in diagnosis and the subsequent delay in disclosure of work related problems by persons with NMD deserve attention. A survey of the opinion of disabled people's organization in the UK about factors hindering return to work or remaining at work revealed, amongst other factors, delayed consultation and a lack of appreciation of workplace issues. Employers were seen as unresponsive to the needs of workers, with negative attitudes to disability [44].

The first challenge might therefore be augmenting general practitioners' (GP) alertness to early symptoms, and timely referral to a neurologist for a proper diagnosis. The diagnosing physician's awareness of the implications for employment and initiation of a timely referral of persons diagnosed with NMD to allied health care professionals (HCPs) may be important in this respect [45]. If the recently diagnosed person is still employed, but not on sick leave and thus not under the care of an OP, a hospital based OT might be the appointed professional to assist in possible employment dilemmas [13, 42].

At a later stage of the disease, when participants themselves became aware of possible negative consequences of not facing their condition they became aware that they had chosen only short term solutions e.g. decreasing hours, which worked negatively in the long term. It might be worthwhile to have peer discussions about work problems and successful and less successful strategies. Timely information from peers for persons with NMD who are struggling with the issue of disclosure, might help them to identify their chances of success. These findings are in concord with another study on employment of people with a slow progressive disability that revealed that struggling alone and hiding the diagnosis did not always seem to produce the desired results [37]. In another study, disclosing an illness was the strongest predictor of receiving work adjustments and social support for persons with chronic illnesses [46]. These studies underline the potential benefits of early disclosure but there is also a risk of not getting support.

Strengths and Limitations of the Study

Persons with one of three types of NMD, varied demographics (age, gender and education) and diverse jobs were interviewed. Data were saturated with a variety of positive

and negative experiences. To minimize bias by misunderstanding, analysis was conducted on Dutch transcripts of the interviews [19]. To guarantee meaningful translation, only the selected quotations used in this article were translated into English in a side-by-side cooperative procedure with the first researcher and a professional translator. The researcher explained to the translator the intended meaning and its context in Dutch. The translated quotes and subtle meaning differences were discussed by Skype[®] sessions with a native speaker, knowledgeable about the content and type of research [47].

All interviews were conducted by the same researcher, while the process of the data collection and analysis of the content of the interviews were conducted with 2nd and 3rd researchers. It was anticipated that the discussion of the findings within a diverse research team would prevent a narrow or biased view of the data, given that only the researcher read all of the transcripts in their entirety [25].

We choose to interview persons with MND who were employed at least 12 h a week. Even participants with relatively severe physical hindrances in our study viewed work as meaningful, likely due to the people sampled. It is possible that persons with NMD who were no longer employed would have had different experiences.

The validity of this study may be enhanced by observations on the job [25] and interviewing employers about their experiences in supporting employees in job retention [48]. However, we did not choose these methods so as to guarantee that participants provided their work narrative under confidential circumstances. Neither was it the intention to interfere in employer-employee relationships. Interviewing employers about company policies in general would not have provided information regarding management of NMD related problems. It is unlikely that an individual manager would experience this rare condition on a regular basis [48].

Although at the start of the interviews the main question was related to their current work, participants tended to narrate their story from the past to the present with a glimpse into the future. Instead of using an open in-depth interview we could have chosen to use a regressive narrative as a starting point to detect a more detailed course of deterioration or decline along with participants' employment experiences [49].

Implications for Professionals and Policymakers

These findings might be useful for professionals and policymakers. Of note was that participants' narratives gave insight into the complexity of the process of working with NMD. It was apparent that participants still at work tended not to complain, and delayed disclosure at work until symptoms became tangible. Participants who gained insight into the complexity of maintaining employment

with NMD concluded that they would advise others to communicate their work problems earlier. Therefore, empowerment of employees by professionals to help them not to postpone, but to communicate employment issues at an early stage seems to be important. Indeed the importance of timely identification of employment issues in the working life of persons with a chronic disease to minimize the stress of deteriorating abilities was emphasized in other studies [50]. The diagnosing physician could play a role in supporting persons with chronic diseases by identifying actual or expected employment issues and providing information on the benefits of referral to a multidisciplinary team or occupational health services [51]. Physicians could be provided with brief checklists to assist them to explore the possible impact of the disease on work and to look for early symptoms of deterioration. These checklists have been developed earlier [13, 43, 52]. Johnson et al. [53] emphasized the importance of proper timing of decisions before recommending action impacting employment. Health care providers' awareness of the complexity of the process and of the issues related to employment were found to be important determinants.

Our study revealed that supportive social relationships at work, especially a considerate superior were perceived as key in job retention. Based upon the findings we might conclude that the main reason that employers support employees in job retention might be the 'goodwill' built up in the past and a good personal employee-employer relationship.

A study of the effectiveness of the Dutch Law (Wet Verbetering Poortwachter) [54] implemented in 2001 obliging companies to develop a return to work plan in case of sick leave and imposing penalties to force both employers and employees to develop an adequate (re-)integration plan resulted in the same findings, namely that in spite of this law the main reason for employers to support employees with a disability was employers' personal involvement, not the sanctioning law [55].

Future Research

This research was limited to the experiences of employees with NMD still at work regarding their strategies pertaining to job retention. Further research including employees with NMD after job loss, and health professionals' views on employment issues for employees with NMD is necessary to better understand possible problems and determining factors in job retention.

Research on the effect of educating physicians and allied health professionals in early recognition of the impact of chronic diseases on employment participation, as well as cohort studies on the long term effect of immediate one-off consultation by an interdisciplinary team to support

persons with NMD at risk for unemployment after diagnosis is recommended.

Seeking the perspectives about work by persons with NMD who have already left work could also be a valuable addition to this research.

Conclusions

Paid employed persons with a slow progressive adult type of NMD who are confronted with decreasing physical abilities in their most productive years valued employment as an important aspect of their lives. The meaning of work as well as the tension of decisions accompanying employment throughout the lives of participants was identified in four themes: (1) *Experiences regarding the meaning of work*: “Work is belonging”; (2) *Solving problems oneself*: “I am not going to tell”; (3) *Reaching a turning point*: “I have to be realistic”; and (4) *Taking into account environmental aspects*: “I can understand both sides”. Paid employed persons with NMD might have a strong willingness to work, irrespective of disease severity, likely due to the persons sampled (11). Despite tensions, participants expressed why they choose to stay at work by elaborating on social, economic and emotional benefits they experience from being employed. This study also showed that participants were challenged to keep up at work versus home, and how this shaped decisions about remaining at work. Participants’ deployed coping strategies focusing on keeping their job by hiding symptoms and postponing disclosure. Participants experienced a moral pressure at work to ‘keep up appearances’, and tensions with regards to when and if to disclose, since disclosure didn’t always make things better. Often the impact of their condition and behaviour on colleagues became apparent to them only after disclosure, when communication became more open. It is then that they perceived assistive products, communication of work problems, work accommodations, considerate colleagues and above all good relationships with superiors willing to support their job retention as increasingly important along with greater dependence due to physical deterioration. Support from superiors was valued most highly, since the participants perceived their role as most important in the final decision making regarding participants’ job retention. Apparently some participants felt also threatened by work reorganization. Indeed macro-economic circumstances and reorganization could overrule employers’ intentions and governmental regulations that are meant to support people with a disability in job retention. In that case participants with an NMD felt disadvantaged compared to healthy colleagues. Implications for health professionals might include awareness of the significant impact of a slowly decreasing physical condition

on employment. Timely communication and appropriate referral of persons with a work problem to a health or occupational professional is recommended in order to inform and empower employees with NMD in job retention.

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References

1. Kayes R, French P. Out of darkness into light? Introducing the convention on the rights of persons with disabilities. *Hum Rights Law Rev.* 2008;8(1):1–34.
2. WFOT. Position paper on human rights. 2006. <http://www.wfot.org/ResourceCentre.aspx>. Accessed 15 Jan 2013.
3. Kalkman JS, Schillings ML, Zwarts MJ, van Engelen BG, Bleijenberg G. The development of a model of fatigue in neuromuscular disorders: a longitudinal study. *J Psychosom Res.* 2007;62:571–9.
4. Turner C, Hilton-Jones D. The myotonic dystrophies: diagnoses and management. *J Neurol Neurosurg Psychiatry.* 2010;81(4):358–67.
5. Dyck PJ, Thomas PK. *Peripheral neuropathy*. 4th ed. New York: McGraw-Hill; 2005.
6. Pandya S, King WM, Tawil R. Facioscapulohumeral dystrophy. *Phys Ther.* 2008;88:105–13.
7. NPCG. *Forecasting Health. Health and Determinants based on figures from the national panel of chronically ill and disabled* [in Dutch]. Utrecht: NIVEL; 2010.
8. Minis MA, Kalkman JS, Akkermans RP, Engels JA, Huijbregts PA, Bleijenberg G, et al. Employment status of patients with neuromuscular diseases in relation to personal factors, fatigue and health status: a secondary analysis. *J Rehabil Med.* 2010;42:60–5.
9. Wevers CW, Brouwer OF, Padberg GW, Nijboer ID. Job perspectives in facioscapulohumeral muscular dystrophy. *Disabil Rehabil.* 1993;15(1):24–8.
10. Fowler WM Jr, Abresch RT, Koch TR, Brewer ML, Bowden RK, Wanlass RL. Employment profiles in neuromuscular diseases. *Employ Profiles Neuromuscul Dis.* 1997;76(1):26–37.
11. Andries F, Wevers CW, Wintzen A, Bush HF, Howeler CJ, de Jager AE. Vocational perspectives and neuromuscular disorders. *Int J Rehabil Res.* 1997;20(3):255–73.
12. ISO 9999. Assistive products for persons with disability—classification and terminology. http://www.iso.org/iso/catalogue_detail.htm?csnumber=50982;2011.
13. Minis MA, Cup EH, Heerkens YF, Engels JA, van Engelen BG, Oostendorp RA. Exploring employment in consultation reports of patients with neuromuscular diseases. *Arch Phys Med Rehabil.* 2012;93:2276–80.
14. Minis MA, Heerkens YF, Engels JA, Oostendorp RA, van Engelen BG. Classification of employment factors according to the international classification of functioning, disability and

- health in patients with neuromuscular diseases: a systematic review. *Disabil Rehabil*. 2009;31(26):2150–63.
15. Furlan AD, Penninck V, Bombardier C, van Tulder M. Updated method guidelines for systematic reviews in the Cochrane Back Review Group. *Spine*. 2009;34(18):1929–41.
 16. Kalkman JS, Schillings ML, Werf SP, Padberg GW, Zwarts MJ, van Engelen BG. Experienced fatigue in fascioscapulothoracic dystrophy, myotonic dystrophy and HMSN-I patients. *J Neurol Neurosurg Psychiatry*. 2005;76(10):1406–9.
 17. Bleijenberg G, van der Horst H, van der Meer J, Knoop H, editors. *Handbook Chronic fatigue* [in Dutch]. Utrecht: De Tijdstroom; 2012.
 18. Nätterlund B. Activities of daily living and quality of life in persons with muscular dystrophy. *J Rehabil Med*. 2001;33(5):206–11.
 19. Cup EH, Kinébanian A, Satink T, Pieterse AJ, Hendricks HT, Oostendorp RA, et al. Living with myotonic dystrophy; what can be learned from couples. A qualitative study. *BMC Neurol*. 2011; 11:86.
 20. Tsutsui T, Horie S, Kaji H. Occupational physician's role regarding return to work of workers with acquired disability article in Japanese. *J UOEH*. 2002;327–36.
 21. Varekamp I, Haafkens JA, Dettle SI, van Dijk JH. Preventing work disability among employees with rheumatoid arthritis: what medical professionals can learn from patients' perspective. *Arthritis Rheum*. 2005;53(6):965–72.
 22. Ybema JF, Evers M. Quality of life. Profile Labour and Health [in Dutch]. Hoofddorp: TNO [Dutch Organization for Scientific Research]; 2005.
 23. VSN (Vereniging Spierziekten Nederland). <http://www.vsn.nl/>; 2012.
 24. Williams RJ. The declaration of Helsinki. *Bull World Health Organization*. 2008;86(8):650–1.
 25. Bogdan RC, Biklen SK. *Qualitative research for education: an introduction to theories and methods*. 5th ed. Boston: Alien and Bacon; 2006.
 26. Dettle SI, van der Gulden JW, Engels JA, Heerkens YF, van Dijk FJ. Using intervention mapping (IM) to develop a self-management programme for employees with a chronic disease in the Netherlands. *BMC Public Health*. 2010;10(353). <http://www.biomedcentral.com/1471-2458/10/353>.
 27. Freedman RI, Fesko SL. The Meaning of work in the Lives of People with Significant Disabilities: Consumer and Family Perspectives. *J Rehab*. 1996; 62(3):49–7. <http://www.auburn.edu/academic/education/sences/classinfo/summer02/article7.pdf>. Accessed 15 Jan 2012.
 28. van Oorschot W. The Dutch welfare state: recent trends and challenges in historical perspective. *Eur J Soc Sec*. 2006;8:57–76.
 29. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of self-management in chronic illness. *J Nurs Scholarsh*. 2012;44:136–44.
 30. Kübler-Ross E, Kessler D. *On grief and grieving: finding the meaning of grief through the five stages of loss*. London: Simon and Schuster Ltd.; 2005.
 31. Julian LJ, Vella J, Vollmer T, Hadjimichael O, Mohr DC. Employment in multiple sclerosis. Exiting and re-entering the work force. *J Neurol*. 2008;255(9):1354–60.
 32. Munir F, Leka S, Griffiths A. Dealing with self-management of chronic illness at work: predictors for self-disclosure. *Soc Sci Med*. 2005;60(6):1307–97.
 33. Gilmour JA, Huntington A, Wilson HV. The impact of endometriosis on work and social participation. *Int J Nurs Pract*. 2008;14:443–8.
 34. Neal-Boylan L, Hopkins A, Skeete R, Hartmann SB, Lezzoni LI, Ninez-Smith M. The career trajectories of health care professionals practicing with permanent disabilities. *Acad Med*. 2002;87(2): 172–8.
 35. McNamara P. How and when to tell your boss and coworkers about your parkinson's disease. <http://parkinsons.about.com/od/livingwithpd/a/working.htm>. 2009. Accessed 13 Aug 2012.
 36. Lorig K. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*. 2003;26(1):1–7.
 37. Chorus AM, Boonen A, Miedema HS, van der Linden SJ. Employment perspectives of patients with ankylosing spondylitis. *Ann Rheum Dis*. 2002;61:693–9.
 38. Haafkens JA, Kopnina H, Meerman MG, van Dijk FJ. Facilitating job retention for chronically ill employees: perspectives of line managers and human resource managers. *BMC Health Serv Res* 2011; (11)104. <http://www.biomedcentral.com/1472-6963/11/104>.
 39. Jans LH, Kaye HS, Jones EC. Getting hired: successfully employed people with disabilities offer advice on disclosure, interviewing, and job search. *J Occup Rehabil*. 2012;22(2):155–65.
 40. Andries F, Kremer AM, Hoogendoorn WE, Wevers CW. Working with a chronic disorder—the development of the work and handicap questionnaire. *Int J Rehabil Res*. 2004;27(1):37–44.
 41. Baanders AN, Andries F, Rijken PM, Dekker J. Work adjustments among the chronically ill. *Int J Rehab Res*. 2001;24:7–14.
 42. Wisenthal A. Occupational therapy provides the bridge back to work. *Occupational Therapy Now*. 2004;6(4). Retrieved from <http://www.caot.ca/default.asp?pageid=1185>.
 43. Holland P, Burström B, Whitehead M, Diderichsen F, Dahl E, Barr B, et al. How do macro-level contexts and policies affect the employment chances of chronically ill and disabled people? Part I: the impact of recession and deindustrialization. *Int J Health Serv*. 2011;41(3):395–413.
 44. Sirvastava S, Chamberlain MA. Factors determining job retention and return to work for disabled employees: a questionnaire study of opinions of disabled people's organizations in the UK. *J Rehabil Med*. 2005;37:17–22.
 45. Pieterse AJ, Cup EH, Akkermans RP, Hendriks HT, van Engelen BG, van der Wilt GJ, et al. Optimizing referral of patients with neuromuscular disorders to allied health care. *Eur J Neurol*. 2009;16(5):562–8.
 46. Munir F, Yarker J, Haslam C, Long H, Leka S, Griffiths A, et al. Work factors related to psychological and health-related distress among employees with chronic illnesses. *J Occup Rehabil*. 2007; 17:259–77.
 47. van Nes F, Abma T, Jonsson H. Language differences in qualitative research: is meaning lost in translation?. doi:10.007/s10433-010-0168-y. 2010. Accessed 30 Jan 2013.
 48. Coole C, Radford K, Grant M. Returning to work after stroke: perspectives of employer stakeholders, a qualitative study. 2012. doi:10.1007/s10926-012-9401-1.
 49. Elliott J. *Using narrative in social research*. London: Sage; 2005.
 50. Varekamp I, Verbeek JH, van Dijk FJ. How can we help employees with chronic diseases to stay at work? A review of interventions aimed at job retention and based on an empowerment perspective. *Int Arch Occup Environ Health*. 2006;80(2):87–97.
 51. Gilworth G, Haigh R, Tennant A, Chamberlain MA, Harvey AR. Do rheumatologists recognize their patients' work-related problems? *Rheumatology*. 2001;40:1206–10.
 52. Dettle SI, Haafkens JA, van Dijk FJ. What employees with rheumatoid arthritis, diabetes mellitus and hearing loss need to cope at work. *Scand J Work Environ Health*. 2003;29(2):134–42.
 53. Johnson KL, Yorkston KM, Klasner ER, Kuehn CM, Johnson E, Amtmann D. The costs and benefits of employment; a qualitative study of experiences of persons with multiple sclerosis. *Arch Phys Med Rehabil*. 2004;85(2):201–9.
 54. Hoogevorst JF, Korthals AH. *Wet verbetering poortwachter* [in Dutch]. Staatscourant. 2001;628:1–19.
 55. Van Elderen TN. *The chronically ill and work; (no) Limitations for entering workforce* [in Dutch]. 1995. Den Haag: Ministry of Social Affairs VUGA.