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ORIGINAL ARTICLE

## Chronic ventilation and social participation: experiences of men with neuromuscular disorders

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### Abstract

**Objective:** The purpose of this study was to investigate how mechanical ventilation-dependent adults with neuromuscular disorders experience their occupational and social participation. **Methods:** Data were collected through two successive focus-group discussions with six men (aged 23–40 years) living in the same specialized nursing home in the Netherlands. **Results:** The results showed that the participants wanted to be involved in activities that provide interaction with others in society or community; they desired social participation. Thematic analysis brought out that the participants wanted to be taken seriously in all aspects of life. Four themes emerged: “Responsibility for risk-taking”, “The influence of dependency”, “Being treated as an employee”, and “Maintaining optimism”. These men appreciated good information from health care providers, wanted to have more autonomy in decision-making and risk-taking – and did not wish to be patronized. They wanted to have a social network to help them suction their tracheal cannula. Also, they would like activities at the activity centre to be more contributing to society and wished to be treated as employees rather than as clients. In view of their short life expectancy, they would also welcome discussions of end-of-life issues in group sessions led by a professional. Facilitating aspects of social participation, i.e. the experience of meaningful occupations in connection with autonomy and self-determination, would provide a more client-centred approach.

**Key words:** *autonomy, chronic mechanical ventilation, focus groups, invasive ventilation, self-determination, thematic analysis*

### Introduction

The right to participate fully and equally in the community is a right for everyone in society regardless of functional status (1). In everyday life, however, people with severe or progressive disabilities, such as neuromuscular disorders (NMD), are often facing challenges in participation. NMD are characterized by progressive weakness, limb contracture, spine deformity, and decreased cardiopulmonary function (2). The two commonest types are Duchenne muscular dystrophy (DMD) and spinal muscular atrophy type II (SMA-II) (3). These disorders are both genetically determined. DMD affects the proximal muscle groups such that the

patient progressively loses strength, can no longer ambulate independently around the age of nine years, and becomes wheelchair dependent at around 12 years (4,5). DMD afflicts only men. SMA-II is less progressive but also produces profound global muscle weakness (6).

Since 1990, when chronic mechanical ventilation was introduced in the Netherlands, the mean life expectancy of men with DMD has increased from 19 years to 24 years (4,7). Some even have reached the age of 40 years. This treatment is either invasive via a tracheostomy or non-invasive via a nasal tube, nasal mask, or mouth mask. Tracheostomy ventilation always requires 24-hour assistance because the tracheal cannula may become dislodged or get

clogged. Non-invasive ventilation, however, may be applied only at night or 24 hours a day (4,8–10).

Before the introduction of chronic mechanical ventilation, boys with DMD were neither expected to reach adulthood nor to have special needs for employment or leisure activities. In the Netherlands, quite a few of them live in nursing homes, if parents can no longer provide the care needed. In 2006, 67 persons treated by chronic mechanical ventilation were living in 20 institutions (mostly nursing homes) in the Netherlands. It is not exactly known how many had NMD (8). Eleven of these 20 nursing homes provided special activities for young adults (11).

The technical aspects of mechanical ventilation in individuals with DMD have been widely researched. Only a few studies, however, have considered quality of life and participation of adult men with DMD (5,12–14). Almost all researched men with DMD lived in the community or at home. For example, Abbott and Carpenter conducted face-to-face interviews with 40 young men with DMD, their parents, and siblings. These young men appeared to have very limited social opportunities or friends beyond their immediate family, while the relationships with family members were often extremely close (14).

Qualitative research among 11 patients living with SMA revealed four coping strategies: establishing strong relationships, normalizing and mainstreaming in society, using an innovative approach to symptom management, and maintaining optimism (15).

Several studies inventoried views and experiences of ventilator-dependent adults and children with different diagnoses (16–18). Brooks et al. (16) administered interviews focused on quality of life, which apart from satisfaction and support also revealed dissatisfactions and barriers. Briscoe and Woodgate (18) interviewed 11 ventilator-dependent adults on their recent transition to chronic ventilation. They identified five themes: “tyranny of symptoms”, “self in peril”, “awakening to a paradox”, “struggling for autonomy”, and “life goes on with a reclaimed self”.

Overall, the literature revealed that having NMD or receiving chronic mechanical ventilation seems to have a profound effect on daily functioning and quality of life and poses challenges to emotional adaptation and social participation. No studies were found describing participation experiences of institutionalized ventilator-dependent adults with NMD.

In the International Classification of Functioning, Disability and Health (ICF), participation is described as “involvement in a life situation” [(19), p 16]. Hemmingsson and Jonsson (20) critically reviewed the ICF concept of participation, as it ignores the subjective experience of meaning, the client’s autonomy, and the environmental influences on participation. They propose to distinguish between participation

from an occupational perspective and from a social perspective. An individual may experience social participation not only when undertaking activities with others (21), but also when having an alternative role in the activity (22). Social participation also happens when a person does not have any involvement in the activity itself, but is just “being there” where things actually happen (23). For this study we were inspired by Hemmingsson and Jonsson’s description of the social perspective (20), and their criticism of the ICF definition of participation. Therefore we used the following definition of social participation: “A person’s involvement in activities that provide interaction with others in society or community” [(24), p 2148]. We propose that the six levels of involvement identified in the literature on ageing people may also be applicable to young adults. These six levels are:

- (1) Doing an activity in preparation for connecting with others.
- (2) Being with others.
- (3) Interacting with others without doing a specific activity with them.
- (4) Doing an activity with others.
- (5) Helping others.
- (6) Contributing to society [(24), p 2148].

The aim of this study was to investigate how mechanical ventilation-dependent young adults with neuromuscular disorders, living in a specialized nursing home, experience their occupational and social participation.

## Material and methods

A qualitative design was applied, which is appropriate to subjective processes and therefore to the study aim. The aim was not searching for one truth; each and every view of the individual participants was considered interesting and of value (25). We held preparatory individual interviews with two ventilator-dependent adults with NMD to map the problems they are faced with and to explore the feasibility of a qualitative design. One was an active member of the patient organization, and she recommended group sessions rather than individual interviews because, in her experience, men with NMD do not talk easily about sensitive topics. The other interviewee confirmed this and also preferred to discuss participation issues with peers. Therefore, we applied focus group methodology, which elicits a multiplicity of views and emotional processes within a group context (26–28).

### Participants

Eligibility criteria were the following: confirmed diagnosis of Duchenne Muscular Dystrophy or Spinal

Table I. Statements presented in the second focus-group discussion.

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I find it more important to have a social network of people who are capable of assisting with suctioning than to have real friends.
I find it important to have contact with other young adults.
I find it important to have contact with non-disabled young adults.
I experience it as a violation of my privacy to always have someone around to assist me.
I sometimes take the risk of not getting help on time by going out on my own.
I find it very disturbing that I cannot do things spontaneously.
I wish I had never chosen chronic mechanical ventilation at the time.
I think my quality of life is low.
It is important to have both leisure activities and work activities.

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Muscular Atrophy type II; age between 18 and 40 years; treated with chronic mechanical ventilation; and living in an institution in the Netherlands. The participants were selected by convenience sampling. In 2009 it was established that only a few Dutch nursing homes housed residents that met these criteria (11). After having consulted the managers of these nursing homes, we decided to restrict the sample to one institution, “The Hamlet”, because here the relatively large number of 20 residents met the eligibility criteria.

“The Hamlet” is the pseudonym of a special institution for more than 300 physically disabled people of all ages, located on the outskirts of a mid-sized town in the Netherlands. The residents live in private apartments with one bedroom, a living room, and a small kitchen. They can rely on 24-hour care and have leisure opportunities, including a pub and three activity centres, one of which is aimed at young adults. The activity centre provides leisure-related activities such as acting and watching movies; and more work-related activities such as typing the restaurant’s menu, or making photocopies. The care coordinators of “The Hamlet” identified 20 residents who met the inclusion criteria. Six men (aged 23–40) agreed to participate. Reasons for refusal were not recorded. Four participants were diagnosed with DMD and two with SMA type II. Four had a tracheostomy and two used a nasal mask during the night. One participant participated only in the second of the two focus-group discussions. The participants had been residents for between three and 15 years; two had previously lived at their parents’ home, and four had been transferred from other specialized facilities. All six were electric-wheelchair dependent. All had had at least vocational training; two of them had also received several years of higher education. Four participants were active on the institutional client board. One participant had a girlfriend; all others were single.

To prepare for the focus-group discussions we visited “The Hamlet” twice, performed intake interviews with the participants, and prepared a discussion guide. Also, we piloted a focus-group discussion with three adults in another nursing home. These, however, lived among people aged 70 and over, unlike those in “The Hamlet”. The session was helpful to prepare the research in “The Hamlet”, but the data were not included in the final analysis and are not presented here.

#### *Data collection*

Two successive focus-group discussions with the six participants were conducted in April and May 2009. The discussions were moderated by an academic with substantial experience in moderating focus groups, together with a co-moderator (SvH). Each session lasted about two hours and took place in the common living room of two of the participants. Other inhabitants or nurses were asked not to enter the room (26,27). Nevertheless, nurses were on standby if suctioning of the tracheal cannula was needed.

The discussion guide for the first session included just a few open questions, which were phrased to elicit personal experiences. Two examples of questions are: “How do you feel about the opportunities for activities you have?” and “How do you feel about your social relations?” We also asked how the type of ventilation influenced their activities and social relations.

The second session was guided by nine statements derived from thematic analysis of the transcript of the first session (Table I). This approach was chosen to further stimulate reflection and to confirm our first interpretation of the results (28).

#### *Data analysis*

Both sessions were tape-recorded and transcribed verbatim. The transcriptions were analysed by reading and re-reading to identify initial ideas and hunches (SvH). First an eyeball approach (26) was used to identify the main issues. Next, thematic analysis was applied using the qualitative software program Atlas.ti version 5.0 (<http://www.atlasti.com>). Thematic analysis was chosen for its flexibility and theoretical freedom (29,30). The initial coding procedure started with inductive open coding. This yielded 40 codes closely linked to the text, for example: “responsibility”, “taking risks”, “safety”, “trust myself”. These codes were then merged into 12 categories that were checked with the topics in the discussion guide. For example, the above-mentioned codes were grouped into the category “how to deal with ventilation”. Finally, four central themes and one

Table II. Analysis scheme.

Central themes	Categories
Responsibility for risk-taking	Implications of chronic ventilation How to deal with ventilation Responses of the health care providers
Influence of dependency	Chronic ventilation: assistance from others Being dependent on other people Dealing with the dependency
Being treated as an employee	Meaningful activities Feeling not being taken seriously Difference between leisure activities and work
Maintaining optimism	Handling a serious disorder/approaching death Coping style Contact with other people

overarching theme were identified. These themes were checked by rereading the transcript, the initial ideas, and the field notes, and then peer-reviewed by the moderator and colleagues in our research group (Table II).

#### *Trustworthiness*

The four components of trustworthiness established for qualitative research (31,32) were all achieved in this study. *Credibility* was achieved by peer debriefing in the research group as well as respondent validation. The second focus-group session served as a member-check, in which the preliminary interpretations were discussed with the participants. *Dependability* was provided by a detailed description of the analysis process, which was additionally peer reviewed by colleagues and by the moderator. *Confirmability* was established by making field notes and writing reflective memos during the visits to the nursing homes and during the focus-group sessions. *Transferability* was enhanced by describing the participants in detail.

#### *Ethical considerations*

The Medical Ethics Review Board of Erasmus MC, University Medical Centre Rotterdam, gave approval. All participants received oral and written information and signed a letter of informed consent. In the intake interviews, the researcher (SvH) took care not to press candidate participants to participate in this study. She pointed out that participants had the right to withdraw from the study at any time for any reason; indeed, one candidate participant decided not to continue after the intake interview. Anonymity was guaranteed by using pseudonyms in the transcript and publications. After each session the researcher sent a debriefing email to all participants, inviting them to reply and to vent their emotions and feelings.

## Results

The first analysis, in which an eyeball approach was applied (26), showed that the participants mainly addressed issues related to social participation. Occupational participation was of less importance for them. We then decided to focus only on social participation in the thematic analysis. This brought to the fore the overarching theme of wishing to be taken seriously in all aspects of life. These men wished to be seen as responsible, autonomous adults who can make their own decisions; they wanted to have self-determination in risk-taking; and desired to be engaged in meaningful work and leisure activities – so as to give meaning to occupational activities. They also wanted to be taken seriously in talking about their approaching death. This overarching theme can be broken down into four themes: “Responsibility for risk-taking”, “The influence of dependency”, “Being treated as an employee”, and “Maintaining optimism”.

#### *Responsibility for risk-taking*

Participants felt it was risky to go out on their own because they might suffocate if the tracheal cannula should get clogged or dislodged. This risk limited their social participation. Some tended to take more risks, especially when the activity was attractive or involved people important to them. For example, Raymond chose to be autonomous and took a taxi alone to see his girlfriend, a trip lasting up to one hour:

If you don't really like something, then you don't take the risk. But if you really like it, you take the risk. Yes, that's what you do. (Raymond)

Others adhered to health care providers' advice never to leave the institution without assistance:

Yes, I myself choose to take no risk at all. (Jeffrey)

All participants wanted to take responsibility for their own choices. They expected health care providers to inform them well on the risks, enabling them to make well-informed choices. They did not like being patronized or being made insecure:

I think that they [the health care providers] should give you your own responsibility. You should decide yourself what risks you want to take and you should know what rules and regulations there are. (Timo)

#### *The influence of dependency*

The type of ventilation had a strong influence on the degree of social participation. Invasive ventilation necessitates permanent assistance for suctioning.

Therefore, these participants felt greatly dependent on others and this hindered their social participation. Rick wears a nasal mask when sleeping, but does not yet need a tracheal cannula. When talking about this prospect, he said:

I would mind having someone around all the time. That might be the thing I am least looking forward to. (Rick)

Some participants solved this problem by creating a friends network and asking for support from relatives who did not shrink back from assisting with suctioning:

It is important to make sure that the people around you are not afraid to help you with suctioning the cannula. Once you've settled this, ventilation doesn't have to be a big problem any more. You can do whatever you like if you're on chronic ventilation. You are dependent, but if you create a network, and do it properly, you are less dependent, so to speak. (Sander)

All participants felt that a strong social network is important, but their social interaction seemed mainly restricted to people they know in or through "The Hamlet".

Because of their dependency on people who can assist with tracheal suctioning, it is hard for them to act spontaneously – and some were bothered by this:

Before I was on chronic ventilation I could go out to town easily. These are the things I miss. Not being able to do things spontaneously and needing someone with me for the ventilation all the time. ... It's not easy to just go and do something; that bothers me. (Arie)

They also felt that they always had to be nice to the assistants and make sure they have a nice day too. Timo came up with a solution for this feeling of dependency:

I was thinking, imagine there is a volunteer you could arrange, and imagine there is some agency you could hire a person from for just a little money. So you could hire someone for just the time you need. You don't have to know this person, and you can do whatever you want. (Timo)

#### *Being treated as an employee*

The participants felt the activities organized at the activity centre were just a way to pass the time and were hardly meaningful either to them or to society:

Well, sometimes I go to the activity centre. They offer some nice activities, but I feel like I always feel when being there, that they just keep you occupied. (Rick)

The participants wanted to be taken seriously as employees; they wanted their educational background and other capacities to be recognized. They would appreciate having meaningful activities that make a real contribution to society:

We are just clients, and that is what we are called. In the past [in his former job], I was an employee. Then you feel taken more seriously. (Arie)

The participants said they should have a choice between leisure activities and work-related activities. In fact, they wanted to have both, fun activities and obligatory activities:

Yes, it is a nice hobby [acting at the activity centre], as a leisure activity, I mean. Some call it work, but I can't see it like that. I don't work and have a spare-time hobby instead. (Raymond)

#### *Maintaining optimism*

On several occasions the men pointed out that they were "just like others". They were optimistic and claimed not to feel depressed at all. They used different coping strategies to manage life with this life-limiting disorder. All demonstrated aspects of the coping dimensions "Optimistic" and "Supportive" (33); they used humour, and had built a social network of friends and relatives.

As they cannot help having an impairment, they had better accept it, as Timo said:

I think it's quite useless to be sick of things, especially if these bear upon your disability. You can't change it, so it doesn't help to get frustrated yourself. So I think I have somehow overcome it over the years. (Timo)

This attitude does not imply denial of the severity of their condition. Maintaining optimism seems conditional for social participation. All men realized that they had few options but to accept chronic ventilation, while they were also aware of the possibility of an early death:

If you die, you don't have anything left. Otherwise [if opting for a tracheostomy] you may be saddled with a restriction for life. (Raymond)

Although they spoke openly about death, the participants had never discussed this with health care providers before. They told us they would prefer to discuss this in a professional-led group session.

#### **Discussion**

This study explored how men with neuromuscular disorders who received chronic mechanical ventilation and lived in a specialized nursing home experienced

their occupational and social participation. Merely being “involved in a life situation” (as the ICF definition has it) was not the main issue for these men. They considered involvement in interaction with other people in the society or community much more important, in line with the definition of social participation by Levasseur et al. (24). Although this definition refers to participation in the context of ageing, it is relevant also in the context of adults living with NMD. All aspects of the social perspective of Hemmingsson and Jonsson (20) were visible in the results. The participants’ desire to be treated as employees rather than as clients at the activity centre has aspects of the experience of meaning in connection with participation in a life situation – they wish to be regarded as “normal” citizens. Appreciating suitable information provision from health care providers and having a choice in risk-taking are aspects that demonstrate a desire for self-determination; striving for “normalization” and building a social network are related to both autonomy and self-determination.

Our results particularly match the results of a recent study by Hjelle and Vik (34), who performed two focus-group discussions with six adult wheelchair users who were not ventilation-dependent. These discussions yielded three criteria found to be important for participation: “being engaged”, “being a member of society”, and “interacting as a citizen”. The authors also suggested it would be valuable to include the subjective dimension of participation in the ICF model (34). The participants in our study expressed a desire for different levels of involvement (24), not only by stressing the importance of “being with others” (level 2), or “interacting with others without doing a specific activity with them” (level 3), but also by wishing to reach the highest level of involvement: “contributing to society” (level 6) by doing meaningful work at the activity centre. In the reviewed studies, however, our theme “Being treated as an employee” was not described. “Responsibility for risk-taking” was mentioned by Briscoe and Woodgate, who found that the participants experienced loss of freedom and independence in spite of health-care providers’ concerns for their safety (18). “The influence of dependency” was also identified by Brooks et al., who also recommended patients should receive more support – from personal support workers or attendant services (15). The participants in our study, however, perceived dependency on others also as a barrier, because it made them feel indebted to the assisting friend or relative. There is some overlap between the coping styles found in our study, described in the theme “Maintaining optimism”, and those found in a study of adults with SMA (17). As in our study, these adults particularly aimed at establishing strong relationships and retaining optimism, as this enabled their participation.

Living in an institution, even if located in a town and housing a number of people with disabilities, is known to limit social participation. Nevertheless, our results closely resemble those of Abbott and Carpenter (14), whose participants (men with DMD) lived at home with their parents.

An important, yet unexpected, finding was that our participants were talking openly about their impending death, unlike adults with DMD in the study by Kohler et al. (13), who were reluctant to discuss the later stages of disease. Also, most of the interviewed men with DMD in the study by Abbott and Carpenter (14) preferred not to think about death very much, but they did not want to ignore it either. In our study, these issues were raised during the second focus-group session, when some trust had already been established. The issue was brought up spontaneously by one participant with SMA, after which the others, including the men with DMD, joined in.

The results of this study are important for health care teams, including occupational therapists, supporting adults with NMD. According to the men interviewed, team members would do well not to patronize their clients, but to provide them with relevant information and to let clients themselves assess the risk of clogging of the tracheal cannula, thereby extending client autonomy and self-determination. We also recommend these adults should be offered professional support and a group environment to enable them to discuss their feelings and concerns surrounding death.

This study is also of importance to occupational therapists and others working in activity centres and other services for adults with disabilities. Activity centres should provide activities that are socially meaningful and useful. They should treat their users as employees, not as clients.

Probably instigated by this research project, the participants decided to ask nursing students to form a pool of personal support workers who could be hired to assist with tracheal suctioning. In this way, they would be no longer dependent on friends and relatives.

### **Strengths and limitations**

Ventilation-dependent adults are hard to reach and speaking is often tiresome for them. The fact that we found six men willing to participate in two focus-group discussions may be considered a strength of this study. During the second session, in which sensitive issues such as (fear of) dying and intimate relations were discussed, the participants confirmed the tentative analysis of the first session, but also added new ideas and deeper understanding.

On the other hand, the participants themselves suggested that their opinions might not be representative of mechanical ventilation-dependent adults who still live with their parents, or in institutions with few other young adults. But also in “The Hamlet” they felt they formed a selected, rather active group, as the other adults with the same diagnosis hardly ever left their rooms and rarely engaged in social activities. Thus, recruitment bias may likely have occurred. Moreover, as only men participated, we did not learn about women’s experiences, which may be different.

#### *Further research and action*

Additional research in this field should focus on the experiences of less socially active persons, perhaps to be recruited via their peers. It could also be worthwhile to learn of the experiences of adults with NMD who still live at home with parents. On the other hand, we would recommend studying professional perspectives as well. Finally, discussing the findings of this study with health care providers and asking them how shared decision-making could be implemented could perhaps result in services that are better attuned to the needs of ventilated adults with NMD. This study also indicates the importance for occupational therapists to further investigate preferences for and experiences of different levels of social participation in (young) adults with other disabilities.

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