

EMPIRICAL STUDIES

Living with severe physical impairment, Duchenne's muscular dystrophy and home mechanical ventilation

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Abstract

Aim: To study life-experiences of people living with Duchenne's muscular dystrophy (DMD), home mechanical ventilation (HMV) and physical impairment.

Background: Since the introduction of invasive HMV in the late 1980s people with DMD in Denmark live longer and have the experience of adulthood and a high degree of physical dependency.

Method: Nineteen patients with DMD and invasive HMV were interviewed in 2007. The interviews were recorded, transcribed verbatim and analysed according to a method inspired by Ricoeur's theory of interpretation.

Findings: HMV not only extended the participants lifespan, it also gave them the capacity to live an active life. They were totally dependent in everyday living, but in spite of this, they did not see themselves as physically impaired. They realised that there were activities that were physically impossible, but they considered themselves to be just the same person they had always been. This dependency was described as "independent dependency".

Conclusion: The lived-experience of physical impairment is found to be "independent dependency" in an active life. To solve problems with loneliness, society needs to work with prejudice and misunderstanding and for better physical accessibility to enable full participation.

Key words: *Physical impairment, Duchenne muscular dystrophy, home mechanical ventilation, respiratory failure, Ricoeur*

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In a qualitative study capturing patient's life-experiences of living with Duchenne's muscular dystrophy (DMD), home mechanical ventilation (HMV) and physical impairment in Denmark, patients told not only about their experiences of living with HMV, but also about their experiences of living with physical impairment. The patients were wheelchair dependent; they could only slightly move their fingers and a ventilator controlled their breathing. They were dependent on help with all daily living activities. Despite this high degree of physical dependency, many of the patients felt independent, and they led active, extrovert lives. The aim of this paper is to present life-experiences of living with DMD, HMV and physical impairment from a patient perspective

and with special emphasis on the experience of living with physical impairment.

Background

DMD is a progressive neuromuscular disease, with loss of muscle strength starting in early childhood leading typically to wheelchair dependency by the age of 10. The onset of respiratory involvement in the teen years leads to respiratory insufficiency and death when the patient is in his twenties without respiratory assistance (Lindsay & Bone, 2004). Since the introduction of invasive HMV in the late 1980s and the establishment of two specialist centres, people with DMD in Denmark live longer, attain

adulthood and their disease progresses further than would otherwise have been the case, to an extent where they are totally dependent in all daily living activities. Practically every DMD-sufferer chooses invasive HMV and typically the treatment will start at the age of 16–19 years with non-invasive ventilation, later progressing to tracheostomy and invasive ventilation (Rahbek et al., 2005). Furthermore they benefit from generous welfare provision, offering inter-disciplinary rehabilitation and education programme at the Rehabilitation Centre for Neuromuscular Diseases (2009). They receive personal assistance in their homes 24-h a day paid for by the local authority, they are provided with their own cars and they receive normal school education supplemented with extra support if needed (Rahbek et al., 2005). From early childhood, DMD-sufferers live with gradually increasing physical impairment and dependency. Therefore there is now a whole generation of DMD-sufferers with the experience of living with severe physical impairment, DMD and HMV who have significant experience of being totally dependent in all aspects in life. People requiring HMV are described from the professional's viewpoint as the most vulnerable group with chronic disability (Stuart & Weinrich, 2001), they appear to miss out on an active social life; and people requiring HMV don't appear to be visibly engaging in social activities in the community (Duke & Street, 2003). The care they require places great demands on families/caregivers—economically, physically and socially, as well as on the health care service (Vitacca et al., 2007). In a qualitative study of four people living with DMD, HMV and tracheostomy (Dreyer, 2004) the participants described how they were living active and outgoing lives, and how they felt strong and independent and the meaning of autonomy was described as “autonomy of the thought”. There appears therefore to be a divergence between the professional's view and the patient's descriptions of being physically impaired.

From the philosophical perspective of Kant's moral philosophy, dependency is the opposite of autonomy; dependency seems inconsistent with independence and only the person who is independent can experience freedom (Henriksen & Vetlesen, 2000). The Danish theologian and philosopher K.E. Løgstrup (1905–1981) marked a break with Kant's moral imperative from a phenomenological perspective when he stated that “A person never has something to do with another person without also having some degree of control over him or her” (The Løgstrup archive, 2009). Løgstrup (1956) argued that dependency is a basic element of human life, where we must deal in the best interests of the other person, but we can never control another person's

life and take over the life-responsibility for another person. Pahuus (2005) describes Løgstrup's ethics as the “ethics of dependency”. In an analysis of physical dependency Martinsen (2010) concluded “people who become dependent on help from others because of loss of body function do not consider dependency as something universal, as described within phenomenology”. In the conclusion Martinsen (2010) doesn't differentiate between persons who have had abilities and then lost them and persons who never had those abilities. Toombs (2001) makes that differentiation and states that the experience differs. Therefore it could be of further interest to investigate the experience of dependency of people living with severe physical impairment from early childhood.

The study

The findings presented in this paper are part of a larger study capturing life-experiences of living with DMD, HMV and physical impairment. In this paper we will present the findings concerning life-experiences of living with severe physical impairment. The aim of the larger study was to study life-experiences of living with DMD, HMV and physical impairment from a patient perspective.

Methods

A way to capture life-experiences is to encourage the participants to talk about their lives (Kvale & Brinkmann, 2009); therefore narrative interviews where chosen in order to collect data. Using this method, the authors endeavour to explain and understand the meaning of life-experiences by interpreting narrative interviews transcribed as a text. According to the French philosopher Paul Ricoeur, interpreting a text is to see something new in what is already taken for granted, and to disclose a sort of being-in-the-world (Ricoeur, 1973b). Therefore a phenomenological hermeneutic approach inspired by Ricoeur's theory of interpretation was chosen for this study (Dreyer & Pedersen, 2009).

Participants

In order to obtain various perspectives on life-experiences (Kvale & Brinkmann, 2009), the age range of 18–40 years was defined and 21 participants were randomly selected from a group of 60 patients in Denmark that were treated with invasive HMV in 2007 by an outpatient nurse. Other inclusion criteria were that the participants should be diagnosed with DMD at a specialist neurological department and be receiving invasive ventilation. Furthermore, they

were required to be able to speak and understand the Danish language. All except one agreed to participate and one other was excluded after the interview because of an incorrect diagnosis. An outpatient nurse from each centre mediated the contact with the participants. A letter containing information about the study and an informed consent form were distributed to all the participants. By telephone the participants again were informed about the study and, for those who agreed to participate, an interview-visit was arranged.

The 19 participants (all men, as DMD only occurs in men) were aged 21–40 years (average 29 years) and they had been home mechanical ventilated via tracheostomy in a range from 3–18 years (average 10 years). All were able to speak because they had a tracheostomy tube without a cuff. They had all been diagnosed with DMD in their early childhood. All were wheelchair-bound and they all had personal assistance 24-h a day. They lived either on their own, with their parents or in shared living with other men with DMD, except one, who lived in an institution. They all had normal school education with the exception of one, who had special school education. Some had high school education and a few were university students, and very few had occupational experience.

Data collection

The interviews were performed by the author (PSD) in the participant's homes. Data were obtained by means of open narrative interviews (Kvale & Brinkmann, 2009). The participants were asked to speak without restraint about their lived-experiences living with DMD, HVM and physical impairment. The opening question was: "Please tell me about your life-experiences and about what is important to you in life". If needed, clarifying questions were asked, such as: "Can you give me an example?" and "Can you tell me more about that?" In most cases, the opening question gave rise to narratives about daily living with DMD, HVM and physical impairment, significant activities, sport and relationships. In a few of the interviews further questions were needed to start the interview or to keep the interview going and to capture life-experiences living with DMD, HVM and physical impairment. The questions were such as: "Can you tell me about particularly good or difficult experiences in your life?", "Can you tell me about the time when you started HVM" and "How do you experience your life with physical impairment?" Data were collected during 2007. The interviews lasted between 40 min and 2 h, and were recorded and transcribed verbatim.

Ethical considerations

Informed consent was obtained both verbally and in writing. All participants were informed that their participation was voluntary and that they could withdraw from the study at any time without any consequences for their further care and treatment. Furthermore, all parties were assured of anonymity and confidentiality when the findings were presented. The Committee for Scientific Ethics approved the study, and the study was reported to Data Supervisory Committee.

Data analysis

The data in this study consists of text. Text has to be interpreted and according to Ricoeur "what has to be interpreted in a text is what it says and what it speaks about" (Ricoeur, 1973a, p. 93). The analysis of the interview text was inspired by Ricoeur (1984) and a Nordic development of a Ricoeur-inspired analysis method that consists of three levels: a naïve reading, a structural analysis and a critical analysis and discussion (Lindseth & Norberg, 2004; Pedersen 1999). The three levels were further developed in Dreyer and Pedersen (2009) where distance in the interpretation and the text-structure was created by using narration linked to the meaning or understanding of what the text speaks about in all the interview texts.

The first reading of all the interview text is *the naïve reading*. With a phenomenological approach the text is read in order to acquire a general sense of the interview text as a whole in order to achieve an immediate understanding of the meaning content. Ricoeur, in "The Hermeneutical Function of Distanciation" states that a story, a poem or other literary type of text explicates a sort of "being-in-the-world" unfolded in front of the text (Ricoeur, 1973b, p. 140), therefore to create further distance to the interview texts *the structural analysis* was carried out on three levels: what is said (quotations), what it speaks about (a story) and theme (and sub theme) (Dreyer & Pedersen, 2009). The story (Table I) is a part of the structural analysis and is written in the first person but capturing meaning units from all 19 participants (Dreyer & Pedersen, 2009). The themes (Table II) identified in the story (Table I) are interpreted, discussed and argued for in *the critical analysis*; performed in a dialectic movement between explanation and comprehension achieved by relating both to the quotes from the interviews and to the story (Table I). In *the discussion* this dialectic movement between explanation and comprehension continues, and with relevant literature and pre-understanding there are

Table I. The story: my life with physical impairment.

Living with physically impairment

I have never seen myself as physically impaired. I see it when I look in the mirror, but I do not picture myself that way in my head; in my head I'm a normal person like everybody else. It must sound odd to you, here I'm sitting and can only move my thumb, and a ventilator controls my breathing, therefore I am both ill and very physically impaired, but I do not feel that way. Being physically impaired is a part of my life; it is a part of who I am. My childhood was positive and ordinary, but in my teens it was hard and lonely because of lack of social and physical accessibility. You get terribly lonely when you are kept out of the social community because of prejudice, where people see you as a cripple in a wheelchair who cannot do anything or because of physical accessibility. When my friends are having parties or other social gatherings I cannot join them because of the stairs. That's the way it is; I have muscular dystrophy. I have come to terms with that, because that's how I am, but I will not put up with social isolation, because we as a society can change that.

Childhood

I went to an ordinary school. I haven't ever been victimised, and my friends were always there to help me. I had a good and normal childhood. After primary school nobody knew what I should do, and I wanted to go to high school, but wasn't allowed to, now I do voluntary work. I do not know many people like me who have received an education and use that education. Maybe one or two, yes I know even one who has his own firm.

My family and my friends are the most important thing in my life; they have helped me throughout my life. My mum is the best; she knows every little detail in my life. For example: it only takes her a second to place my hand correctly on the joystick that controls my wheelchair. When I moved away from home it was difficult to lose her as a helper, but you don't move away from home and take your mum with you. Even though I am dependent upon the help of others, I am an independent person and I have to live my own life.

Soccer

I admit it, I am a sports fanatic. I love it; I watch sport on television, I watch all the local games, and I have even been to World Championship games abroad. Once I played wheelchair soccer, but I stopped after my back operation. It's a pity because I have many friends who still play-even after they got their ventilator. My best friend may get picked for the Wheelchair Soccer World Championship national team. He is so cool; it must be the biggest dream coming to be reality?

My dream is to go to the United States. Maybe it's a big one to plan-with the wheelchair, the lift, the toilet chair and an extra ventilator etc., but it can be done with good planning. I have to succeed; I want to experience a basketball match in "Gods own land".

Emotional and sexual aspirations

I think about it every night. Why didn't I get a girlfriend? Why wasn't it me the girls talked to in the canteen? Why didn't I invite a girl to a movie? It was too difficult, all that bother with ramps and everything, and maybe I did not dare. I knew a bloke that felt in love with his helper, and now the local authorities do not allow him to have female helpers. Luckily I got older and more mature and courageous. Now I do things I would not have done ten years ago. The internet has helped me a lot; there I can communicate with everybody. So I can say; you just have to be patient and suddenly you will succeed; now I have had a girlfriend for one and a half years.

Being a nice person

I think of myself as a kind and nice person with a positive outlook on life. I actually think that's why I am doing so well. I think of the things I'm able to do instead of what I can't do, and I have many dreams for the future; maybe I could be a professional poker player, furniture designer, university student or move in with my girlfriend in a great apartment. Get started, get out and experience life; live life: "come to terms with your impairment, there is no cure, get the best out of life; seize the day".

argued in favour of one or several suitable interpretations. In Ricoeur's (1973b) thinking this is referred to as the final act of comprehension; a new sort of being-in-the-world.

Results

Naïve reading

The naïve reading was our initial spontaneous impression of how the patients experienced living

with physical impairment, expressed as a meaning of the whole.

The participants described how they were extremely dependent on help with all aspects of their daily living. They could use their fingers and control their wheelchairs and their computers, and they all were able to speak. Despite these extensive dependencies, they lived active lives with education, sporting activities and travel and they saw themselves as independent human beings. They described dreams of, for example, participation in sport and the desire

for a girlfriend and a normal family life. There were a lot of descriptions of physical impairment where physical actions were impossible, but psychologically they did not feel impaired. They described themselves as normal, like everybody else, and as the person they had always been. Important factors in the participant's lives were their families and friends and a positive outlook on life was essential. In some situations they felt excluded from society because of poor accessibility. Within this initial notion, the participants described extensive physical dependency but also independent living. Some questions are therefore raised regarding dependency versus independence. In what way is the feeling of independence connected to physical dependency? Furthermore, how does the impaired person himself imagine impairment? In what way is the progressive increase in impairment over years significant to the experience of dependency?

Structural analysis

In the structural analysis the meaning of being physically impaired will be presented as a story (Table I), capturing different meaning units and using narration linked to the meaning or understanding of what the text speaks about according to all the interview texts. It is written in the first person but captures meaning units about being physically impaired from all 19 participants. The story encompasses life experiences regarding childhood, sport, dreams of a love-life, dreams and aspirations associated with being a teenager, and being a "nice person".

In the further analysis-reading the story (Table I) and the quotations from the interviews-some themes became apparent (Table II). According to the participants they had lived their whole lives with physical impairment, but they did not feel impaired. Furthermore, they recognised that they were physically dependent, but they describe themselves as independent human beings, which is an important theme for further analysis. A love-life was central because it stated something very important about the participant's experiences in life with physical impairment, especially in their teenage years. The theme "a positive outlook on life" was another important issue because it was something the participants described as crucial when living with physical impairment.

Table II. Themes.

The meaning of being physically impaired
Dependency and independency
Emotional and sexual aspirations
A positive outlook on life

Critical analysis

In the critical analysis the interpretation continues with the discussion and argumentation of the themes (Table II) identified in the story (Table I) by relating both to the quotes from the interviews and to the story (Table I).

The meaning of being physically impaired. All the participants had been diagnosed with DMD in their early childhood and had lived their whole lives with the inevitability of increasing physical impairment. They had known that they would need a wheelchair and eventually a ventilator. The participants' impairment would make it impossible for them to eat or dress themselves. In spite of this they did not feel impaired:

No I have never really seen myself as being physically impaired, of course I can see it, but in my head I cannot imagine it, there I am just a normal person like everybody else.

Instead, they focus on the things they are able to do such as reading, communicating and using their computer. Their impairment does not come overnight so they learn to live with it and changes are described as transitional periods where habits and routines are adapted to match new circumstances, a participant describes: "it is just the way I am and I would not be the person I am if I did not have DMD, so it is an absurd thought". They try to live as normally as possible, but especially in their teens they have trouble with physical and social accessibility. When their friends are going to the disco or watching movies they are sometimes unable to participate because of stairs. Social relations are complicated by prejudice, where other people perceive the participants as being mentally impaired or they feel sorry for them.

Dependency and independency. Family and friends are most important in the participants lives and especially the mothers are important in care; they know how to do things and can perform care where everything is right the first time and no explanations are necessary. Therefore it is difficult for the participants to move away from home because their mothers' role as a helper is reduced. Furthermore, this transition has consequences for the carer (the mother) who now needs to find a new job. "It is unpleasant and awkward, at the age of 21 firing your own mother, but you don't move away from home and take your mother with you". As the need for physical help grows it becomes more important to

find the right helper, who can help in the right way, and cope with extensive dependency. The participants are physically impaired and totally dependent but participation in many activities such as sport, travel and education shows that they live independent and autonomous lives. Furthermore, their most important interest in life is sport; both being an enthusiastic spectator and an active participant. School experiences and childhood were described as being normal, happy and safe: "I went to an ordinary school like everybody else and that I am happy about; I was the only handicapped person there". They know that they are impaired but they do not want to live that way: "It means a lot to me that I can live as normally as possible like many other people do".

Emotional and sexual aspirations. The teen years were described as difficult, worrying and lonely. They were becoming men and they thought a lot about their social life and their sexuality:

As a teenager you have to be aware of grown-up stuff and that is difficult with a handicap. It is not easy to do what you want and do what the others do. I did not participate so much in parties and it was difficult with girlfriends, and therefore I have never had that experience.

The participants had to struggle with their loneliness. In many situations they were unable to participate in "the wild teenage life" because of their physical impairment. As they became older they came to terms with it. The desire to have a girlfriend is still there, but it does not take up so much space; they do not think about it every night: "As I get older it does not mean so much to me. It's not that I don't want a girlfriend but I don't lose sleep at night because of it as I once did". A few described having a girlfriend or a wife as the happiest event at all; intimacy, conversation and joint interests were crucial in a life together. There was a description of a long-distance relationship using the internet and webcams that made it possible to have a girlfriend living in another part for the country.

A positive outlook on life. The participants want to live a normal life like everybody else, as independent human beings living autonomously. They want to learn, travel and participate in sport; they have dreams and desires in life like everybody else. One participant reflected on this in the following way: "come to terms with your impairment, there is no cure, get the best out of life; seize the day". They felt that not being bitter or self-pitying was the reason

why things went well in life for them. They just had to get started, get out, enjoy life and fulfil their dreams.

Summary—a comprehensive understanding

HMV not only extended the participants lifespan, it also gave them the capacity to live an active life. They were totally dependent in everyday living, but in spite of this, they did not see themselves as physically impaired. They realised that there were activities that were physically impossible, but they considered themselves to be just the same person they had always been. Despite dependency, they strive to live a normal life with activities as sport, travel, normal school education and where the family is the most important element. The struggle with loneliness and a desire to experience a love-life are important life-experiences in the teenage years when living with physical impairment. The person living with physical impairment has to come to terms with this impairment and enjoy life and fulfil their dreams. The lived-experience of physical impairment is found to be "independent dependency" in an active life. To solve problems with loneliness, society needs to work with prejudice and misunderstanding and for better physical accessibility to enable full participation.

Discussion

In our study normality seems to be the goal in life despite extensive physical impairment, which is in accordance with Robinson (1993), who describes managing life with a chronic condition as constructing and living a story of "life as normal" by practicing normal things. From an outsider perspective, physical impairment is associated with dependency, vulnerability and a life far away from "normality" (Stuart & Weinrich, 2001). Seen from a philosophical aspect, dependency can be described as inconsistent with independency (Henriksen & Vetlesen, 2000), or as interdependency, where humans always are reciprocally dependent on each other (Løgstrup, 1956). The findings in our study indicate that physically impaired people experience dependency but in a manner which nevertheless is not regarded by themselves as being dependent. It is something known and accepted and as far as possible disregarded. They have the experience of being independent human beings even though, in their daily living activities, they are totally physically dependent upon help, for example when a person with impairment is extremely dependent in getting dressed and independent in choosing what clothes to wear, or is dependent on another person to perform

suctioning but independent in giving the order of how exactly to perform the procedure. Therefore, dependency is not inconsistent with independency and not only experienced as interdependent but as “independent dependency”. In our study, being a physically impaired person from early childhood was reflected upon as being the reason why the experience was different to that of other people, where physical impairment was acquired later in life. This is in accordance with Toombs’ (2001) who in the same way differentiates between the experience of a person who had abilities and then lost them and of a person who never had those abilities. Furthermore, these findings differ from Dreyer (2004) in showing “independence of thought”. Furthermore, in an active life despite physical impairment, independency is a *real* experience. Independence in decision-making is not compromised by dependence in the carrying out of physical actions. It is therefore in decision-making that independence is a real experience—in this study we call this “independent dependency”.

Morse, Wilson, and Penrod (2000) described physical impairment in two different ways; as the *feeling* and the *appearance* of physical impairment. If a person is physically impaired they are aware that this is apparent as they cannot walk, eat or dress themselves. But they do not feel that way, they feel normal; they are the same person they have always been. This way of describing physical impairment as feeling and/or appearing is close to the findings of Deatrick, Knafl, and Murphy-Moore (1999), where they identified cognitive and behavioural strategies. Our study shows that cognitive strategies are important, because even though there are changes in daily function as the person becomes more dependent and changes physically and thereby also in appearance, from an insider perspective the person still feels the same. Deatrick et al. (1999) describe the concept of normalisation, where one of the attributes is “acknowledging the condition and its potential threat to lifestyle”. In our study this is referred to as “coming to terms with” and the importance of gaining a positive outlook on life, where self-pity and bitterness is of no use and is to be avoided. The participants in our study reflected on this as being the reason why they did well in life. Strandberg and co-workers (Strandberg & Jansson, 2003; Strandberg, Norberg, & Jansson, 2003) found “in a study from both a patient and a nurse perspective” that “to be liked” and “liking the patient” were important factors influencing the quality of care. Like Strandberg and Jansson (2003), the authors of this paper believe the influence of “likeability” on care received and given needs further attention and research, because it is

of great importance in all care-giving and care-receiving relationships.

The changes in physical impairment are transitional periods where habits and routines become adapted, but the person’s own feeling of being is unchanged. Kohler et al. (2005) found no correlation between physical impairment and quality of life in DMD, and recommended that medical professionals take the, perhaps surprisingly high, quality of life with DMD into consideration when decisions regarding mechanical ventilation and other life-sustaining therapies are made. It is possible for impaired people to live a high-quality and active life despite no possibility of cure and recovery. In this study the difficulty in getting around in a wheelchair and other people’s prejudice and misunderstanding were described as leading to loneliness and social isolation. This description of social function is shared by Boyles, Baily, and Mossey (2008), who argue that the understanding of disability has changed from being purely “functional”, to also being understood as “social”. Furthermore, enthusiastic participation in the active teenage lifestyle is difficult for an impaired person because of difficult physical accessibility, leading to social, emotional and sexual isolation. People with DMD have now the experience of adulthood (Rahbek et al., 2005) and therefore also the experience of a teenage period with special social and psychological problems. Like Rahbek et al. (2005) we believe that the professionals, the rehabilitation system and the school system should be aware of the challenges and problems associated with this phase of life. Our study shows that in life with impairment, the teenage years seem to have particular problems with sexuality and social isolation, which become easier to cope with in adulthood. Taleporos and McCape (2001) found that sexuality was a major concern to people living with physical disability and establishing sexual partnerships was difficult due to the many barriers such as social attitudes and physical differences. Furthermore, sexuality and sexual esteem should not be ignored in people living with physical disability and may warrant special attention so that disabled people regain their right to be sexual (Sakellariou, 2006; Taleporos & McCape 2001).

To achieve this independent and active living as described in the study, it is important that personal helpers can help in the right way and thereby facilitate individualised living with sport, travel and a private life. As Brown (2000) argues, in order to avoid social isolation, as described in our study, the political aspect has to be addressed; society has to work for integration where disability is an apparent but not real barrier to participation. Or as Toombs (2001) states, those with disabilities must be able to flourish in our society. Society has to acknowledge

normality and dependency and make it possible for physically impaired people to manage independent dependency in daily living and be included in the community and society.

Methodological considerations

The study is strengthened by the random selection of one third of all invasively ventilated DMD patients in Denmark with variation in age and only one patient electing not to participate. To ensure an open phenomenological approach to data collection the interview situation had an open and narrative style (Kvale & Brinkmann, 2009). To ensure reliability in the transcription it was carried out verbatim as closely to what was said as possible. The reader is not expected to “find the findings” by himself (Sandelowski & Barroso, 2002), and therefore the findings are presented as stories, followed by a critical analysis capturing “what is said” and “what is spoken about”. Therefore the analysis can be followed, giving credibility and reliability to the interpretation. We are not trying to re-describe what the participant believes he is saying, but to create an objective text describing what was experienced, from all the interviews. The aim is not to guess the author’s meaning or intentions, but to move beyond this and gain a deeper understanding of what the text (data) refers to in the world (Ricoeur, 1973b). Using narratives from interviewing to presenting findings made it possible to explore subjective experiences about life with DMD, HMV and physical impairment.

Study limitations. In Denmark receiving a paid helper-team is conditional on leading an active and outgoing life and this could be assumed to affect the results. But all the participants had their own helper-team, even the person living in an institution, so losing their right to a helper-team did not seem to be considered a risk for the participants in this study. The participants said about their relations with their helpers, perhaps because in Denmark there is a long and strong tradition for DMD-sufferers receiving care from their own helper-team. To gain a deeper understanding of this aspect, interviews with the helper and/or observational studies would have been needed. The study was conducted within a Western European context and life with physical impairment and HMV may be totally different in other cultural settings, because the social and educational background of the young people with DMD as well as their families, ethical values, attitudes and norms regarding impairment, illness, care and treatment may be very different.

Implications for practice

People living with HMV have a large degree of autonomy and live active and outgoing lives. Clinicians working with the training of newly tracheostomised ventilator users need to be aware of normality being a goal in life despite extensive dependency; considered as independent dependency in living. Therefore, the training programme needs to cover individual care-solutions taking into account active living with, for example, sporting activities, a teenage lifestyle and parties, travelling and emotional relationships. Furthermore, to minimise problems with social isolation and prejudice, society has to work for integration despite disability. Society has to acknowledge normality and independent dependency and enable physically impaired people to be included in the community and society.

Conclusion

The goal for those living with impairment is normality, despite extensive dependency and extreme physical impairment. Physical impairment is found to be both feeling impaired and having the appearance of impairment. The impaired person is aware of the physical limitations and decreasing ability but as a feeling of being as a person there is no change. It is important for impaired persons to come to terms with their impairment and gain a positive outlook on life. Although they are aware of their physical limitations, impaired people do not feel impaired and they aim to live an active life with independent dependency. This is often inhibited by problems of physical access and social acceptance, leading to loneliness and social isolation, especially in the teenage years, where the attainment of sexual maturity is also a challenge. Therefore society needs to work with prejudice and misunderstanding and for better physical accessibility to enable full participation in society.

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