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To cite this article: Åsa Israelsson-Skogsberg, Andreas Palm, Berit Lindahl, Agneta Markström & Magnus Ekström (2024) Young adults' narratives about living with home mechanical ventilation – a phenomenological hermeneutical study, *Disability and Rehabilitation*, 46:19, 4495-4502, DOI: [10.1080/09638288.2023.2278187](https://doi.org/10.1080/09638288.2023.2278187)

To link to this article: <https://doi.org/10.1080/09638288.2023.2278187>



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Published online: 06 Nov 2023.



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RESEARCH ARTICLE



Young adults' narratives about living with home mechanical ventilation – a phenomenological hermeneutical study

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ABSTRACT

Purpose: An increasing number of children and young adults with complex medical conditions and respiratory failure are treated with home mechanical ventilation (HMV). The current study aimed to describe how young adults using HMV experience their everyday life with the ventilator, their physical impairments and their opportunities for an educational and professional career.

Materials and methods: Data were collected via narrative interviews with nine young HMV users (3 females and 6 males, aged 18–31 years) in their homes. Two were ventilated invasively, six were ventilated non-invasively and one was treated with continuous positive airway pressure (CPAP) via facemask. Data were analysed using a phenomenological hermeneutical method.

Result: A multi-professional team contributed to participants' safety and ability to participate in society through higher education and professional work. A good and valuable life, mostly feeling healthy were experienced but also prejudice and stiffened social society structures.

Conclusion: The findings of this study prove the importance of having long-standing access to a competent and supportive available multi-professional healthcare team when living with a long-term complex condition. These teams provided well-functioning human and technological support in everyday lives.

ARTICLE HISTORY

Received 19 March 2023
Revised 26 October 2023
Accepted 28 October 2023

KEYWORDS

Disability; experiences; home mechanical ventilation; long-term mechanical ventilation; mechanical ventilation; neuromuscular disease; spinal muscular atrophy; young adults

> IMPLICATIONS FOR REHABILITATION

- An increasing number of children and young adults are treated with home mechanical ventilation due to respiratory failure.
- The home mechanical ventilation treatment provided rest from breathing and improved sleep quality in such a way that work and higher studies could be managed.
- Longstanding access to a supportive multi-professional healthcare team provided feelings of being safe, which in turn boosted self-confidence in life and preparedness to meet new challenges.



Introduction

An increasing number of children and young adults are treated with home mechanical ventilation (HMV) and survive into adulthood [1–5]. In Sweden alone, approximately 600 children are now being treated with HMV [4]. Children and young adults with long-term HMV have chronic respiratory failure and often suffer from several, complex and progressive underlying conditions, which in turn often means an increased need for care and support [6].

The population of children and young adults with HMV treatment is heterogeneous, spanning from those with no spontaneous breathing treated with controlled and life-supportive HMV to those with HMV as support solely during rest and/or sleep [7]. HMV treatment can be given invasively through a tracheal cannula, or non-invasively (NIV), via a mask over the nose/mouth, depending on the person's needs [6]. The treatment aims to normalise

respiratory function and sleep, improve cognitive function, and reduce morbidity and mortality. Reducing the effort needed to breathe promotes growth, physical activity, and other conditions that allow users to better reach their developmental potential [7]. In Sweden, children with respiratory disorders caused by neurological and pulmonary diseases and facial and upper airway malformations are monitored in specialised children's respiratory units. Specialised multi-professional teams work in these units, and they often accompany children and their families for long periods of their lives [8].

HMV often includes having a progressive disease where the abilities to breathe, walk or eat independently are gradually lost [6]. This loss creates a growing dependence on others, in a period where teenagers often seek an independent life, not seldom with reflections on who they are and what they want to do with their lives [9]. In Sweden, essential legislation for people living with HMV entitles them to have personal care assistants (PCAs) financed

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by governmental taxes for up to 24 h a day [10]. PCAs are the basic foundation for young adults with HMV to, when ready, get their own apartments, education and work careers in the same manner as other young people [11]. Research from a family perspective in the HMV context describe that parents' role and functioning within the family often changes [12] and effects their ability to care for the well-being of other family members [13,14].

Teenagers with Duchenne muscular dystrophy (DMD) and cerebral palsy have described their teenage years as worrying and lonely times, containing uncertainties about social life, sexuality and an inability to participate in "the wild teenage life" [15,16]. A core concern among children and young adults with a long-term condition, is the wish of having social connectivity to fit in and be accepted [17,18]. Children with HMV rate their overall quality of life lower compared to the general population and children with other long-term conditions [19]. Their everyday lives are sometimes complex often due to their physical disabilities, but this does not include a sense of being sick unless something extraordinary happens [11]. It is challenging to be young, manage a complex disease, make education and career choices and at the same time create independence from one's family [9].

There is knowledge gap about HMV-assisted young adults' experiences growing up when physical impairments and ventilators are vital part of life. Experiences of joy, happiness, needs and potential challenges are largely unexplored. More knowledge is important for establishing strategies for person-centred support that emphasise an equity and sustainability perspective as well.

We aimed to investigate how young adults with HMV experience their everyday life with special focus on living with the ventilator, physical impairments and opportunities for an education- and professional career.

Materials and methods

Design

The actual study used a phenomenological hermeneutical methodology [20–23] aiming to bring forth an understanding of often taken for granted phenomena or situations in life [21]. This approach involves exploring peoples everyday lived experiences.

Participants and settings

Inclusion criteria were young adults living with HMV (tracheotomy, NIV or CPAP), aged between 18–30 years with an ability to tell us about their everyday lives. Participants were recruited via nurses and physicians working at outpatient respiratory clinics at four hospitals in Sweden and through the social media. The participants were well known to the healthcare professionals but not to the interviewer.

Nine people were included (3 females, 6 males, with a median age of 24 years [range 18–31]) (Table 1). Seven participants were recruited via nurses and physicians from outpatient respiratory clinics, and two were initially contacted via a parent whose child had participated in a previous research study. Two participants had tracheotomy, six had NIV and one had CPAP therapy. Two had been treated with respiratory aid since their neonatal periods, and the remaining seven had been treated since toddlerhood. Three participants had the HMV around the clock, while six only used it during rest and/or sleep. All participants had diverse long-term medical diseases; seven had neuromuscular disorders, one suffered from a craniofacial disorder and one suffered from a central breathing disorder (Table 1). Seven participants had PCAs

Table 1. Characteristics of participants.

Participant	Condition	Age (years)	Sex	Ventilator regime
Loa	Neuromuscular disorder	24	M	NIV
Taylor	Neuromuscular disorder	18	M	Invasively ventilated via tracheotomy
Kari	Neuromuscular disorder	28	F	NIV
Kim	Neuromuscular disorder	27	M	Invasively ventilated via tracheotomy
Mio	Craniofacial disorder	18	F	CPAP
Rami	Neuromuscular disorder	31	M	NIV
Alex	Central breathing disorder	22	M	NIV
Charlie	Neuromuscular disorder	26	M	NIV
Tintin	Neuromuscular disorder	22	F	NIV

CPAP: continuous positive airway pressure; F: female; M: male; NIV: non-invasive ventilation.

around the clock, one had home care service, and one participant had no extra support at all. Five participants lived on their own (with PCAs) and four with their parents and siblings. Two were students, four were employed, and three were seeking for work.

Data collection

Data were collected between March 2022 and October 2022. Two interviews took place in the interviewees' homes, and seven took place via the digital platform Zoom [24]. An initial round of small talk was important to break the ice leaving the participants feeling free and confident to share their unique knowledge in the promise of confidentiality. PCAs were present in two interviews, and a parent was present in one interview. The audio-recorded interviews lasted between 36 and 80 min. Each interview began with the open question, "Can you please tell me who you are?" followed by "Can you please tell me about your family?". The conversations that followed focused on issues related to health and healthcare, family life, education, living conditions, employment and leisure. Three of the interviewees had participated in a previous qualitative study [11], and follow-up questions were asked about what had happened since the last interview.

Analysis

All interviews were transcribed verbatim, read openly several times and the interpretation process was carried out as a movement between being close and using preunderstandings to take a distanced reflective approach to the text [20,21]. The method is based on a lifeworld approach and the philosophical writings by Ricoeur [22,23] and later developed to a research method by Lindseth and Norberg [20,21]. The analysis consists of three methodological steps aiming to move between understanding and explanation, and between the objective and subjective approaches, that is, a naïve reading, a structural analysis and a comprehensive understanding. The naïve reading constituted our first immediate grasping of the meaning and ended up receiving a sense of what was at stake and moving in the texts as a whole. It meant a subjective understanding that guided the second step, the structural analysis which constituted an objective examination and explanation of the meanings. Here the text was divided into meaning units, condensation abstracted into subthemes, and

Table 2. Structural analysis – examples of analytical steps.

Meaning unit	Condensed meaning unit	Abstracted meaning unit	Subtheme	Theme
<p><i>There's someone who's been around since I was a kid. And I know where to find her, if you like, you can always pick up the phone if there's anything. Because she's always said that, and I've done that when I've needed to, and she's always been there. I'm really grateful that she's been there and really been involved. There are no words for how much you can thank her for that, so it's very just positive.</i></p> <p><i>Because it becomes a bit of a security person, so to speak. If there's anything, I know she'll answer and that makes me feel even more secure, because she knows exactly what I need and what doesn't work for me. So it's just safety.</i></p>	<p><i>Someone been around since I was a kid. I know where to find her; you can always pick up the phone. She's always said that, and I've done that when I've needed, she's always been there. I'm grateful that she's been there and involved. There are no words for how much you can thank her for that. It becomes a security person. If there's anything, I know she'll answer and that makes me feel even more secure, she knows exactly what I need and what doesn't work for me. It's just safety.</i></p>	<p><i>I know she is there – she has always been there – that makes me feel safe.</i></p>	<p><i>To be responded to as a unique person means to feel safe and capable</i></p>	<p><i>An everyday life with HMV means being encountered in various ways</i></p>

theme presenting similar meanings (Table 2). The last step aims to obtain a comprehensive understanding involving critical reflection and considering the naïve reading, structural analysis, and various theoretical perspectives in relation to the study aim. This step aims to reach and present a deep and new understanding of the entire research phenomena, i.e. a possible being in the world [20,21].

Ethical considerations

The study was approved by the Swedish Ethical Review Authority (2021-03426), and was conducted in accordance with the World Medical Association's Declaration of Helsinki [25]. Written informed consent was obtained from all participants. The data were reported to reduce any possibility of identifying the participants [26].

Results

Our naïve reading and first understanding about what was the subject matter in the text, written in everyday language, was expressed as follows:

Naïve reading

Having HMV reduces the workload of breathing and helps to obtain good sleep to manage an ordinary life. HMV support is a gateway to a regular life with everyday responsibilities giving the energy to search for a job or study. Nevertheless, a life with HMV and a long-term illness means being dependent on the support from others in several aspects. This means living an everyday life that may rapidly change due to factors that are beyond the individual's control. Stable health care contacts established in childhood evoke feelings of gratitude and safety. However, sometimes life means to feel angry and sad when healthcare staff talk over one's head and when being addressed like a child – even if being a young adult. Living with a long-term illness and HMV sometimes requires developing a fighting spirit, advocating for employment, and fighting for the opportunity to feel that one's capacities are used. On the other hand, having a job where one's unique skills are appreciated and the working environment is adapted to individual conditions could be a reality. This naïve understanding of the whole constituted the point of departure to be validated in the next step, i.e. the structural analysis.

Table 3. Subthemes and main themes.

Subthemes	Main themes
<p>Being supported by medical technology</p> <p>Personal care assistance – a vulnerable but necessary precondition for life</p> <p>Owning an apartment – a possibility for freedom, but might be difficult to achieve</p> <p>To be responded to as a unique person means to feel safe and capable</p> <p>To confront prejudice</p> <p>To be prepared to defend and argue for legal rights</p> <p>To be extra vulnerable to external influencing factors – but not perceive illness</p>	<p>An everyday life with HMV is a walk on a line between independence and dependence</p> <p>An everyday life with HMV means being encountered in various ways</p>

Structural analysis

This step of the analysis revealed two main themes built up by seven subthemes (Table 3). Meanings with quotes are presented for each subtheme. The structural analysis identified two main themes: "An everyday life with HMV is a walk on a line between independence and dependence" and "An everyday life with HMV means being encountered in various ways". Each main theme consists of three respectively four sub-themes. Quotes are presented in factious names for each subtheme.

An everyday life with HMV is a walk on a line between independence and dependence

Being supported by medical technology

The ventilator has been a companion since childhood, which could mean three days after being born, and the rest of the life of the individual; "I'm embedded with the machine from day one in my life" (Alex). The ventilator is like a natural part of the body, all hours of the day via a tracheotomy or face mask, or put in place when it is time for rest or sleep at night. It reduces the workload involved in breathing, provides the opportunity for a good sleep, and to wake up alert and responsive in the morning. The HMV in place can mean a signal that it is safe to fall asleep, as described below:

When I'm wearing the machine and it's time to sleep for me, I can still keep looking at my phone while it is on. But then I know that I can go to sleep; it is safe. I've learned that just bang, now it is okay to sleep (Alex)

There are a few nights when the ventilator is not used, such as during power cuts. However, there is no doubt that the

ventilator makes life easier to manage according to breathing issues (6). It is a well-known companion in life.

For me it's like a permobile, it's just something that's damn nice to have and it would be hard without ... so good... when I'm in hospital I always have it with me, For me, it's not a medical device, even though it is, it's a part of me (Kari).

To put on the ventilator means entering a state of mindfulness when not being forced to think about breathing. When breathing is taxing, the HMV allows relaxation. It aids calmness, alertness, and general well-being. But, on the other hand, being dependent on a ventilator at night can also mean waking up at night with a wet, moist face mask and trying to go back to sleep in that same mask. Living with an HMV can also include the hope that one would outgrow the need for it, which often means sadness in accepting the fact that the need for the ventilator will probably remain throughout your life.

Personal care assistance – a vulnerable but necessary precondition for life

Living with a progressive disease, where HMV supports breathing, often leads to a need for help with personal hygiene, movement, eating and drinking – which requires PCAs in the home, day and night. Their hands are a prerequisite for the life to go on, actually a question about life and death; “Without the PCA I would have died. PCA is a minimum requirement for being human, and the most important legal right we have in Sweden as a disabled person” (Kari). Their hands provide the possibility to take control over life.

My PCAs means a lot in my daily life. They give me all opportunities to live a life the way I want, to be in charge, and control all aspects of life instead of someone else is doing it for me (Loa).

The relationship with PCAs is often a special kind of friendship, as well as a life support, where it is important to have fun and appreciate their togetherness: “If you carry me around, you have to have fun at the same time” (Kari). Creating trusting relations is important, as in some cases, in which individuals are totally dependent on the ventilator for breathing, skilled PCAs are a matter of life or death, being present 24h each day. Having PCAs in the home 24h a day is a challenge. A supervisory role over PCAs have been taken since childhood, which in several aspects means growing up quickly. PCAs are family, relatives or people interviewed by oneself, even as a child. A responsibility for creating a strong and fair working environment, in their own home is taken. PCAs' schedules and vacations are planned, and conflicts in the working group handled, because of a strong conviction that the working environment becomes more sustainable with few people involved.

I manage the interviews and decide who is working. And it's me, together with those who have worked here before, who teach them. I've been doing it since I was 18, with a little help from my mother. You bring with you the ability to deal with people, to be willing to compromise and be diplomatic, to know what people want and don't want (Charlie).

Owning an apartment – a possibility for freedom, but might be difficult to achieve

The vision for one's own home may be a dream of a small town-house with a terrace in the future and space for a wheelchair and friends. One's own apartment means a feeling of freedom. Freedom to be alone for a while and not to sit in a room, always together with the PCAs, because there is no more space in the apartment. To be given the opportunity to move to one's own apartment can

also elicit a feeling of freedom for the family who remains at home, who suddenly have only the main family in the home.

When they (the family) get up in the morning and hardly have clothes with hair standing on end, they were maybe not as comfortable when I was living at home. Especially when I have several PCAs. It is not one person but several different people who are in your home every day. They were used to it, but they thought it was nice afterwards. I think everyone thought so (Charlie).

However, the process of getting an own apartment may involve a long wait. A long time in the housing queue is not enough - it must be the right opportunity, where a lot of things fall in place, as it is impossible to take just any apartment. An apartment located upstairs, without an elevator, is out of the question. An apartment located at a distance from the centre is aggravating for the PCAs, who must be able to travel without major problems to their workplace – a home.

An everyday life with HMV means being encountered in various ways

To be responded to as a unique person means to feel safe and capable

A stable long-standing contact with an available multi-professional HMV team, specialists in the field, since childhood is described as the best healthcare contact. These contacts mediate feelings of security, which gives confidence to try new and unfamiliar situations. Well-functioning respiratory care provides prerequisites for being professionally active or pursuing higher studies. When breathing problems occur, quick visits to the clinic are arranged and necessary adjustments to the ventilator are made. Just knowing that they, the experts within the HMV area, are there if needed, creates feelings of safety.

Because she becomes a bit of a security person, so to speak. If there's anything, I know she'll answer and that makes me feel even more secure, because she knows exactly what I need and what doesn't work for me. So it's just reassurance and just really great (Alex)

These multi-professional HMV teams consider individual preferences for important details. If it is important that the ventilator mask not negatively affect the appearance, everything is done with great dedication to solve the situation in the best possible way.

Being seen as a unique person also means employers providing opportunities for a dynamic work-life, in which the ability to work at the time of day they feel most alert becomes available. Flexible and dynamic work reduces the stress of not being able to obtain the PCAs needed for arriving to work on time:

It's a clarification, maybe not for me personally if I'm tired, but there might be something going on with my assistance. If my assistance doesn't work properly, it will affect my work. My assistance has to work if I should be able to work (Kari).

Higher studies contributed to a sense of relief, as the milieu consisted of adult people, and the study tempo was higher in comparison to primary and secondary school, where individuals described experiences of being under-stimulated.

To confront prejudices

To live with HMV, often caused by a progressive disease, means at times to meet a gaze that includes prejudice and stiffened social society structures: “It's not just the assistance; it's living with a disability in a society that's not made for you. Being exposed to it on a daily basis does something to you as a human being”

(Kari). Having one's head spoken over, directly to the PCAs, evokes feelings of being regarded as a child that cannot speak for oneself:

It's pretty much the whole social structure. It's very often that people who see a wheelchair make their own decision that he's not able to talk or think, they talk over my head turning directly to my PCAs. Maybe you can forgive people out there in the normal, but people in the medical profession should know better. They talk to me like a child, and they don't have to do that (Loa)

A life with HMV and a progressive disease, sometimes means a daily feeling of being thrown around between authorities who do not want to take responsibility or listen to the individual's experiences related to the disease. Even if this body and illness are well-known to the one who has lived a life in it. This creates feelings of receiving low expectations of one's person. Being thrown around between authorities evokes feelings of being a wrecking ball in a system where no one wants to take responsibility for the whole situation. This might imply being isolated at home and sitting in front of the computer for very long time periods.

I'd like a lot of more work. I sit at the computer every day. People say that working with a computer is different. But I feel my body, and I could do more working hours a day. But the Public Employment Service and the Social Insurance Agency says no – it has to be done within our framework so we put you on this amount (Kim).

To be prepared to defend and argue for legal rights

The Social Insurance Agency reassessments for PCAs benefits can bring anxiety and uncertainty to those whom it concerns. Just knowing that PCAs *can* be taken away causes anxiety, even if there is visible severe disabilities testifying that a life without PCAs is impossible to manage. Maybe had the PCAs been taken away during childhood – which ended in a situation where the parents had to appeal against the decision to get the PCAs back. The life circumstances have brought strength to fight.

Individuals living with HMVs also require a lot of consumables. An assistive technology centre with a well-defined structure makes life easier and more manageable. An assistive technology centre with a disorganised way of working has a lot of impact. The solution relies on a well-functioning working group with PCAs, collecting vitally important consumables in different places with their own car.

At one location they say you can pick up this little plastic thing at the assistive technology centre. And at the assistive technology centre they say that they do not want to be responsible for the plastic thing – you'll have to take it to your health center. And then you go around for half a day just to get the materials (Taylor)

To be extra vulnerable to external influencing factors – but not perceive illness

Everyday life could be ordinary in several aspects with the HMV used only at night, and in some cases in daytime when upper respiratory infections cause breathing difficulties. This ordinary life does not necessarily mean to perceive illness, which develops a sense of freedom. Stable long-lasting healthcare contacts have provided security, creating a daily life where things can be taken in new exciting directions – despite long-term illness:

My doctor does that very well, she takes the drama out of it, it's not so medicalised. It's not that you're sick and need help,

but rather why don't you want to breathe well? It's nice to do that. So that you don't get sick (Kari).

Detailed planning is required in order to make life work properly and have control over what is going to happen. But some parts of life might be impossible to foresee or to compensate for, which means a mindset unworried about everything that may happen, and instead trying to handle the situation as best they can when it arises.

But when the corona pandemic hit the world in spring 2020, life became placed on pause. The uncertainty and insecurity that existed lead individuals to stay inside for a very long time.

The first year was okay. I couldn't go out, I was inside. But it also meant that my friends from abroad started working from home so we could sit and talk during the day, so I still got in touch. But when the second year came and I'd been inside for a year, I felt - oh, this is getting hard, I'd love to meet people (Kim)

When the restrictions were finally lifted, a strong wish to get out from home as much as possible arose. To meet people, to see people, and do things in general in an effort to make up for what had been lost.

Comprehensive understanding

The HMV support brings peace of mind, reducing the effort to breath and improving sleep quality, so individuals can manage to have an ordinary life. It brings feelings of freedom, liberation, and an openness to the world. In some respects, an everyday life with HMV means being safe when competent healthcare teams are accessible. Feeling safe increases self-confidence and inner strength. Being full-fledged supervisors since their youth and performing supervisory functions in combination with studies or work develops a high level of competence in several areas. This can be related to a definition of health [27] that defines it as a capability to cope with and to manage one's own malaise and well-being conditions. A point of departure that health is not solely related to diseases, infirmities or physical parameters. But rather a capability to be healthy; an ongoing process not only relegated to diseases, infirmities or physical parameters.

However, being a person with HMV and living with a progressive disease means sometimes having to meet prejudices and stereotypes about what a person with a disability should be. To deviate from the norm creates a wish for normative awareness, which, when used constructively, could be helpful in highlighting barriers to equality of care.

Discussion

The HMV treatment provided rest from breathing and improved sleep quality, making work and higher studies manageable. This is consistent with previous research that underscores the fact that HMV treatment does not reduce HRQOL [11,28]. The devices are found to be reliable and trustworthy, regarded as a self-evident extension of one's body [29] and identity [30]. The HMV being a part of one's own body was also described in the present study.

Long-standing access to a competent, supportive and available multi-professional healthcare team was important. These teams provided feelings of safety, which in turn, gave confidence in a life feeling prepared to meet new challenges. Supportive relationships, that include healthcare professionals, seem to co-construct young adults' healthcare engagement, which in turn, may optimise health behaviors and outcomes [31]. This study's results also confirm this. There is an ongoing process in Sweden to transform

healthcare into a more accessible, high-quality, integrated healthcare [32] with shared responsibility and trust. A health-promoting, preventive and proactive healthcare system that contributes to equal health, safety and independence. Our study points out the importance of having access to well-functioning, high-quality, local healthcare when living with a complex long-term condition. A competent, well-known healthcare provider also seems to be important regarding seamless transitions to adult healthcare for young adults with neuromuscular disease (NMD) [33,34] and HMV treatment [2]. Successful and well-supported transitions attributed their success to having a consistent healthcare provider throughout the process – a clinician well acquainted with young adults and their needs was vital [2,33,35]. This is important knowledge when life expectancy has increased for some subtypes of NMD and the pathway to being old with NMD includes several complex transitions [36].

The participants in our study experienced a good, valuable and mostly healthy life when working and performing higher studies despite their daily challenges. Illness occurs when there is a complication to the underlying disease, such as respiratory tract infections. This is in line with early research [11,15,37] describing that many young adults affected by NMD live successful lives, including positive experiences from higher studies [38]. Nevertheless, there were also experiences of prejudice and stiffened societal structures in our study. Individuals were faced with lower expectations from those with whom they dealt. For example, authorities did not listen to their individual work capacity. Experiences regarding societal stigmas when living with a neuromuscular disease have been reported before; being treated like a baby, like they are mentally disabled, or like they are just too innocent [33,37]. This is important when research underscores [38] that societal stereotypes with low expectations of people with disabilities contribute to low rates of employment. Experiences of being under-stimulated in primary and secondary school when connecting with peers and pursuing studies were also present in our study. An explanatory model might be that a huge responsibility for one's own life situation had already been taken, which meant being forced to grow up faster than peers without physical impairments. Research from a family perspective have showed that caring for a child with HMV is burdensome [13], this is a life situation that affects siblings as well [14]. Some families are left with the responsibility for providing support for their adult children [39]. Parents and family members working as PCAs can both endorse and diminish disabled people's control over their own lives and involvement in society [40].

Exposure to external influencing factors is important knowledge, when care contacts are vital to the participants' feelings of safety. Examples of external influencing factors include being particularly sensitive to power outages when the ventilator's battery time is limited. Our findings showed that living with PCAs around the clock meant being vulnerable, relying on access to well-functioning health care for optimal respiratory support, not being able to take just any apartment, or not having a mandate to decide over one's work capacity. Research in the United States of America has shown that young adults with NMD were influenced by need for PCAs in their college of choice [38] where they experienced tension coordinating PCAs and were forced to use relatives as helpers to support them with higher education and employment.

Methodological considerations

To present a trustworthy study, we have carefully described each step in the research process [41]. Moreover, quotes were inserted

to verify our interpretation. There are always several probable interpretations when analysing a text. However, in interpretative research, the chosen presentation of the findings needs to be more probable than any other possible interpretation [20]. The interpretation is also dependent on the researchers' pre-understanding. A phenomenological–hermeneutic approach used in this study is earlier used in research about HMV treatment from the perspectives from a children, sibling, adult, and parent perspective and therefore well-suited to the actual project. The actual researchers are active in the clinical field as physicians and nurse lecturers and are well-experienced with treatment and research within the HMV area. The interviewees in this study had well-functioning and long-standing contacts with specialist teams regarding breathing support, which can also be regarded as a limitation. One of the participants was 31 years old when being interviewed, though the inclusion criterion was set at 30 years, which also can be regarded as a limitation. This is explained by the fact that this group is very difficult to reach. For example, we did not receive any responses concerning participation via social media. Our participants are considered as representing a purposeful sample [42] as they were capable of telling about their experiences in their own worlds [41]. Another limitation might be an imbalance regarding sex. However, this was not a part of our research question. Writing the analysis when part of the data was gathered with a PCA or parent present is a task that requires great care, so as to ensure that the voice of the participant is heard. It also requires accuracy in the transcription and analysis of text material. In this study we consider the presence of PCAs as a strength as they made the participants feel comfortable and there were no drops-outs from the study. The participants were from a small pool of people, and strategies to protect participant identification were important, this can be considered as a limitation as it omits the description of participants.

Conclusion

The findings of this study point to the importance of having long-standing access to a competent, supportive and available multi-professional healthcare team when living with a long-term complex condition. These teams provide well-functioning human and technological support in everyday life. This stable platform seems to be fundamental to creating increased accessibility to education and labour markets, which facilitates equal possibilities in society for young adults with HMV.

Acknowledgments

The authors offer their most sincere thanks to the participants who participated in the study.

Disclosure statement

The first author received funding from the Lund University, Medical Faculty, Health Science, including 50% time for research. Folke Bernadotte Foundation, Ebba Danelius Foundation, Sigurd and Elsa Goljes Memory and RBU supported the study financially.

Funding

The author(s) reported there is no funding associated with the work featured in this article.

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