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The transition from children to young people living with home mechanical ventilation

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ABSTRACT

Purpose: This study aimed to examine how young people living with Home Mechanical Ventilation experience the transition from childhood to young adulthood in relation to everyday life, perceived health and transition into adult professional healthcare.

Methods: Nine young adults (three females and six males aged 18–31) were interviewed, and data was primary analysed using phenomenological hermeneutics. In the actual study, data was reworked using secondary analysis as described by Beck. Two interviewees were ventilated invasively and six non-invasively, and one was treated with continuous positive airway pressure (CPAP).

Results: The results are presented in two main categories. First; moving towards adulthood; and second, To handle changes in health and healthcare contacts. The study highlights the importance of ongoing social relations and being part of a socializing and physically active community. The transfer from paediatric to adult healthcare was solid and worked out well but was a process in which the participants struggled to find their own voice.

Conclusions: The transition into adulthood is a sensitive and challenging time for young people with HMV, but stable, close relationships and a well-organized transfer can enable this group to feel safe and able to find and use their own voice.

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Home mechanical ventilation; health; long-term mechanical ventilation; neuromuscular disease; secondary qualitative analysis; transition; young people


Background

An increasing number of children and young people are treated with home mechanical ventilation (HVM) and survive into adulthood (Amirnovin et al., 2018; Cheng et al., 2020; MacLean & Fauroux, 2023; Onofri et al., 2020; Swedevox SNRf, 2022; Waldboth et al., 2021; Willis, 2020). This treatment trajectory comprises several multifaceted transitions (Agarwal et al., 2015; Cheng et al., 2020; Møller et al., 2022; Xiao et al., 2023) including being transferred from paediatric to adult care (Amin et al., 2017; Chatwin et al., 2015; Onofri et al., 2020). Approximately 600 children are being treated with HMV in Sweden (Swedevox SNRf, 2022).

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 (Brookes, 2019). The population of children and young people undergoing HMV treatment is heterogeneous, spanning from those with no spontaneous breathing who are treated with controlled and life-supportive HMV to those who use HMV as support

solely during rest and/or sleep (Amaddeo et al., 2020). Dependence on HMV often includes several complex and progressive conditions such as neuromuscular diseases, spinal cord injuries, and congenital airway malformations. These conditions initiate a long-term medical technology dependence (MacLean & Fauroux, 2023), and there is an increased need for care and support when the ability to breathe, walk or eat independently is gradually lost (Brookes, 2019). Being dependent on medical technology impacts psychosocial functioning in multiple important areas, which often causes disruption in emotional and social lives (Agarwal et al., 2015). Swedish legislation entitles HMV-assisted people to have personal care assistants (PCAs) for up to 24 hours a day (Swedish National Board of Health and Welfare, 1993). PCAs are essential for young people with HMV to be able to live their lives as they wish (Israelsson-Skogsberg et al., 2018). Health is in this actual study understood from a caring science perspective in relation to each person's life situation. Health is viewed as a process reliant on the present situation, human

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relationships and interaction with the world where one experiences meaning (Bergbom et al., 2021). In the actual study, the concept health also relates to the expression “to be able to live and carry out one’s major and minor life projects” (Dahlberg et al., 2009). This aligns with earlier research descriptions of the meaning of wellbeing experienced as independent from health and illness but including feelings of vitality and the capacity to connect with others (Todres & Galvin, 2010).

In Sweden, children with respiratory disorders caused by neurological and pulmonary diseases and facial and upper airway malformations are cared for in specialized children’s respiratory units by specialized multi-professional teams, and they often accompany children and their families for long periods of their lives (Karolinska University Hospital, 2022). When individuals turn 18, a healthcare transition process occurs from paediatric- to adult-oriented care.

Transitions are associated with changes; they entail a moving from a being to a new becoming. Thus, our approach in this study was grounded in a transition perspective. Persons involved in transition processes tend to be vulnerable in terms of health and wellbeing due to a risk of having negative transition experiences and outcomes (Meleis et al., 2000). The patterns of transitions often include both multiplicity and complexity, and many people experience several transitions at the same time (Im, 2014). It is therefore important to understand the extent of overlap and the relationship between the different events that are triggering the transitions (Im, 2014; Meleis et al., 2000). The transition into adulthood is a particularly sensitive and challenging time for young individuals with chronic complex conditions (Onofri et al., 2020; Waldboth et al., 2016). The transition process has been described as falling off a cliff and being occupied by feelings of abandonment, loss, and uncertainty at a time when social connectivity, fitting in, and being accepted are core concerns (Dellenmark-Blom et al., 2016; Lambert & Keogh, 2015). The transition process is uniquely challenging to persons living with chronic respiratory failure as they often are declining in health and losing independence as they approach adulthood (Waldboth et al., 2021). The process occurs at a vulnerable time in life when the young person expects to take more responsibility for their own health (Onofri et al., 2020), which requires advanced planning, collaboration, and communication between paediatric and adult care teams.

Thus, this study takes its point of departure in a caring perspective of health and wellbeing as well as the theoretical framework of the concept of transition.

Knowledge of transition processes is important for both adult and paediatric clinicians (Willis, 2020), especially as young adults with numerous medical impairments often undergo complex transition processes

requiring coordination by key workers in adult and paediatric care (Brookes, 2019). Qualitative research in the HMV area is sparse, but a few studies have described life with a ventilator from children’s (Israelsson-Skogsberg et al., 2018), parents’ (Israelsson-Skogsberg et al., 2020; Lindahl & Lindblad, 2013), siblings’ (Alrø et al., 2021; Israelsson-Skogsberg et al., 2023) and adults’ (Lindahl, 2010) experiences. Moreover, knowledge is limited about how transition processes are experienced by young people with HMV. Understanding people’s lived experiences is vital to evolve healthcare practice and research (Wan et al., 2019). This study contributes to addressing this knowledge gap by examining how young people living with HMV experience the transition from childhood to becoming a young adult with a special focus on everyday life, perceived health, and the transition into adult professional healthcare.

Materials and methods

Design

A secondary qualitative analysis of data (Beck, 2018; Heaton, 2004) guided our study. Data from the original study was collected between March and October 2022 and analysed through a phenomenological hermeneutic method (Israelsson-Skogsberg et al., 2023). During the primary analysis (Israelsson-Skogsberg et al., 2023) of original data, it was noted that the transition process from being a child to becoming a young adult was a complex phenomenon that formed an important element of everyday life, but it was not fully examined by the research team. Therefore, we decided to expand the analytic process and extend our research results through a more thoroughly description of the phenomenon of transition. A secondary analysis of qualitative data means an analytic expansion and promotes a comprehensive use of the data (Beck, 2018; Heaton, 2004; Thorne, 1994). The analysis was carried out through using a conventional qualitative content analysis following Hsieh and Shannon (Hsieh & Shannon, 2005). This approach is suitable when the study design aims to describe a phenomenon based on the participants’ unique perspectives.

Participants and settings

Nine people (three females and six males) aged 18 to 31 with long-term ventilator support participated in the original study’s interviews (Table 1). Nurses and physicians working at various respiratory outpatient centres at four Swedish hospitals invited the participants to join the study. An invitation was also sent out via social media. Two participants received breathing support via a tracheostomy, six had NIV, and one had CPAP therapy. Three participants received 24-hour treatment, and six used a ventilator during the

Table 1. Characteristics of participants.

Participant	Condition	Age (years)	Sex	Ventilator regime
1	Neuromuscular disorder	24	M	NIV
2	Neuromuscular disorder	18	M	Invasively ventilated via tracheotomy
3	Neuromuscular disorder	28	F	NIV
4	Neuromuscular disorder	27	M	Invasively ventilated via tracheotomy
5	Craniofacial disorder	18	F	CPAP
6	Neuromuscular disorder	31	M	NIV
7	Central breathing disorder	22	M	NIV
8	Neuromuscular disorder	26	M	NIV
9	Neuromuscular disorder	22	F	NIV

NIV = Noninvasive ventilation.

CPAP = Continuous Positive Airway Pressure.

F = Female.

M = Male.

Table 2. Subcategories and categories.

Subcategories	Categories
The importance of being part of a community	Moving towards adulthood
Making progress in the educational system	
How PCAs add value to achieve an active and sustainable life when growing up	To handle changes in health and healthcare contacts
The unpredictable dynamics of health—a challenging balancing act	
Moving from paediatric to adult care	
To develop an own identity and a strong voice	

daytime when resting and at night. Seven had been treated with HMV since toddlerhood and two since the neonatal period. Five participants had their own apartments with support from PCAs, and four lived together with their families (parents and siblings); none lived in a partner relationship. Four were employed, three were seeking work, and two were students. The participants are considered to represent a purposeful sample (Polit & Beck, 2021), as they were capable of talking about their experiences in their own words (van Manen, 2016).

Data collection

Seven interviews were held as video conference meetings (Zoom, 2023), and two interviews took place at the interviewees' homes as suggested by the interviewees. The interviews held via video conference meetings were recorded by a voice recorder and *not* recorded via the video conference meeting. A parent was present at one interview, and PCAs were present at two interviews. The interviews started with an introductory question—"can you please tell me about yourself, your life, and your family?" - and lasted 36–80 minutes. Open probes were used such as "can you share your experiences of family life, education, dwelling, and relations to health care?"

Analysis

The transcripts from the original dataset were, carefully re-examined through several readings, re-readings, and simultaneously reflected on in order to increase the understanding of the actual

phenomenon (Beck, 2018). The understandings of the interviews were shared within the team, and the analysis started with an immersion in the dataset in order to gain a sense of the whole and then identify tentative codes; thus, the researchers allowed the analysis to evolve directly from the data. Codes with similar meanings were grouped into subcategories and then sorted and organized into categories (Table 2) (Hsieh & Shannon, 2005).

Ethical considerations

The Swedish Ethical Review Authority (No. 2021–03426) approved the study, and it followed the *European Code of Conduct for Research Integrity* (2013). *Informed consent was obtained from participants, all of whom received information about the study verbally and in writing.* The study participants were from a small and vulnerable population, and a careful strategy was devised to reduce the possibility of identification.

Results

Moving towards adulthood

The content in this category focused on positive possibilities, delights in life, and to seeking help when needed. Moreover, fighting for one's desires, taking risks, embracing change, and not waiting to try new things emerged as essential aspects of a good life. Each subcategory emphasizes the importance of believing in oneself and having a positive mindset.

The importance of being part of a community

Most of the participants had been treated with HMV from early life. However, growing up could imply a gradual deterioration in their physical functions, which, for some, meant no longer having the capacity to exercise with a sports team of which they had been part of since childhood. More breathing problems and getting enough air during exercises were challenging, and exercise could cause pain. The situation triggered a feeling of a shift from being a natural part of a community to having a kind of barrier between themselves and friends from childhood, who continued to exercise in the team, which created a sense of alienation:

They said that I could participate in training on my own premises. But it's still not the same because everyone else is doing something else then. I was sad; I thought it was boring at the end. It's been a big part of my life, and I still enjoy sport and exercise (Interview 5)

Some participants talked about an engagement in an advanced online computer game community in which they practised and competed several times a week. This community was a core base for their social lives and a place to be challenged, involved, active, independent, and happy. It became a boost in everyday life. This was narrated as:

I want us to get as far as we can against better teams. And show them that we also can even if we have difficulties. When we play, you do not see if we have a handicap. We are like everyone else then (Interview 2)

When moving towards adulthood, memberships in para-sport clubs became important as they gave participants the possibility to try different sports activities and meet friends, whether those with serious ambitions or those who wanted to just have fun and socialize. There was room for everyone.

Developing and keeping close friendships from childhood into adulthood became a factor that safeguarded the vulnerable teenage-related process of being exposed to parties with alcohol and drugs. If something unexpected happened when they were hanging out with friends, they had experiences of feeling safe as their friends knew what to do. This was described as not being perceived by others or themselves as different or sick:

They've always been there, and if there's something wrong they're there to stop it (Interview 7)

Being part of a community could also include challenging one's comfort zones, for example, being confident enough to start a university education and participate in Freshers' week. Using a wheelchair often initially seemed difficult for new classmates to relate to, but they quickly realized that a person with

technology was like everyone else. The participants were more confident today about entering such situations and about showing who they were than when they were children:

We have had the Freshers' week for two weeks now. I am involved in everything. People quickly realise that I am just as normal as they. It is about having the courage to put yourself in those situations as well (Interview 8)

Making progress in the educational system

Starting high school could, for some participants, mean living for four years in a group accommodation where residential staff supported them. The staff there only had time to help with fundamental needs, such as food and hygiene, and had no time to support social activities. Access to their own PCAs was a prerequisite for participating in individual activities. Growing older and having more support from PCAs created feelings of being in charge of their own lives.

Being part of the educational system could imply experiences of being odd and never connecting with peers, because one's circumstances in life were so different. During the time some of the participants spent in school, they sometimes felt understimulated. Some found that demands put on themselves were too low, as everyone did everything for them. Some participants spoke of a yearning to grow up, be older, and have the opportunity to participate in higher studies where they would be better positioned:

I think many people, especially perhaps with my diagnosis, often experienced being quite understimulated at school. It's too slow, it's hard to connect with others of your age when you're young. Because you have a completely different life situation, you have had to become an adult quickly and you meet prejudices about people with disabilities as well (Interview 3)

There were also participants who had had an easy and enjoyable time at school. Good friends contributed to feelings of being included, the necessary support was in place, and impaired muscle function was not really a problem in this respect:

The fact that I wasn't the fastest in the class wasn't important (Interview 6)

How PCAs add value to achieve an active and sustainable life when growing up

Life without a PCA would be like living in an institution; it would be impossible to meet friends outside the home or live with one's own family. PCAs also gave parents the possibility to keep working. PCAs gave individuals an opportunity to grow up and

become young adults, with all that implies. They gave them opportunities to have extraordinary experiences, such as riding a roller coaster in an amusement park, being manually lifted in and out of a wheelchair, or joining friends to rent a cottage together. Sleeping over on air mattresses, electric wheelchairs, and PCAs created joyfulness.

Relationships with PCAs were often long-lasting, and in some cases had been ongoing since childhood. This relationship changed from babysitting to a close friendship when the individual became a young adult and could include meeting up outside the PCA's working schedule and being invited out and befriended by the PCAs' friends.

In the transition from childhood into adolescence, it was important for the interviewees to be given opportunities to be children via the PCAs, just as, when growing up, they had the right to be teenagers. When becoming teenagers, being allowed to do what other teenagers did was vital. Interviewees said that PCAs should not interfere if they wanted to drop out of school, or try smoking and drinking:

When I was a teenager, during the interview with PCAs, my parents always said; if she wants to smoke or drink, she must be allowed to do so. I had to have the opportunity to do what other teenagers wanted to do. But I wasn't interested so it wasn't a problem. But this was really important (Interview 3)

Being in need of and having PCAs since childhood shaped and developed the participants' personalities as they had been responsible for supervising their PCAs throughout their lives. Having a PCA as a child was challenging, but it became easier when they got older, and life became more understandable. On the other hand, some experienced being more protected as a children when parents dealt with conflicts in the PCA group and were always present to guard their children's best interest. Nonetheless, it was stated that without PCAs the possibility of independence and individual freedom would not have existed.

The participants were asked what messages they wanted to send back to themselves when they were in their teens. Their messages emphasized the importance of taking responsibility for one's own life and not relying solely on others. Participants who felt like the odd one out during childhood claimed that everything would get better when they were older; everything would be better when it was time to go to university. One participant stated:

Do not be an idiot. Take responsibility for things yourself. Do not rely on everyone else to do things for yo (Interview 4)

To handle changes in health and healthcare contacts

The content in this category focuses on the participants' wish to take control over their lives, an essential part of which was a movement towards finding and using their own voice.

The unpredictable dynamics of health—a challenging balancing act

All participants had been in a hospital countless times since they were small children. This shaped their perception of hospital appointments as young adults. Some wanted to avoid the hospital environment due to traumatic memories from so many hospital stays, while others narrated sadness and loss that hospital visits were not so frequent anymore:

Even if it wasn't fun to go to the doctor you looked forward to go to the play therapy afterwards where you could play ping pong and billiards and all kinds of things. So it was a lot of fun (Interview 5)

Several participants talked about grief when they realized that they would probably never would be able to manage *without* HMV support. A growing and developing body was not expected to decrease the need for breathing support. There were disappointments about surgical procedures during childhood that did not turn out as planned. When they were younger, there was still hope that surgical procedures in the future could offer an alternative, but when they were growing up, the surgeons hesitated due to the imminent risk of ruining previous complex interventions.

I asked if they knew whether it would get better. They don't know if it will, but probably not. I find it hard that it always will be like this. When I was smaller, they thought let's wait a few years and see when you grow up (Interview 5)

Health developments could mean that NIV was no longer effective and a tracheotomy had to be inserted due to gradual deterioration or an urgent need. Treatment with tracheotomy was perceived as more strict compared to NIV, as bacteria and mucus plugs could be fatal. It required more medical equipment and a great deal of planning when the person affected left home. Major positive impact were a clearer mind, alertness, and a higher level of well-being compared to the previous NIV treatment.

The participants were asked how they perceived their future, and a common theme was the desire to be able to take control of their one's lives. From their point of view, the main thing was to be as independent as possible and to exercise self-control and autonomy. Nevertheless, some expressed laconically that "*it doesn't quite work that way*". There was a longing for employment and a secure place of

their own that allowed easy access to work and leisure activities. Some mentioned a desire to start a family but were simultaneously afraid of passing on negative genes to future children. It was emphasized that living in the present and not worrying about the future were important.

I'm not usually so worried about things that might happen. I try to deal with the situation when it arises. You try to plan as best you can, to control what you can. But there are a lot of things that are out of your control (Interview 8)

Moving from paediatric to adult care

Most participants reported a seamless and well-organized transfer from specialized paediatric healthcare to adult healthcare with careful transfers of information between the delivery and receiving units. The adult healthcare could, in some respects, offer the combination of specialities that became a facilitating factor. Another difference was that some interventions took longer in adult healthcare than when they were children. One example was the process of repairing an important technological element in the electric wheelchair that had broken. The transfer meant saying goodbye to healthcare professionals who had followed them closely all their lives. A great deal of gratitude was expressed to people whom they felt had always been there for them over decades.

She knows who I am and what difficulties I have. What help I need. She knows my medical records by heart. From when I was young to when I am an adult, she has also been able to see if there is something that has gotten better or worse (Interview 8)

To develop an own identity and a strong voice

When the participants turned 18, there were expectations that they would take over healthcare contacts, speak up, and decide for themselves in healthcare situations where parents previously had been involved and supportive. The transfer was described as a responsibility placed on them as they could not expect the healthcare system to take care of everything automatically. Having parents nearby acting on their behalf had given them some safety as explaining their own feelings and perceptions could be difficult. There were also experiences of being afraid of forgetting important details:

It has been quite nice over the years that my mum has been there and sort of talked for me because sometimes it can be hard to explain myself what I think or feel. If I've been in pain, she's been able to explain it better than I have (Interview 5)

On the other hand, some participants had gradually learnt to explicitly discover their own words to verbalize their needs and were determined that their disability should not be a barrier. They focused on opportunities rather than obstacles, and a strong confidence helped them to go wherever they wanted.

Some parents did not want to step aside and let go when their child turned 18, and the participants had to struggle to take control for themselves. Other parents had found a way of dealing with their child's liberation and were convinced that their child was doing very well on their own. One person said:

When I am sleeping at a friend's house, I might get an SMS - is the machine on? I can just send a thumb up - and it is done. It has not been complicated, they trust me and I know what I have to do (Interview 7)

Discussion

This qualitative study highlights the importance of the ongoing progress of social relations and being part of a community where one can socialize and be physically active for HMV-assisted young people. The transfer from specialized paediatric healthcare to specialized adult healthcare was solid and worked out well but awakened existential thoughts and sadness due to the awareness that the need for HMV would never go away. The transition also included a process where the participants struggled with finding their own voice.

The study participants spoke about para-sport clubs, which offered a context allowing them to be physically active. Some participants were part of a sports team, but there were also experiences of being unable to join in due to physical barriers. Participation in sport activities provides opportunities to feel included, have fun, develop competencies, and experience peer group belonging (Carroll et al., 2021; Gibson et al., 2017). However, despite this knowledge, disabled young people are engaged in fewer leisure and social activities than their non-disabled friends and have more "passive" recreational activities (such as watching television) (Gibson et al., 2017). Carroll et al. (2021) described this situation as indicating attitudes and practices that still function to exclude individuals who do not fit able-bodied norms. Research (Carroll et al., 2021; Straus et al., 2023) points to the importance of breaking down the barriers to disabled youth's participation in sport, which requires attitudes such as asking oneself "*how can we make it work for you?*" thus opening up possibilities for what a person with ventilatory support can do. Yamaguchi and Suzuki (Yamaguchi & Suzuki, 2013) showed that the HMV assisted participants with Duchenne muscular dystrophy (DMD) in their study describe an active independent life despite physical dependency. Solid

relationships supported engagement in meaningful activities that, in turn, supported feelings of autonomy (Straus et al., 2023). Finkelstein & Marcus, (2018) described that “*a life worth living*” from the perspective of a young man with DMD involved social relationships that created autonomy; decisions and actions were characterized in ways that could be mistaken for signs of non-autonomy. Participation is of utmost importance to individual health and well-being, and it is also a matter of social justice (Straus et al., 2023). This is in line with the existential and lifeworld-oriented view of well-being that empathize vitality, movement and peace as cornerstones, as well as the importance of have meaningful life projects (Dahlberg et al., 2009). Adults living with spinal muscular atrophy (SMA) have identified autonomy, social participation, and competence along with resilience, determination, hope, and an optimistic view of life as important for psychological well-being (Wan et al., 2020). Research (Dimakos et al., 2016) has also underscored the importance of facilitating integration for people with disabilities through the promotion of friendships and other social relationships in a variety of contexts. Young adults with SMA have suggested peer support groups as an important issue (Mazzella et al., 2021; Wan et al., 2019). Strong established social connections and supporting networks with friends seem to be a reality for some adult persons with SMA (Wan et al., 2019), a finding which is in line with this study’s result. The theory of transition (Meleis et al., 2000) stresses, besides the importance of identifying factors such as types, patterns, and properties of transition experiences, the need to depict facilitators and inhibitors that affect the processes of transitions and outcomes in a positive way. The need to feel and stay connected, for example making new social contacts and/or continuing old relations with family and friends, is a prominent theme in many transition narratives (Meleis et al., 2000).

The participants in our study had a well-organized transfer from paediatric to adult healthcare, which was an interesting finding. This result may be related to the fact that the study participants belonged to experienced and specialized well-functioning healthcare units with a designated transition coordinator. Meleis et al. (2000) stated that feeling connected to healthcare professionals who could address important questions and with whom one felt comfortable and connected was an important factor in a positive transition. This finding is in line with (Sparud-Lundin et al. 2017) who underscored the importance of a designated transition coordinator when transferring young people with long-term medical conditions and special healthcare needs. Earlier research underscores a need for better collaboration between the adult and paediatric units for the successful and smooth transition of children

with HMV (Agarwal et al., 2015). A need for guidelines regarding the transition between paediatric and adult pulmonary care for children with neuromuscular diseases (NMD) has also been pointed out (Cheng et al., 2020). Early individualized planning, collaboration, and a staged transition with the involved specialists, community providers, the family, and their adolescents working in collaboration may be helpful in overcoming transition barriers (Dale et al., 2020; Israelsson-Skogsberg et al., 2018; Onofri et al., 2020; Willis, 2020). These points seem to have worked out well for our study participants.

Some participants spoke about turning 18 and the expansion of the process of finding and using their own voice. This was a process of learning to take responsibility for care contacts in situations where parents used to have a lot of input and influence. It was a process of increasing the level of confidence so that the participants dared to believe more and more in their own abilities. According to transition theory (Im, 2014; Meleis, 2010; Meleis et al., 2000), confidence in progress manifests in an understanding of the processes of an inhabitant’s medical diagnosis, treatment, recovery, and daily life with limitations.

Heath et al. (2017) point out that, with clarification of the parental role and with support, rather than being excluded, parents can facilitate the healthcare transition and support their child to become experts in their own condition and care. It is important for healthcare professionals to support parents, as well as young adults, within transitional care interventions. Meleis et al. (2000) describe awareness as a defining characteristic of transition, as one must have some awareness of the changes that are occurring in a process of transition. The level of awareness influences the level of engagement, which is another property of transitions. The concept of engagement is defined as “*the degree to which a person demonstrates involvement in the process inherent in the transition*”. Examples of engagement include gathering information, preparing, and proactively modifying daily life activities.

Many parents in Sweden are employed as paid PCAs for their disabled children (Olin & Dunér, 2016), which seems to be a complicating factor from the perspective of developing independence. This points to the importance of an individualized approach from those involved: it is important to pay attention to social support needs throughout the life trajectory (Howard et al., 2020). Participation in and influence on care can be a strengthened factor for autonomy, independence, and feeling confident in everyday life (Lindberg et al., 2016). This is in line with previous research that underscores that trustful relations should lead to satisfaction with services, greater compliance with treatment and improved health in adulthood (Hislop et al., 2016).

Strengths and limitations

The study participants constituting the original dataset had well-functioning and long-standing contacts with specialist teams regarding breathing support, which can be regarded as a limitation on capturing extensive experiences. The participants had predominantly positive experiences of the transition between paediatric and medical adult care, which can be explained by a link to a supportive, specialized, and well-functioning healthcare unit with a designated transition coordinator. Overall, the participants reported positive experiences and spoke little of difficulties in life, fears of gradual deterioration, or issues regarding shorter life expectancy. This finding is in line with earlier research describing young men with DMD (Finkelstein & Marcus, 2018; Gibson et al., 2014) who spoke about having established identities, such as being typical “guys” and distanced themselves from the label of “disabled” (Gibson et al., 2014) and preferred to talk about life “here and now”. (Finkelstein & Marcus, 2018).

Nine young people can be considered as a small group of interviewees. However, the young people in this group have severe physical disabilities and a daily life that requires rigorous organization, and they are very difficult to reach for research purposes. They represent a small group of about 600 people (Swedevox SNRF, 2022) meaning that their voices are unique and vital to include in research, which this study has done. A similar approach has been taken in international research in the HMV context.

This study included young people with mainly neuromuscular disorders who were treated with NIV. There is a need for further research on other relevant groups of young adults with different diagnoses and HMV treatment.

Beck (2018) and Ruggiano & Perry, (2019) stress that re-analysis of qualitative data is cost-effective as it takes time to travel and collect data. Thus, a secondary analysis of data means a maximal use of data in situations where people are difficult to recruit. It would have been beneficial to conduct repeated interviews to be able to ask the participants in-depth questions arising from the data analysis. However, our data comprise a small group of vulnerable people and asking them to make time to participate in interviews demands careful analysis and reporting. Thus, we consider in line with (Heaton, 2004), Beck (2018) and Ruggiano & Perry, (2019) that it is important to gain knowledge of the use of a secondary rework of qualitative data as it widens the research results.

Considerable effort was made to give an accurate description of the study context, which is important for the transferability of the findings (Graneheim et al., 2017), when findings may be valuable for other groups of young people with

long-term illnesses. A careful description of every phase in the research process including preparation, accomplishment and reporting of findings safeguard the trustworthiness of findings (Graneheim et al., 2017).

The participants lived in different parts of the country and had major variations in physical conditions, which impacted the possibility to meet face to face. Therefore, seven interviews were held via video conference meetings which created opportunities to meet and collect data of very good quality.

The research group represent a multidisciplinary perspective, that is, the medical, and caring sciences, which is regarded as a strength of the present study and enhances the transferability into various disciplines and contexts.

Implications and future directions

This study highlights that the participants had a rather seamless transition from paediatric to adult care and the importance of being attentive of individual difficulties as this process is critical in finding one’s own voice and position. More research is needed concerning healthcare professionals’ experiences of transitions processes in HMV context as well as the experiences of municipal and private companies managing PCAs and professionals representing social insurance offices. The participants also spoke of their hesitation about starting a family due to genetic diseases and their sadness that HMV treatment would continue throughout their lives. This is an existential vulnerability that is important to acknowledge.

Conclusion

This study provide knowledge about the importance for young people living with HMV to be physically active and part of a social network and community based on individual conditions. This finding underlines the importance for stakeholders of examining various possibilities to facilitate participation in physical activities for young adults growing up with HMV. The participants in our study have had a well-organized transfer from paediatric to adult healthcare that has assisted them, as young adults, to feel safe and learn to speak on their own behalf.

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Ethics approval and consent to participate

The Swedish Ethical Review Authority (2021–03426) approved the study, and it followed the European Code of Conduct for Research Integrity. Informed consent was obtained from participants, and all received information about the study verbally and in writing.

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