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ORIGINAL PAPER

Perspectives of parents of home mechanically ventilated children on the supply of medical aids

Yvonne Lehmann[1,3], **Dajana Sciortiono**[2,3]

[1]*Berlin Campus for Health Professions Education, Germany*
[2]*German Hospital Federation, Germany*
[3]*Charité – Universitätsmedizin Berlin, Institute of Health and Nursing Science, Germany*

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Abstract

Aim: The supply of medical aids and training in their use are essential for home mechanically ventilated (HMV) children and their parents. *Design:* A qualitative interview study was performed to gain deeper insights into parents' views and to derive sound recommendations for designing this form of care with the most common need for multiple medical aids (devices and accessories). *Methods:* Twelve problem-centred interviews were conducted with parents of children receiving HMV and subjected to qualitative content analysis. *Results:* Parents found ventilation-specific medical devices and accessories to be generally reliable, but not always well designed for children or well selected. Parents also identified challenges and problems regarding structural, procedural and personal aspects of the supply of medical aids. In particular, deficits in task performance and cooperation between stakeholders and involved healthcare institutions became apparent. When parents or home care nurses lacked competence in using the technology, unsafe situations easily arose. *Conclusion:* The study highlighted the need for further developments in the supply of ventilation-associated medical aids. Furthermore, the need for qualified professionals and for educational strategies to promote safety amongst parents as users of medical aids in home care became clear.

Keywords: devices, home mechanical ventilation, parents, qualitative research, supply of medical aids.

Introduction

The number of people who need various medical aids and technology-intensive forms of home care is rising worldwide (Amin et al., 2023; Rose et al., 2015). One specific, heterogenous group that requires such care consists of people of all ages on home mechanical ventilation (HMV), be it non-invasive (with a mask) or invasive (with a tracheostomy). The focus here is on children aged 0–17 years on HMV and their parents.

In recent decades, the life expectancy of children with complex chronic illnesses on long-term ventilation has increased significantly. Thanks to advances in medical technology, many of these children are now reaching adolescence and adulthood (Amin et al., 2017; Edwards et al., 2010). If ventilation is well adjusted, it can become a naturally accepted part of life (Earle et al., 2006; Noyes, 2006), enabling good quality of life as well as social participation (Israelsson-Skogsberg et al., 2018; Lindahl & Lindblad, 2011). However, numerous challenges must be overcome, including ensuring quality and safety during the supply and use of medical technical devices and accessories. Quality and safety are determined by the availability of technically perfect, user-friendly aids, the correct use of these aids, by beneficial home care environment factors, and the interactions between these factors (Amin et al., 2017; National Research Council [NRC], 2011).

The process of providing medical aids for people with long-term ventilation (and for other people with complex chronic illnesses and disabilities) cannot be described linearly with a clearly defined end; rather, the process is a cycle, especially for children. For example, the time after aid provision is usually also the time before the next needs assessment, because adjustments are necessary due to the growth and development of an adolescent (Page et al., 2020). Therefore, to maintain the success of long-term ventilation in children, regular check-ups and readjustments of the therapy

Corresponding author: Yvonne Lehmann, Berlin Campus for Health Professions Education, Waldstraße 86–90, 13403 Berlin, Germany; email: yvonne.lehmann@bildungscampus-berlin.de

and the necessary aids are required (Amin et al., 2017; Windisch et al., 2017).

The provision of healthcare for chronically ill children with medically complex conditions requiring intensive technical and nursing care – such as HMV – also influences the lives of their parents and their entire families (e.g., Israelsson-Skogberg et al., 2018, 2020; Page et al., 2020). These individuals' extensive involvement in caring can lead to enormous long-term burdens and restrictions to their own social participation and quality of life (ibid.). Both self-care and educational support from caregivers have a major impact on the quality, safety, and sustained, reasonable, and satisfactory maintenance of multi-dimensional technology-intensive and needs-based home care. It is therefore essential to build trusting relationships with professional care providers, especially physicians, medical device providers, and home care nurses (Fratantoni et al., 2019; Ørtenblad et al., 2019).

According to current guideline recommendations, educational and supportive assistance to parents as a critical element of discharge planning should begin well before home care is established (Fratantoni et al., 2019; High et al., 2022; Sterni et al., 2016; Windisch et al., 2017). In addition, this support should ideally be continued as an elementary component of the interdisciplinary long-term follow-up care for HMV children and their parents via multidisciplinary treatment and healthcare teams in a coordinated, integrated manner in line with individual needs (Amin et al., 2017; Bennett et al., 2018; Fratantoni et al., 2019).

The quality and safety of care in general – and HMV in particular – have also been repeatedly questioned. The associated possible risks of losses in terms of the state of health, self-determination, social participation, and quality of life of ventilated patients, as well as the high follow-up costs for the insured community, have been frequently discussed both internationally and in Germany (Central Federation Association of Health Insurance Funds, 2017). Recently, increasing evidence in Germany has shown that the care situation for families with ventilated children and for other children and young people with a pronounced need for care and medical aids is particularly challenging (Catolano & Bayer, 2020; International Support Group for Child and Youth Rehabilitation [rehaKIND], 2022). Some concerns have been raised about the products (devices and accessories) themselves, for example regarding their long-term functionality and ease of use. However, the quality of HMV-related tasks and processes has come under even greater scrutiny (Central Federation Association of Health Insurance Funds, 2017).

Aim

Against this background, an investigation was undertaken into how parents of ventilated children perceive the supply of medical technical aids in HMV and how the supportive care and educational needs of their children are met by the care providers involved. Based on the results, recommendations were derived for the future design and delivery of HMV, particularly with regard to educational and safety elements.

The present study was part of a multi-phase health service research project "Safety dimensions of aid supply in homecare for ventilated patients" (SAVENT, 2019–2022). Three work packages were sequentially conducted, summarised, and discussed in order to develop recommendations for the future organisation and management of medical device care for long-term HMV patients (in Germany). Other results of the project have been published in German as a working paper (Lehmann & Sciortino, 2022), as a results report for the funding organisation (Lehmann et al., 2023), and in the form of discussions of partial elements with health policy objectives (Ewers & Lehmann, 2022; Lehmann & Stark, 2024; Stark & Lehmann, 2023).

Methods

Design

An explorative qualitative cross-sectional study was conducted using interviews with parents of HMV children. The methodology and reporting of the study followed the COREQ checklist (Tong et al., 2007).

Sample

A purposive sampling technique was used to recruit study participants with a maximum variation in the characteristics of the ventilated children and the sociodemographic characteristics of their families, for example, in terms of underlying diseases, age, the duration and form of ventilation, extent of skilled nursing care, and living conditions (rural or urban area, different regions of Germany, family size, parental employment). The scope of the data collection was also determined by the time and human resources available. Therefore, 8–10 interviews were planned.

Nurses who had daily contact with parents were used as gatekeepers. They provided basic information orally and distributed an introductory letter about the study to eligible participants. In addition, German self-help organisations for parents of disabled children were used for recruitment. Parents interested in participating in the study contacted the research team directly to schedule an interview. All participants had to be parents of an HMV child or adolescent (0–17 years), be able to communicate in German, and provide written consent in order to participate in the study.

Data collection

In preparation for each interview, parents were asked to complete a questionnaire regarding sociodemographic, disease-specific, treatment-related, and other relevant information about their HMV children and themselves as parents. This process enabled us to separate the documentation of key information that could be recorded in a question–answer format from the interview itself. In addition, the case-based summary of information from the questionnaire allowed us to prepare for the interviews and to contextualise the interview statements. Only after the completed questionnaire and signed written consent to participate was delivered to the research team – either electronically or by mail – was an interview date scheduled. Due to the pandemic situation during the research period, the interviews (conducted between May and September 2021) were structured as web meetings via Microsoft (MS) Teams or telephone. The interviews followed the concept of problem-centred interviews (Witzel & Reiter, 2012) with a flexible guideline covering the following four topics: (1) current living conditions, (2) ventilation-associated technical aids (devices and accessories) and their current procurement and use, (3) initial experiences with the home care situation, and (4) safety in HMV and strategies for its maintenance. Two researchers were present during all interviews, with one (DS) conducting the interview and the other (YL or AK or SSt) taking notes in an interview protocol on the course of the interview, possible disturbances, and topics addressed before and after the interview recording.

Data analysis

The interviews that were video-recorded with MS Teams were converted into audio files. All electronic audio data (from MS Teams and telephone interviews) were transcribed verbatim in accordance with the content-related semantic rules of Dresing & Pehl (2018), and pseudonymised. The transcripts were imported into qualitative data analysis software (MAXQDA version 20.3) together with the interview protocols and information from the questionnaires. All data were reviewed by two researchers (YL and DS, both with backgrounds in nursing science and public health) and analysed using a content analysis approach (Schreier, 2012). Main categories were defined a priori, and subcategories were developed based on the data. The construction of the main categories was sensitised by the research goals and questions, as well as by conceptual considerations regarding quality and safety in technology-intensive home care (Ellenbecker et al., 2008; NRC, 2011). To ensure transparency and intersubjective comprehensibility, the codes and categories – as well as their interpretation – were discussed, condensed, and revised within the research team (Schreier, 2012).

Results

Twelve interviews were conducted with 14 individuals – nine with mothers, one with a father, and two with both parents. Ten interviews were conducted as web meetings; the other two were conducted via telephone. All interviews were recorded. The duration of the interview recordings ranged from 37 to 118 minutes (mean, 69 minutes). In one case, at the request of parents with limited knowledge of German, a nurse whom they trusted was included in the interview in a supportive role.

The ventilated children were between 4 and 15 years old (mean, 10.7 years) at the time of the survey. They had lived with ventilation in their parents’ home for 0.5–14 years (mean, 5.2 years). Besides the children with HMV, there were ten cases of older and / or younger siblings living in the household. All families received support from a home care service. Ten out of 14 parents (9 mothers, 1 father) had reduced or completely given up their own employment in order to care for their ventilated child. Tables 1 and 2 summarise additional information on the characteristics of the participating parents, the ventilated children, and their current living conditions.

The results are presented here in three main categories and six subcategories (Table 3).

Initial experiences with the use of ventilator-specific aids

For all children and parents, the journey with both non-invasive and invasive mechanical ventilation began in the hospital. For some, this was the result of an ad hoc deterioration in health immediately or a few days after birth, while for others, it was the result of a slow, progressive deterioration in the child’s health over time. In the latter cases, the children (as far as possible) and parents had already been familiarised to some extent with the devices and accessories that they would need in the future. However, they often could not recall in the interviews exactly what had been explained or demonstrated.

Table 1 Interviewed parents' sociodemographic characteristics

Characteristics		**Number**
Interviewees	mothers	11
	fathers	3
Interviewees' educational qualifications	no school-leaving qualification	1
	intermediate school-leaving certificate	3
	university-entrance qualification	10
	vocational qualification	6
	university degree	8
Interviewees' employment	full-time	4
	part-time	6
	unemployed	4
Residential area	urban	9
	rural	3
Number of children in the household	1 child	2
	2 children	4
	3 children	2
	4 children	4

Table 2 Ventilated children's sociodemographic, disease-specific, and treatment-related characteristics

Characteristics		**Number**
Sex	female	6
	male	6
Age		4–15 years, mean 10.7 years
Ventilation (years)		0.5–14 years, mean 5.2 years
Start of ventilation	since (shortly after) birth	4
	preschool age (< 6 years)	4
	school age (> 6 years)	4
Administration of ventilation	invasive (tracheostomy tube)	8
	non-invasive (mask)	4
Duration of ventilation (hours / day)	< 16 hours	7
	> 16 hours	3
	24 hours	2
Conditions	neuromuscular	3
	genetic / congenital metabolic or other	7
	complex	2
	after inflammation or accident	
Care degree (1–5[a], in accordance with German nursing care insurance)	grade 1	0
	grade 2	1
	grade 3	0
	grade 4	3
	grade 5	8
Average duration of home care service by qualified nursing staff (hours / day)	≤ 8 hours	3
	8–16 hours	5
	> 16 hours (but not around-the-clock)	2
	24 hours / 7 days a week	2
Attending a (inclusive) day care centre or school	yes	10
	no	2

[a] *Care degrees in accordance with German nursing care insurance: 1 = minor impairment of independence; 2 = significant impairment; 3 = severe impairment; 4 = most severe impairment; 5 = most severe impairment of independence with special demands on nursing care, e.g., 24 / 7 particularly pronounced challenging needs for monitoring, care, and medical aids (Volume XI of the Social Insurance Code: Nursing Care Insurance, 1994).*

Learning in an exceptional situation

Most parents described the initiation of ventilation as a severe break from normal life and an exceptional existential situation for their child and themselves. At this stage, some respondents were overwhelmed by the technology and all that it entailed. In their exceptional existential situation, parents had to learn how to use the devices and accessories. *"This is a big, new chapter where you […] have to learn everything from the beginning"* (Int. 8). For many parents, it was particularly difficult to become accustomed to the devices attached to their child's body and to the associated nursing care procedures, and they faced it all with varying degrees of anxiety. One mother described the situation as follows:

> *"But if you look back at the beginning, it was all very, very difficult and exhausting with a lot of anxiety. [...] After all, it's your child's body that you're handling with changing equipment and suctioning secretion and so on [...]." (Int. 8)*

Some health professionals (mostly nurses) tried to motivate parents to start caring for their children as soon as possible. Some children were first discharged from the (mostly tertiary) hospital to one of the few available subacute care facilities to prepare the parents for the complex care at home. For other children and parents, however, there was no structured preparation for care in their own homes.

Table 3 Main categories and subcategories of the results

Main categories	Subcategories
Initial experiences with the use of ventilator-specific aids	learning in an exceptional situation
	gradually building trust in technology and restructuring life at home
Medical aids: their procurement and use	numerous medical aids needed
	complex daily routine with the ventilation devices and accessories
Safety in the technology-intensive home care process, and strategies for maintaining it	feeling the need to be constantly on guard
	feeling the need for educational support

Gradually building trust in technology and redesigning life at home

Although the parents received some support from a medical device and equipment supplier and an in-home nursing care service, they experienced various initial problems while trying to adjust to the ventilation, technology, and life at home.

On the one hand, problems resulted from the new living conditions, the continuing need for personal and skilled care, and the imperative to develop new daily routines. On the other hand, some parents repeatedly encountered problems in handling technical equipment. One interviewee described the situation as follows:

> *"The first night I spent alone with my child at home was sleepless. I couldn't sleep because I was looking at the device all the time, looking at the monitor, looking at my child, being much more aware of the different noises than before, when a nurse was there. Every time my child's breathing changed – sometimes shallower, sometimes deeper, sometimes with a cough, sometimes without a cough [...] – it was fraught with worry [and] anxiety [...]." (Int. 6)*

Initially, the medical technology was perceived as a foreign element in the home environment. The noises and light signals were perceived as disturbing and reminiscent of the hospital atmosphere. False alarms that went off caused uncertainty. There was also a fear of equipment failure or of not being able to recognise relevant changes in the child in time.

Some parents reported that their confidence in medical devices gradually increased as they learned that alarms, mistakes, and malfunctions were often the result of operating errors, the need to replace accessories / consumables, or over-sensitive alarm systems, rather than the result of broken equipment. At the same time, the alarms gave parents a sense of security:

> *"Yes, if there are problems with ventilation or mucus, and if [my child] coughs, the devices beep immediately. I think it's great that they beep immediately." (Int. 9)*

The family's home life was restructured to include ventilation, the necessary devices and accessories, as well as the associated care processes. The only alternative would have been to place the child in an inpatient facility, which was out of the question for the parents.

Medical aids: Their procurement and use

Numerous medical aids needed

The presence of medical devices and medical accessories / consumables at the time of the survey was recorded in the preinterview questionnaire in the form of multiple-choice and open-ended questions. Table 4 lists the ventilation-specific and other medical aids used at home.

Complex daily routine with the devices and accessories

According to their accounts, the parents interviewed were responsible for coordinating the complex care of their children. They were often confronted with multiple care management tasks in order to keep their complex daily routines with the required aids running as smoothly as possible: *"[...] so that our little home intensive care unit runs, so to speak"*, as one interviewee put it (Int. 4). Even minor events – such as replacing a medical device due to a health insurance provider's cost-saving initiatives, the delivery of an inappropriate tracheal cannula, or a missing ventilator component – had the potential to disrupt care routines that had been meticulously developed:

> *"So, we are dependent on [medical aids] for better or worse. Without the equipment and a good supply, [home care] just doesn't work. Full stop." (Int. 10)*

Obtaining necessary medical prescriptions for accessories / consumables on a monthly or quarterly basis was described as time consuming and prone to failure. Although it was the contractual responsibility of the medical device and equipment supplier, incorrect or inappropriate equipment was sometimes delivered. Parents were forced to carefully check each delivery to avoid ending up with the wrong equipment.

Most children required equipment that was tailored to their size, including interfaces such as masks and tracheostomy tubes. Parents noted that devices and accessories were not always well designed for children or were not well selected.

As parents' understanding of the technological aspects of the care evolved, they began to investigate possible innovations in the medical technology market. They looked for ventilators, masks, or tracheal cannulas that were better designed, tailored to their children's needs and more comfortable. Although these devices were available on the market, children and their parents did not always have access to them, for example because of decisions made by health insurers or by medical device and equipment suppliers. One interviewee described her experience as follows:

> *"The whole system is extremely non-transparent: what it costs, how it is billed, what I am entitled to, [...] and what devices are actually available. As a mother, I am always searching […] for information, for devices, for new knowledge, [and] for doctors, too […]." (Int. 6)*

Table 4 Existing medical aids used at home

		Number
Ventilation-specific devices	ventilator (or 2 ventilators if duration of ventilation > 16 hours / day)	12
	suction and inhalation devices	11
	cough assistant	7
	pulse oximeter	12
	liquid oxygen device or oxygen compressor	9 / 4
	transcutaneous oxygen monitoring, capnometry device, high-flow device	1 each
	accessories – freely formulated additions: tracheal cannulas; ventilation masks; filters; various cables and tube systems (e.g., for ventilation, humidification); suction catheters	
Non-ventilation-specific devices	care bed	11
	material for enteral feeding	9
	material for incontinence care	11
	wheelchair	9
	patient lift	3
	stair lift	3
	further devices – freely formulated additions: bathing and showering aids: toilet aids; sitting, walking, and mobility aids; orthoses and splints; (electronic) aids to support communication (e.g., talkers, speech computers)	

In some cases, the prescribing physicians helped the parents to apply for the best solution with the relevant health insurance company; however, these applications were often rejected. Repeated appeals to the health insurance companies were sometimes necessary, as were proceedings before the social courts. Parents perceived the associated processes as overly bureaucratic, time-consuming, stressful, and humiliating.

Several parents also reported that it was difficult to find specialists who were familiar with their child's complex medical condition, including the need for ventilation and specific medical aids. Specialised centres were often located far away, and the wait for the next appointment frequently took months. This situation impeded regular check-ups, as well as adjustments in therapy and necessary aids. In the eyes of the parents, the child on ventilation was deprived of beneficial aids during this time, which often had negative effects on the child's health, development, and opportunities for social participation.

Safety in technology-intensive home care process, and strategies for maintaining it

Parents' comments revealed that, on closer inspection, ventilation-specific devices and accessories were rarely a problem. Indeed, parents seldom questioned the technical quality of the devices. Moreover, it was personal, institutional, and system-related issues, rather than device-related issues, that were found to compromise the quality and safety of home respiratory care.

Feeling the need to be constantly on guard

In Germany, authorised suppliers of medical technical aids are responsible for the timely provision, control, maintenance, and technical emergency assistance of medical devices and accessories, as well as for instructing and counselling patients and their caregivers on the use of this equipment in the home care setting. According to several parents, the various service providers involved in HMV were of limited help. For example, the legally required instruction on how to use the devices given by the medical technology providers' staff varied from person to person, focused mostly on technical elements, and was often episodic and ad hoc:

> *"So the instructions from the medical technology provider are really only the bare minimum. [...] For example, they didn't deal with disorders at all [...]." (Int. 12)*

Home care nurses – who were more frequently present and thus more readily available – often seemed to have little familiarity with the medical technology in each case. The staff appeared as helpless in solving problems with the medical technical devices as the parents themselves, which hardly inspired confidence in the competence of the in-home nursing care services. As a result, as many parents realised: *"[...] I actually have to be able to do everything myself." (Int. 5)*

In general, respondents often felt that they had to be on constant alert, partly because the professional care providers did not always pay the attention to detail that the parents expected, which sometimes (nearly) led to accidents in HMV. Parents reported that despite these eye-opening experiences, they usually had no choice but to come to terms with the circumstances. Due to their health insurance company's contracts with certain providers of medical technical aids, it was not easy to switch insurance companies. Moreover, the quantitative lack of well-trained nurses hindered high-quality and efficient home care. Indeed, it was not uncommon for parents to fear that if they were overly critical, the nursing service would no longer provide care.

Feeling the need for education support

As one of the interviewees stated, *"Well, I've been doing this for eight years already. [...] And it's now like brushing your teeth. You got used to the technology [...]"* (Int. 3). However, such positive and confident-sounding statements should be viewed with caution. It is possible that real dangers remained due to unconscious knowledge deficits as well as self-developed and creative but technically incorrect – and therefore risky – procedures. Some parents also pointed this out. As another father commented: *"I [as a medical layperson] am executing a process here that I cannot understand technically"* (Int. 4). In many cases, events continued to occur that appeared to be avoidable, such as when nurses or parents could not replace tracheostomy tubes during an accident, or when ventilator or oxygen saturation alarms were not set appropriately.

Over time, new questions and challenges continued to arise. Because parents did not feel adequately informed by professionals, some respondents searched for information on the Internet or looked for people in similar situations to share information and knowledge. Self-help communities were perceived as a valuable yet only partially reliable resources. Finally, several surveyed parents expressed gratitude that compared to many other countries, Germany generally offers comprehensive care options. At the same time, however, they expressed frustration that the care system often appeared overly bureaucratic and inflexible to them and their children. They wished for more support *"[...] so that relatives [wouldn't] have to do so much themselves and so that the obstacles that are put in [their] way [could] also be removed." (Int. 6)*

Discussion

The results of the present study revealed that medical technical aids, which initially appeared to be the most important component of HMV, were rarely a problem upon closer inspection. Indeed, real mechanical or electronic malfunctions – such as insufficient ventilator performance (e.g., inspiratory / expiratory pressure) or software-related alarm failures – were uncommon (Chatwin et al., 2010; Farré et al., 2005; Nawaz et al., 2020). Users tended not to question the technical quality of the devices, but they did not always find them well suited for children. From the parents' perspective, deficits were mainly related to various care structure-, process-, and person-related elements. Overall, numerous avoidable and objectively describable safety risks, subjectively perceived insecurities, and untapped potential for needs-based care were found in the technology-intensive care of HMV children. Problems and opportunities for improvement were identified at all stages of the aid supply process and at all levels of healthcare.

Although parent education is essential to ensure a safe transition from hospital to home, little is known about how this education is delivered (High et al., 2022). Similarly, in our study, despite targeted inquiries, limited differentiated statements could be obtained from parents. Few parents appeared to have been offered a systematic discharge education programme focused on teaching caregiver skills. Elements such as learning needs assessment, simulation training, resourcefulness training, patient-specific action plans, disaster preparedness, and symptom and technology management (High et al., 2022) were only occasionally mentioned, which often meant that there was no optimal preparation for the home care situation with HMV.

This finding draws attention to the role of providers in HMV and their legally mandated safety responsibilities in adjusting, maintaining, and training users in the use of these devices. Inadequate user training leads to uncertainties and to the misuse of aids, with a potentially adverse impact on patient health (Chatwin et al., 2010; Simonds, 2016; ten Haken et al., 2018). This conclusion is supported by the findings of the present study. Currently, there are hardly any mandatory qualification requirements for the provision of services in Germany. Therefore, it is critical to establish and test uniform quality requirements in care contracts between health insurance companies and the providers of medical technical aids. The focus should be on the qualification and competence requirements of provider staff.

At the same time, the challenging task of continuously supporting and educating parents as caregivers cannot be left to the providers of medical technical aids alone. Home care services, in particular, should also play an essential role in ensuring that ongoing support and education is provided in a way that meets the needs of the technology-dependent patients and their relatives – in this case, parents (Lloyd et al., 2006; Windisch et al., 2017). Of course, this process requires that nurses have sufficient competencies not only in handling medical technical devices and accessories, but also in dealing with underlying diseases, illness trajectories, and coping processes of patients and their relatives in addition to educational concepts and approaches. The knowledge, skills, and values that have so far been imparted in relevant qualification programmes appear to be inadequate and / or insufficiently applied or not effective in care practice. The lack of qualifications and skills amongst professional nurses – as repeatedly reported in the present study – points to an urgent need for reform of the existing nursing education and training in Germany. Most nurses are trained in nursing schools, which are below the level of the higher education sector. To date, only around two percent of German nurses have a bachelor's degree (Wissenschaftsrat, 2022).

According to German recommendations, nurses working with ventilated patients in home care settings should have completed 120 hours of further training (80 hours of theoretical training and 40 hours of practical experience) (Central Federation Association of Health Insurance Funds, 2023). However, not all nurses complete this training. The extent to which such programmes meet the high demands on qualifications and skills in technology-intensive home care should also be called into question.

Appropriate framework conditions – such as structured induction and ongoing training and supervision of nurses – are needed to ensure that acquired knowledge and skills can be sustainably integrated into everyday care (Klingshirn et al., 2021; Lehmann, 2021). Given the significant workforce shortages in this area, it is likely that these tasks are often neglected and / or require further conceptual development. The assumption of these conceptual and other tasks by nurses with a higher education degree and extended competencies – such as Advanced Nursing Practice in technology-intensive home care – should therefore be tested (Klingshirn et al., 2021; Stark & Ewers, 2020). Indeed, Germany has a lot of catching up to do in this respect (Wissenschaftsrat, 2022).

In summary, our findings highlight the need for future research and development in order to optimise education for parents of HMV children (High et al., 2022; Natsume et al., 2022). Education should always be adapted to the current situation of the patients / children and their relatives / parents, taking into account the specific support and learning needs of each individual, as well as their abilities, throughout the trajectory from hospital to home care to living with dependency. Moreover, education should not be limited to technical elements or application issues; rather, it is critical to consider the personal coping and adaptation processes of the users and the challenges they face in living at home with an illness and with technology (Lindahl & Kirk, 2019; Ørtenblad et al., 2019).

Certified ventilation and weaning centres, which have been established for adult patients and work according to with defined quality standards, are largely lacking for ventilated children in Germany (German Society for Muscular Patients [DGM] 2022; van Egmond-Fröhlich et al., 2021). This situation may have negative effects on these children's health, development, and opportunities for social participation. In this regard, there are calls to examine the possibilities of increased telehealth approaches in order to make the scarce structural and human resources accessible to as many affected children as possible (Muñoz-Bonet et al., 2020; Schöbel et al., 2021).

Finally, concrete and binding regulations as well as effective control mechanisms for ensuring high-quality HMV service provision are largely missing (Lehmann & Ewers, 2020). The results obtained here support the conclusion of previous work regarding the notion that appropriate and safe care for HMV patients requires the definition, review, and evaluation of existing but still-to-be-expanded standards of quality, qualification, and safety (Klingshirn et al., 2021; Lehmann 2021). Although a German guideline on home mechanical ventilation provides recommendations on the necessary healthcare structures, professional qualifications, discharge procedures, follow-up, and healthcare monitoring (Windisch et al., 2017), these items are not mandatory, focus mainly on the acute care setting, and lack overarching healthcare coordination and integration strategies (Stark & Ewers, 2020).

The deficiencies in the care of individuals with technology- and labour-intensive care needs outlined above and discussed elsewhere are to be addressed through the implementation of a new law and associated recommendations (GKV-IPReG). However, the extent to which improvements will be achieved remains to be seen. A growing shortage of qualified doctors and nurses is currently preventing full implementation of the law. Compromises can be observed between the qualification and competence requirements deemed necessary on the one hand and the very limited quantitative and qualitative human resources on the other. However, these compromises are ultimately detrimental to needs-based and safe care.

Finally, it should be noted that we have limited data on adverse events in home care (Neunhoeffer et al., 2022). In Germany, there is no consistent incident reporting system to capture improper or inattentive use of medical devices and equipment, or problems such as infections, accidents, oxygen toxicity, difficulties in the physical setting in which the care is provided, or other technology-related adverse events in HMV. However, various studies and the findings presented here have shown that such issues do occur (Chatwin et al., 2010; Farré et al., 2005; NRC, 2011). There is therefore a need for a system that systematically records and evaluates risks, errors, and safety-related events in the home. The knowledge gained from such a system could be used to further develop safe care for HMV patients, especially children.

Limitation of the study

The results of the present study were obtained with an explorative approach and a small sample size of 12 interviews, which was made possible by a research-pragmatic perspective and has limited generalisability. The research was conducted in Germany under circumstances that may differ from those in other countries in terms of the legal framework for the provision of medical technical aids, the role of medical device and equipment suppliers, their specific responsibilities, and their collaboration with other service providers in home care. Therefore, not all findings may be fully transferable to other countries.

The heterogeneous group of HMV children was clearly similar to the groups used in previous studies (e.g., Amin et al., 2023; Amirnovin et al., 2018). The sample captured a wide range of different backgrounds, living and care situations, care experiences, and personal views. However, distortion of the results due to participation bias cannot be ruled out. The level of parents' education was predominantly high, so this group may have been overrepresented, as is also the case in reports by other authors (e.g. Israelsson-Skogsberg et al., 2020; Page et al., 2020; Woodgate et al., 2015). Against this background, we also considered it justifiable approach to interview parents who were only able to express themselves to a limited extent in German by allowing a nurse from their home care service to provide support in order to supplement their answers.

Overall, the multi-dimensional nature of the sample and the depth of the interviews conducted were sufficient to provide a solid basis for answering our research question. The parents' mutually confirmatory and complementary assessments indicated the relevance and validity of the obtained results. Exploring the views of staff working for medical device and equipment suppliers and in-home nursing care services was not part of the study.

Conclusion

The results of the present study indicate that particular attention should be paid to further developing comprehensive safety structures and processes for cross-sectoral and cross-professional care for HMV children. Furthermore, the findings highlight the need for ongoing support and education to promote parents' competencies and sense of safety in this environment, both of which require evidence-based concepts of supportive care and education in medical technical aid supply. Finally, qualified professionals need to be better prepared for their demanding tasks in technology-intensive home care.

Ethical aspects and conflict of interest

The study was conducted in accordance with the fundamental ethical principles for medical and nursing research involving human subjects, as stated in the Declaration of Helsinki (World Medical Association, 2013) and the Code of Ethics of the German Society for Nursing Science – DGP (DGP, 2016) and approved by the Institutional Ethics Committee of Charité – Universitätsmedizin Berlin (EA4/114/19 from 24 July 2019). Data were managed in accordance with the German Federal Data Protection Act. Informed consent was obtained from all parents involved in the study.

The authors declare they have no conflict of interests.

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Author contributions

Conception and design (YL), data collection (DS, YL), data analysis and interpretation (YL, DS), manuscript draft (YL), critical revision of the manuscript (YL, DS), final approval of the manuscript (YL, DS).

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