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Personal care assistants' experiences of caring for people on home mechanical ventilation

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Aim: The aim of this study was to describe personal care assistants' (PCA) experiences of working with a ventilator-assisted person at home.
Methods: Data were collected from fifteen audiotaped semistructured interviews with PCAs supporting a child or adult using home mechanical ventilation (HMV). Thirteen women and two men participated; their working experience with HMV users ranged from one to 17 years (median 6 years). Data were subjected to qualitative content analysis in an inductive and interpretive manner.
Findings: Five categories emerged from the data: Being part of a complex work situation; Taking on a multidimensional responsibility; Caring carried out in someone's home; Creating boundaries in an environment with indistinct limits; and Being close to another's body and soul.
Conclusions: The participants felt very close to the person they worked with, both physically and emotionally. They had a great responsibility and therefore a commensurate need for support, guidance and a well-functioning organisation around the HMV user. There is international consensus that advanced home care will continue to expand and personal care assistance is key in this development. We suggest that one way to move forward for PCAs working with HMV users is to create multiprofessional teams led by a key-person who coordinates the individual needs. More research is needed within this area from a broad perspective including the HMV-assisted persons, relatives, personal care assistants and management organisations.

Keywords: home health care, ventilator care, home health aides, qualitative studies, assistive technology.

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Introduction

Medical advances and critical care have contributed to raising the numbers of technology-assisted people living in their own homes (1, 2). Increased attention to patients' wishes has also played an important role in the development of high-tech home care (3). One such group comprises those using home mechanical ventilation (HMV), which has a particular need for new knowledge and understanding (4, 5). HMV users are a mix of people with varying underlying medical conditions that lead to alveolar hypoventilation (CAH) (5, 6). Ventilatory support may be required either during sleep or over 24 hours (7) invasively (with tracheostomy) or noninvasively (with a facemask) (3). At the turn of the year 2011–2012 (8), there were 2300 HMV users registered in Sweden (24/100 000). Under Swedish legislation, people with various disabilities are given the opportunity to receive care from personal care assistants (PCA). The Swedish National Board of Health and Welfare (9) defined personal care assistance as:

> A personally tailored support that can be given to a person who, because of serious and permanent disabilities requires assistance with basic needs.

Swedish disability policy is based on the principle of universal equality of dignity and rights. The purpose of personal care assistance is to promote equality in living conditions and full participation in society (10). The care recipients, in this case HMV users, are free to employ their own PCAs. Dependency on care may engender a feeling of inferiority and loss of independence (11) which is more easily coped with if the person can influence the organisation of their care (6, 12).

Leece and Peace (13) describe how disabled adults who employ their own PCAs have a greater sense of autonomy. Nevertheless, life on a ventilator can be a challenge. The ability to breathe is connected with life itself; it is an absolute physiological and existential need (2).

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HMV users are forced to rely on both lifesaving devices and other human beings in order to sustain life and health. The ventilator compensates (14) for the missing function, that is breathing. The experience of breathlessness has been described as an extreme and frightening symptom involving panic and fear of impending death (15–17). Research (14, 18–20) has pointed out that HMV is associated with a wide variety of ethical challenges and more knowledge is needed on how to integrate technology and the ethics of its use with care practices. Wang et al. (21) describe technology as complex and frightening for both families and healthcare professionals. Ahlström et al. (22) point out the challenge of having staff in the home day and night, with the accompanying loss of privacy, a HMV user can have up to twenty PCAs working in their home (23).

The organising of PCAs' responsibilities vary across countries but there is international consensus that more knowledge within this area is needed (18, 24–28). There are no formal competence requirements for PCAs working with HMV-assisted persons in Sweden (9) even though they are responsible for a life-supporting home ventilator and the HMV user's everyday care and safety. The largest employers of PCAs in Sweden are the municipalities but there are also private companies (29). Although personal care assistance is a relatively new area of research, it is known that difficulties may arise that do not occur in a similar way in other care occupations (25). It is an intimate work situation characterised by the PCA's constant presence in the recipient's life (30). When a professional enters another person's private life, there may be difficulties establishing boundaries, in terms of work and leisure, friendship and a professional relationship (20). Tensions may arise because the recipient's dwelling is both a home and a workplace (25).

Theoretical framework

Our theoretical framework is grounded in a caring science perspective, meaning that caring is regarded as unselfish and loving giving to the other (31, 32); it is about responsibility and watching over the other; in this study, it can be carried out by a lay person. The core ideas (Ethos) in caring are to safeguard the health and lives of people and to alleviate suffering. It is characterised by responsibility and a wish to do good (33, 34). A person-oriented professionalism is about investing something of oneself in the meeting with others, about putting the other in the centre. It is not only about paid work, but also represents a fundamental human calling where engagement and closeness are central (35). Eriksson (36) writes that human suffering can be alleviated by human care and solicitude; seemingly simple everyday activities can provide power and dignity. PCAs are in a position where they can ease suffering; they respond to the fact that someone depends on them (19).

Rationale

There is national and international consensus that the need for vital and competent home care will continue to increase in relation to changes in patient population and acute care (1, 19, 20, 26, 37). This situation constitutes a new and growing challenge for health care. People with impaired communication skills requiring HMV and form a small but growing group in our society (3, 21, 38–42), and HMV treatment is one type of advanced home care that demands new knowledge. MacIntyre (43) points out that there is a rapidly growing population of patients who have survived acute critical illness but need ongoing specialised care, e.g. HMV. This fragile group requires caregivers with unique skills encompassing critical care, rehabilitation competence and medical expertise. If HMV users are to feel that they are living a good life, it is essential that qualified PCAs work in their homes on a continuous basis (6). At the same time, research clearly shows that PCAs working with vulnerable HMV users in home settings are often left alone with responsibilities that far exceed their level of knowledge and training (20). Consequently, more knowledge is needed about the work situation of PCAs in relation to their experiences of caring for HMV-assisted people, and about their needs and requests in order to offer them adequate training and support in their work. In summary, there is little existing research in the area (5, 23, 27, 41, 44) which was the motivation behind this study. Therefore, the purpose of this study was to describe PCAs' experiences of working with a ventilator-assisted person (adult or child) at home.

Methods

Design

Qualitative methodology focuses on understanding the human experience as it is lived. Data collection often takes place through a careful compilation and analysis of narrative and subjective materials (45). The decision to use interviews as the data source was a natural choice as we wanted to share each PCAs' unique lived experiences (46). To ensure methodological coherence, Morse et al. (47) state that the research question must match the method which in turn matches the data and analytical procedure. Rigour has been considered throughout the process of analysis (48) from the choice of the most suitable data collection method that would answer the research question to carefully describing the analysis process (49, 50).

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Data collection and participants

The data comprised a purposive sample and consists of tape-recorded semistructured interviews with 15 PCAs. Seven interviews were collected by the first author (Å.I) and eight by two district nurses enrolled on a masters' programme. The interviewers used a common thematic interview guide (46), which helped them to implement comparable interview situations.

The initial invitation to eligible interviewees was made via the PCA's employers who received information about the study which they then passed on to the PCAs. Once a PCA had agreed to participate, they were contacted by the interviewer. Data collection took place from November 2010 to March 2011. A diary was used and notes were written after each interview ensuring that impressions which emerged from the interview session would be remembered. The participants were all working as PCAs, supporting a child or an adult receiving HMV treatment to sustain health – and life itself (Table 1). No importance was attached to whether the HMV user was a child or an adult. Thirteen women and two men participated (Table 2). Some were employed by the HMV users and some by a private company or the municipality; some were accustomed to working in pairs.

Eleven interviews took place in the interviewee's homes, two in quiet room at a university, and two at the home of an HMV user. The interviews started with an introductory question: "Could you please tell me about your working experience with HMV-assisted people?" The tape-recorded interviews explored experiences in conversations about feelings, thoughts and lived experiences related to work situations. The interviews lasted 50–80 minutes and were transcribed verbatim by the author.

Table 1 Characteristics of home mechanical ventilation (HMV) user

HMV user nr	*Adult/Child*	*Ventilator regime*
1	C	Tracheostomy
2	C	Tracheostomy
3	C	Tracheostomy
4	C	Tracheostomy
5	A	Facemask ventilator
6	A	Facemask ventilator
7	A	Facemask ventilator
8	A	Facemask ventilator
9	A	Tracheostomy
10	A	Tracheostomy
11	A	Tracheostomy
12	A	Tracheostomy
13	A	Facemask ventilator
14	A	Facemask ventilator
15	A	Facemask ventilator

Table 2 Characteristics of personal care assistants

Personal care assistant nr	*Female/ Male*	*Working experience as a personal care assistant (years)*	*Working experience with HMV users (years)*	*Education*
1	F	3	3	Childminder
2	F	4	2	Assistant nurse
3	F	8	8	Assistant nurse
4	F	12	6	Assistant nurse, personal care assistant education
5	F	7	7	Assistant nurse, personal care assistant education
6	M	11	11	Assistant nurse
7	F	5	5	Personal care assistant education
8	M	9	9	Personal care assistant education
9	F	3	3	Assistant nurse
10	F	4	1	Assistant nurse
11	F	5	5	Assistant nurse
12	F	5	5	Care assistant
13	F	6	6	Assistant nurse
14	F	10	10	Assistant nurse
15	F	17	17	Personal care assistant education

Data analysis

The goal of qualitative content analysis is to provide knowledge and understanding of the phenomenon under scientific scrutiny and is often used in nursing research (49, 50). The actual data were analysed using the method as described by Elo et al. (49) in an inductive and interpretive manner; there was an openness towards the researcher's interpretation.

First the text was first transcribed verbatim, read and re-read in order to gain familiarity with and a deeper understanding of the content; the text was then divided into parts containing similar content. A short word describing the content was written in the right-hand margin. Codes with similar meanings were grouped together as subcategories. By interpreting the data, subcategories containing similar events were identified and grouped into higher order categories, to describe and abstract the phenomenon of interest.

Findings

Five categories with subcategories emerged from the analysis (Table 3).

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Being part of a complex work situation

Work was not considered stressful, in the sense that they had to rush during their shift, but the working situation was *demanding and energy-consuming* in that they worked many hours and always had to be alert. The work demanded that they should be mentally prepared for anything to happen during their shift regarding the HMV user's breathing. There was a balance to be kept between spatial closeness and distance in terms of leaving the HMV user undisturbed but still having complete control of the ventilator. The work could be very lonely:

> When you work as a PCV you don't have any work colleagues to talk to during the day. There isn't anyone there like you are used to having. We often work long shifts and I miss having colleagues to talk to (1)

All the participants expressed a conviction that *their work had great value*. They were able to offer help and the HMV user and the family often expressed their appreciation. Working as a PCA had given them a broader perspective on life and personal growth. They felt grateful to share another human being's life and experiences.

> To have the chance to work in care, to get an understanding of what it means to be disabled. To realize that it is not over, there is a lot left to live for. I think that's the big thing I've learned (8)

One participant expressed the opinion that personal care assistance is a "run-through" occupation, something to do when you are on your way to another job or education. A question frequently posed during the interviews was: *How can I find a way to get professional development?* It was important to be offered a continuing education programme. It was also important that all PCAs in the working group received the same education regarding the HMV user's medical devices so that they all performed working tasks in the same way. Some PCAs had completed a PCA education which taught them how to see problems from different perspectives and share experiences with other PCAs.

Table 3 Overview of categories and subcategories

Categories	*Subcategories*
Being part of a complex work situation	Demanding and energy-consuming
	Work of great value
	How to find a way to get professional development?
Taking on a multidimensional responsibility	Prerequisites for taking on the responsibility
	Obstacles to taking on the responsibility
	Empowering the HMV-assisted person
Caring carried out in someone's home	To feeling and showing mutual respect
	To have rights and duties towards each other
	Working with medical technology in someone's home
Creating boundaries in an environment with indistinct limits	To consider the working tasks they were expected to do
	To draw the line between being professional and being friends
Being close to another's body and soul	To be physically close to each other
	To cross the boundaries to the family's preserve
	To be emotionally but professionally close to each other

Taking on a multidimensional responsibility

The responsibility comprises different aspects; it was multidimensional. The participants talked about the responsibility for another person's breathing, actually for another person's life with great respect; it was seen as heavy and took a long time to get used to. They had different ways of handling it but feeling secure in their knowledge about the medical devices was a *prerequisite for taking on the responsibility.* It was important that medical devices were reliable and easy to handle. Some of them tried to prepare themselves for emergency situations. Knowing exactly what to do and being prepared meant a lot. They had an "emergency bag" with essential equipment and they rehearsed imagined scenarios.

> What do I do in an emergency situation? What do I do if the tracheal cannula comes away? I think like pictures in my head, what will I do? (12)

Another aspect of the multidimensional responsibility was connected with having a properly functioning organisation, to know that they had the support of their managers and peers when needed. This could concern technical questions about the ventilator and breathing problems, but also the feeling of having a peer behind you. The feeling of familiarity with the HMV-assisted person, knowing their preferences and values made the responsibility easier.

However, there were several *obstacles to taking on the responsibility.* Some participants spoke about a suboptimal organisation which caused them distress. They clearly remembered situations when they had problems and needed immediate help but received no support from within their own organisation and were forced to dial 112 and turn to an emergency ward. Such situations gave rise to a sense of vulnerability and made the responsibility difficult to handle.

> Just think, if she dies on my shift [when the ventilator makes strange noises]. I want us to go to the hospital but the HMV user won't go. There is a conflict. But it's a big responsibility for me to see to it that she gets air. (11)

Disputes with the family about how to perform certain tasks could also hinder taking responsibility. PCAs told

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about situations where they had been on a course and learned new skills for performing a special task but next of kin had a completely different opinion about the correct way to do things. In such situations, it took courage to oppose the next of kin.

Another dimension of the responsibility involved *empowering the HMV-assisted person* to take more personal responsibility for their life. This was regarded as a major goal. They wanted to help the HMV user to grow as a person and become more independent.

> She [the HMV user] is also responsible for being able to feel good. It's not just the assistants around her; she has to take responsibility herself for her health. (12)

Caring carried out in someone's home

All the participants expressed a belief that one absolute condition for providing caring in someone's home was *feeling and showing mutual respect.* The participants emphasised that they had to be sensible of the fact that they worked in an environment that was neither their home nor a hospital. Consequently, they could not judge the HMV user's choice about the arrangement of their home. One PCA described how adapting oneself to the family is often a question of interpreting implicit wishes. The PCAs acquired the skill to interpret these unspoken desires and to show respect for the user and family.

> As a PCA, ideally you would be like a fly on the wall. You have to be there and help in a good way, preferably before she has said anything, and then you should be part of the background again. (4)

A person with PCAs has many legal entitlements. Some of the PCAs felt there was ambiguity about the duties the HMV-assisted person and the next of kin had regarding them. PCAs, HMV users and next of kin needed to be aware of the *rights and duties towards each other.*

> The ventilator-assisted person has a lot of rights, according to the law. But even if you have a lot of rights, you can't just walk all over people around you. (4)

There was consensus regarding the ventilator; it was a good thing as it prolonged and improved the quality of life for the HMV user. However, *working with medical technology in someone's home* was a multidimensional issue. Some of the PCAs felt secure and regarded the ventilator as easy to handle, but it could take years to get used to various skills such as suctioning airways or responding correctly to the ventilator's alarms. The PCAs talked about how very careful they were about hygiene in the home and how aware they were of infections in relation to the HMV user.

The working environment was not always ergonomically organised. The interviewees talked of apartments that were cluttered with a variety of equipment. Their work could be heavy, as lack of space meant that they had to carry a lot of equipment around. PCAs who worked with children said they literally had to chase the inquisitive child with the ventilator tubes. However, all the participants were convinced that handling questions about daily life with a ventilator-assisted person was more difficult than handling the ventilator itself.

Creating boundaries in an environment with indistinct limits

The PCAs emphasised the fact that it is the HMV-assisted person who decides what to do and when to do it, but in some cases it was difficult for them *considering the working tasks they were expected to do.* Sometimes the PCAs felt anxious about certain tasks and there was a risk of being confronted with tasks they did not want to do, some of which they found morally unacceptable. This was a particular burden for those who worked alone. Drawing the boundaries then became a constant problem:

> In the beginning she didn't want to have the [ventilator] mask on her face at all, she refused and resisted. But the parents wanted her to have it on. We have discussed this with the parents a lot, we can't, and we aren't allowed, to use force. It's the setting of a boundary that we have been busy with all the time. Where is the limit for what is good for her? Should we force her? But at the same time she does not always realize herself what is for her own good. (13)

The participants who worked with a child sometimes experienced great difficulties in setting limits. Situations arose when the PCAs and the parents disagreed about child-rearing and what their respective duties were. The PCAs could see some tasks as clearly being the parents' duty, for example, helping the child to brush their teeth, while the parent saw it completely differently. They described how they did not want to argue or alienate the parents, nor to be perceived as a problem. Some of the PCAs were forbidden by the parents to talk about difficulties with their colleagues, which were perceived as highly problematic.

> When you work as a PCA in a family you can't talk all over the place, maybe not with the family and certainly not with your work colleagues. That can be hard. (2)

When the working situation was complicated, it was very important to have supervision from a mentor or manager to be able to set limits. The manager could also be a help in the dialogue between the PCA and the next of kin.

There was disparity in how the PCAs felt about the importance of maintaining a professional role rather than being a personal friend of the HMV user. Establishing good relations and getting to know the person were

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important. Some of the interviewees regarded finding where *to draw the line between being professional and being a friend* as being the basis of the profession.

> When I go to my HMV user I don't feel that I am going to work. I'm going to visit a friend, that's how well it works between us. It's a great feeling but it's not always so appreciated by the employer. But it works here brilliantly (10)

Long working hours spent close to the HMV user and their next of kin could complicate setting limits for the PCA even if they were certain about the best way to proceed.

Being close to another's body and soul

Work was largely about being close to the other's body and their personal territory. *To be physically close to each other,* day and night;

> As a PCA we sit close all night, perhaps 70 cm from the ventilator-assisted person and 40 cm from the ventilator. It's natural, if that person is supposed to live and feel well. (2)

The PCAs often worked with young people who wanted to explore life, go to concerts, movies, etc. In such noisy environments, it was even more important to have constant physical contact with the HMV user as it was sometimes impossible to hear the ventilator's alarm. The PCA needed to have eye contact, see facial expressions or have a hand on the HMV-assisted person's shoulder throughout.

The character of the physical closeness could change according to the developments in the HMV-assisted person's health. In some cases, a change occurred because the HMV user's physical status improved;

> Today is the first day in two and a half years that I have left the mother alone [with her son]. She was alone with him for an hour. It's the first time since he was born. (1)

However, change could also occur because of gradual deterioration. The relationship then became even more based on physical closeness. In such situations, periodic conflicts inevitably arose between PCAs and users, and it became important to dare to face the conflicts. This was not always easy because the HMV user could also be the PCA's employer but it was important for the PCAs from several aspects;

> She [the HMV user] is just like any other teenager. She is sore about something and won't listen. We want her to grow as a person so we can't let her do whatever she likes just because she's on a ventilator. (12)

When you work as a PCA and you are part of a family, it is necessary *to cross the boundaries to the family's preserve*, that is a domain that seems to be especially reserved for someone else. Crossing boundaries could be complicated and the interviewees described how they constantly tried to detect what the family wanted them to do or be.

The interviewees felt both personal and professional friendship towards the HMV user and some of them created close and deep relations. *To be emotionally but professionally close to each other* was simultaneously a gift and a challenge;

> When you work as PCA you learn to know your user inside out. If you work in geriatric care you don't have that possibility. I think it's a wonderful feeling. Until the day she dies. Then it's not a wonderful feeling – then you wish that you had chosen to work in geriatric care. (10)

One participant explained how she and her user often had conversations about life and death, about sorrows and past losses. The PCAs were conscious that life for the HMV user was fragile – pneumonia could be fatal. The emotional closeness also extended to the next of kin. Some PCAs had worked many years in the same family and become involved in their joys and sorrows. One participant narrated how they tried to support the HMV-assisted person's family in their grief, for example trying gently to encourage a wife to participate in some nursing care activities and thus get closer to her husband again.

Discussion

Our findings show that working as a PCA can be expressed as being dedicated to work. Their work environment was complex, regarding both caring activities and ethical demands. Although the PCAs' work is so crucial for people in need of technological support, there is a lack of research from their perspective which influences the development of educational programme for PCAs negatively (25). What was striking in our study was the physical and emotional closeness the PCA and HMV user, and in some cases the family, shared. The PCAs regarded this closeness as a gift giving them a broader perspective on life. This is in line with Wang et al. (21), who describe how primary caregivers who supported ventilator-assisted children at home were enriched by the relationship. It gave them an increased empathy. The closeness was also regarded as a professional challenge in that the user, or the HMV user's family, was also the PCA's employer. Our findings show that the PCA sometimes felt exposed to difficult situations if their views differed from those of the HMV user or the parents. Earlier research (51) maintains that home care involves entering a place dominated by the culture, habits and power of another person. It requires a great deal of wisdom to deal with this complex scenario. When you enter someone's home as a professional, the boundary to privacy shifts. The loss of privacy can interfere with family routines and changes in family interactions can occur. The participants in our study emphasised the importance of showing

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respect for the lifestyle of the HMV user and the family. Lindahl et al. (51) write about professional friendship as a response in the HMV users and their families, where those involved have not deliberately chosen each other's friendship. We believe that this concept can deepen the understanding and portrayal of the work performed by PCAs.

The interviewees, who worked with ventilator-assisted children, talked of working situations encompassing ethical dilemmas and uncertainty about boundaries. Previous studies (19, 21, 44, 52) show that the next of kin to a child with HMV has to be vigilant and very watchful. Research (53) indicates that it may be difficult for PCAs to know how they should behave when people have differing ideas about their function and behaviour. However, little is written about personal care assistance for children.

The participants spoke of a responsibility to help the HMV user to grow as a person and maintain control over their own life. Earlier research (22, 54, 55) describes empowerment as a question of ethics and democracy and underlines the importance of supporting PCAs by providing them with ethical knowledge and supervision. Possessing this knowledge, the PCAs are capable of empowering disabled persons with self-esteem and dignity.

These aspects can be compared to the participants in our study who made huge efforts to support the HMV users in breaking free from the feeling of constraint. The results are in line with earlier research which claims that PCAs tried to make the most of their clients' abilities to achieve the best possible quality of life (25, 56). When Lindahl and Lindblad (19) interviewed parents of ventilator-assisted children, the PCAs were described as being in a position to ease suffering. Fox (11) writes about two aspects of care, namely care as a gift and/or as a vigil; the latter refers to the watchful eye of the carer. A relation that is a gift can create a positive loop with a reduced perception of dependence. Earlier research (19) has used the expression professional, compassionate care. Compassionate care can be more practically construed as a response to seeing the vulnerability in other people and acting in a meaningful way towards it (57).

The participants in our study experienced a sense of loneliness in their work, which brought vulnerability at both a professional and personal level. They felt lonely and there was no room for mistakes; it was a huge responsibility to ensure another person's breathing. This is in line with earlier research (20, 25). Some of the PCAs in our study were working with the most advanced form of HMV, tracheostomy, where fulltime care and ventilator support were needed for survival. These PCAs bore a heavy responsibility in a complex environment, in some cases without access to support or guidance. Education and access to support were requested by all participants. Research (5, 19, 22, 25, 44, 56, 58) emphasises how valuable it is to work in multiprofessional teams around this kind of patient population. Lejonqvist (59) argues that multiprofessional teams with integrated clinical competence make it possible to share and learn from each other and bring confidence in developing the working environment, patient care and the personal self.

There is consensus that the need for advanced home care will continue to increase. Simultaneous studies in the United States and Canada (60–63) reveal problems recruiting PCAs, probably because they are low-paid, unprepared for the demands and have few opportunities for advancement. Dybwik et al. (44) describe Norway as having a large gap between the expectations of people with complex homecare needs and what the community care services are able to provide. PCAs play a central role in promoting opportunities for children and adults with impaired respiratory function to have a good life. As time costs for PCAs are increasing (25, 30), there is a need for knowledge development, including a social and economic perspective, regarding the situation of PCAs and HMV users (54).

Methodological considerations

Inviting PCAs to participate in the study was not possible without help from their employers. This might have affected data. However, clear information about inclusion criteria was given to the employers in advance orally and in writing. The sample size is small but the participants represent what Polit and Beck (64) conceptualise as maximal variation and the PCAs mediated rich and diverse descriptions and meanings from various work-related situations. Within the framework of this study, we have not investigated whether there were any differences between the experiences of caring for an adult and those involving a child. This might be regarded as a weakness but further research could illuminate this situation. The authors have had discussions with peers and together reflected critically on the process throughout the analysis. Elo et al.(48) emphasise having a critical discussion about weaknesses and strengths in order to make the research process transparent and reproducible when using qualitative content analysis, thus supporting its trustworthiness. Each qualitative research interview is unique, but a common thematic interview guide (46) to guide the interview in the same direction concerning the study aim was used. The interviewers were experienced nurses with further education, trained in scientific methodology. The participants were free to decide where the interviews would take place. The interviews were conducted in Swedish and the quotations presented have been translated into English by a native speaker. Both authors are critical care nurses and have clinical experience of

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working with ventilator-assisted persons. NN is also an experienced researcher within the HMV area and in the use of qualitative methodologies.

Conclusion

Working as a PCA means experiencing physical and emotional closeness to the care recipients. Work includes joy and pride but also feelings of loneliness and vulnerability; it also means carrying great responsibility involving major challenges. Today's societal trend to move advanced care from the hospital to the home will continue to expand. This change brings into focus issues concerning personal care assistance with regard to organisation and management and the field of knowledge and responsibilities of the PCAs. We suggest that one way to meet this challenge is to create multiprofessional teams around this kind of patient population, including a key-person who bears the main responsibility for coordinating all the issues and who shares knowledge and bring confidence to the PCAs. To conduct quality-assured advanced home care, easy access to professional support is required for the occupational group concerned, in this study PCAs. More research is needed within the area, from a broad perspective including the HMV-assisted persons, relatives, PCAs and management organisations.

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Author contributions

Both authors have participated sufficiently in the work with manuscript to take responsibility for the content. A more substantial description is as follows: Åsa Israelsson-Skogsberg is responsible for designing the study, recruitment of interviewees, the data collection process, analysis of data and the writing up of the manuscript. Berit Lindahl designed and planned the study, had access to the complete data set and contributed with intellectual input in the analysis process, in drafting the manuscript and revising it critically. Both authors approved the final manuscript.

Ethical approval

According to Swedish law (Codex, 2014), approval from an Ethics Committee is not necessary when a study concerns staff who is considered to consent to participation autonomously. The principals of the Helsinki Declaration (WMA, 2013) guided the consent process and consequently information was given about confidentiality and the possibility of withdrawing from the study without giving any reason. The participants received information and then gave their written consent.

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