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Being the Parent of a Ventilator-Assisted Child: Perceptions of the Family–Health Care Provider Relationship When Care Is Offered in the Family Home

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Abstract

The number of medically fragile children cared for at home is increasing; however, there are few studies about the professional support these families receive in their homes. The aim of the study was to understand the meanings that parents had about the support they received from health care professionals who offered care for their ventilator-assisted child in the family home. A phenomenological-hermeneutic method was used. Data included the narratives of five mother–father couples living in Sweden who were receiving professional support for their ventilator-assisted child. The findings indicate that receiving professional support meant being at risk of and/or exposed to the exercise of control over family privacy. The professional support system in the families' homes worked more by chance than by competent and sensible planning. In good cases, caring encounters were characterized by a mutual relationship where various occupational groups were embraced as a part of family life. The findings are discussed in light of compassionate care, exercise of power, and the importance of holistic educational programs.

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People on ventilators living at home comprise a mixture of adults, teenagers, and children with various medical conditions and needs, such as neuromuscular diseases, lung and airways diseases, and congenital disabilities. The number of children requiring ventilator-assistance is increasing (Carnevale, Rehm, Kirk, & McKeever, 2008; Kirk, 2010; Lewarski & Gay, 2007). Lewarski and Gay (2007) believed that the increasing use of home mechanical ventilation (HMV) among children has changed the home-care clinical landscape regarding the provision and manufacture of equipment. Lack of evidence-based standards in relation to HMV treatment may also make training and transitioning from hospital to home a frightening and unsafe experience for HMV users and their families.

Kirk (2010) interviewed technology-dependent children to learn how medical equipment influenced their identity and relations with others. She found that the children perceived a balance between positive and negative aspects. This balance was conceptualized as illness and identity work where social networks played an important role. In an editorial, Carnevale and coauthors (2008) stressed the importance of developing knowledge about these families by examining the impact of home ventilation-assistance on social life, health, everyday geography, relationships with technology, and finances. Although Western countries have different health and social welfare systems, the researchers believe the challenges for this population of families are similar and poorly understood.

This study offers a Swedish perspective about the experience of families with a ventilator-assisted child and makes a contribution to the growing body of knowledge about the experiences and needs of these unique families. In 1992, a radical change in the Swedish health care system was initiated, putting municipal authorities in charge of home-care nursing. The National Board of Health and Welfare (LSS 1993:389; LASS 1993:389) then put into practice two laws regulating support and service for the disabled and the right to receive support from personal care assistants. In most cases, a personal care assistant has formal education as a certified nurse assistant, but a layperson could also be employed. The costs for this personalized support in Sweden are borne by the regional social insurance office.

While there are many studies that focus on parenting a child affected by chronic illness (Tong, Lowe, Sainsbury, & Craig, 2010; Wong & Heriot,

2008), few have reported on the life situation of parents with a child in need of HMV (Lewarski & Gay, 2007; Wang & Barnard, 2008). However, there are research reports which illuminate parents' and families' experiences of caring and raising children whose lives depend on complex technologies (Carnevale et al., 2008; Heaton, Noyes, Sloper, & Shah, 2005; Rehm & Bradley, 2005). Morse, Wilson, and Penrod (2000) chose a mother-and-child focus for their study about the experience of having a disabled child. One common theme in the existing findings is an awareness of the benefits that having a ventilator-dependent child brought to the family (Wang & Barnard, 2008). However, the need for security and comfort in social situations, family vulnerability, and lack of support for caregiving responsibilities were also identified as serious concerns by parents.

Studies on professional support offered to families within the family home are lacking. This article is an attempt to compensate for this. The concept of "professional support" (Lindblad, Holritz-Rasmussen, & Sandman, 2007) as used in this study applies to a person who delivers a professional health service in the family home, that is, is a professional caregiver. In contrast, parents, siblings, relatives, and friends are seen as informal caregivers.

Despite ongoing developments in health care and HMV research in the Scandinavian countries (Ballangrud, Bergseth Bogsti, & Johansson, 2009; Dreyer, Steffensen, & Pedersen, 2010; Dybwik, Tollali, Nielsen, & Brinchmann, 2011; Lindahl, 2010; Laub & Midgren, 2006), no published studies were found that focused on the experience of families with a child with HMV and their need for domestic professional support. A metasynthesis which examined international research related to family members' experiences of everyday life with a ventilator-assisted child revealed that more research concerning family learning processes and resources and nursing support systems are needed (Lindahl & Lindblad, 2011). The study also highlighted the fact that the children using HMV were never alone. Instead of having friends their own age around them, they were surrounded by adults. Moreover, one of many parental challenges was to help the child to connect to the self, other people, and the world.

The present study focused on several broad questions: How is it possible to raise a ventilator-assisted child in a way that fosters identity, a sense of embodiment, and relationships with other people, especially those of the child's own age? What kind of support do parents need from health professionals and society? As these children have complex care needs, there is a risk that the parents, particularly the mothers, will be denied a life outside the home (Heaton et al., 2005). It is difficult to obtain help from people who are specially trained and who could look after the child (Lindahl & Lindblad,

2011). Therefore, the aim of this study was to examine the meanings of domestic professional support for parents of children on assisted ventilation.

Method

Life-World and Narratives

Lindseth and Norberg (2004) have developed a phenomenological-hermeneutic research method aimed at elucidating essential meaning from life as it is lived through human experience. The method is inspired by the writings of Paul Ricoeur (1976, 1998) and has an approach grounded in a life-world perspective and the collection of narrative data (Lindseth & Norberg, 2004; Ricoeur, 1998). When narratives, mostly in the form of in-depth interviews about lived experiences, are written down as text, the meaning breaks away from the world of the author (Ricoeur, 1976) and the text assumes an autonomous position. This meaning can be interpreted (Lindseth & Norberg, 2004), appropriated, and returned to a wider audience. The analysis process moves back and forth among three phases—naïve understanding, structural analyses, and comprehensive understanding. The method is frequently used in research that has a caring science perspective, especially in the Scandinavian countries. Examples of its use are Lindahl, Sandman, and Rasmussen (2005, 2006) who described the meanings of a life on a ventilator from an adult perspective and Lindblad's (2006) work about being the parents of a child affected by disability.

Participants and Settings

Parents, both fathers and mothers, contacted through two different Swedish outpatient clinics involved in respiratory care, were invited to participate in an interview. Inclusion criteria for participation were that the parents had children who had ventilator treatment and lived at home, that they had experiences of receiving professional support at home over approximately 2 years, and could speak and understand Swedish without using an interpreter. The health professionals at the two clinics distributed a written invitation to parents who met these criteria. The letter of invitation described the study and how to contact the researchers if the parents were interested in participating. Ten parents, five fathers and five mothers within five families contacted the research team and agreed to participate (see Table 1). The couples chose the setting for the interview, either their home or any other preferred location. The parents lived together in all five families and were therefore interviewed as a couple.

Table 1. Descriptions of Family Circumstances.

Family	Siblings in the family	Child care/ occupation	Employment outside home	Professional caregivers in the home
A	Two siblings	Child care	Father employed full-time	Yes
B	No siblings	Attends school with PCA	Mother employed part-time Father employed full-time	Yes Yes
C	Two siblings	Attend school with PCA[a]	Father employed full-time Mother at home	Yes
D	One sibling	Employment	Own housing	Yes
E	Three siblings	Attend school with PCA	Father employed full-time Mother at home	Yes

Note. PCA = personal care assistant.

The age of the children varied, as did the causes for the HMV treatment (see Table 2.). The children all needed continuous care and monitoring and were therefore never left alone. Two children suffered from cognitive disabilities. The remaining three had disabilities related to mobility. One of the children, a young man, had recently moved to his own apartment. His parents had the most extensive experience of receiving professional support for their child.

Data Collection

The interview with each parent dyad used a narrative approach (Kvale, 1996; Mishler, 1996) and began with an open-ended question: "Can you please tell me about your experiences of professional domestic support enabling you to manage the care of your child at home?" "Please tell me about positive and negative experiences." Follow-up questions were used to deepen and clarify the parents' narratives. All interviews were conducted in the families' homes except one which took place in the hospital in connection with a visit to an outpatient clinic. The tape-recorded interviews were transcribed verbatim. Three of the children were present at the interviews, sitting close by so that the parents could keep a watchful eye on them. One child was at school during the interview and one adult child was in his own apartment. The interviewer's overall impression was that the homes were ordinary homes, that is, unaffected by the high-technology care performed there.

Analysis

Ricoeur (1998) saw a text as any discourse fixed in writing that calls for reading and involves interpretation. The research interpretation process

Table 2. Description of the HMV-Dependent Child.

Family	Age of HMV child	HMV regimen	Reason of treatment	Caring needs	Year treatment initiated	Supervision
A	3 years	Tracheostomy	Cognitive disability	Total needs	From 4 months	Constant
B	8 years	Mask	Cognitive disability	Total needs	From birth to 5 years	Constant
C	8 years	Mask	Motoric disability	Total needs	From 6, 5 years	Constant
D	23 years	Tracheostomy	Motoric disability	Total need	From 3 years	Constant
E	4 years	Tracheostomy	Motoric disability	Total needs	From 2 years	Constant

Note. HMV = home mechanical ventilation.

Table 3. Descriptions of the Analysis Process From Meaning Units to Theme.

Meaning units	Abstractions	Subtheme	Theme
It has been a great pleasure having people in the house, one travelled a lot and then I felt very secure (6).	Having care assistants in the house brought joy and security.	Staffs become an essential support to child and family	Letting the right person into your home
It happened twice//it was a coincidence that we saw that money was missing from his wallet// . . . and on another occasion a sum of SEK500 was missing from his credit card (4).	Twice we have found out that staffs have stolen money from our child.	Staffs become a potential threat to child and family	
He needs help with everything, from dressing to undressing, and everything in between. Regarding the ventilator, it concerns its functioning and the suction of phlegm etc. (5).	Our child is in need of help with everything that is holistic care.	Professional support at home means having to create a smooth everyday life	
They [care assistant] should only have medical responsibility . . . they should not do anything, we should do everything//She [mother] took some ice-cream on her finger so he could taste—then they reported us to the dentist for deviation (2).	Not being allowed to take your responsibility as a parent.	Personal relations with public authorities as paradoxical	

starts with a naive reading of the whole text, which constitutes an initial grasp of the whole formulated in a phenomenological language (Lindseth & Norberg, 2004). The next step in the analysis is to carry out various structural analyses aiming at explaining meanings. Here, the researcher takes on an objective and distanced attitude to the text and divides it into various narrative passages and sequences. Passages with similar meanings are then grouped together, condensed, and formulated into subthemes and finally into themes (see Table 3).

The last step in the interpretation process—the comprehensive understanding—involves reflecting on the preceding steps of the analyses in relation to the research question, literature, and the researcher's preunderstandings. This last

step represents an interpretation aimed at explicating a possible way of being and living in the world (Lindseth & Norberg, 2004; Ricoeur, 1976, 1998).

Ethical Considerations

Before giving the invitation to the parent participants, an ethical review process was conducted by Gothenburg University Ethics Committee (No. 263-09). The parents received verbal and written information about the study from the staff at the outpatient clinics and a prepaid, addressed envelope. If they agreed to participate, they returned this envelope to the researcher. One of the researchers (second author) then contacted the parents to set a date and time for the interview. The parents were given the guarantee of confidentiality and anonymity in any subsequent publication and informed that they could withdraw from the study without any explanation. Further information was provided about the study at the time of the interview.

Findings

After reading the text with open minds—but nevertheless touched by the narratives—our research team (first and second authors) arrived at the following naïve understanding about the parents' narrations about receiving professional support.

Naïve Understanding: An Initial Interpretation of the Whole

Professional support for parents with a child dependent on HMV has several meanings. It means sharing worries, pleasures, and caring tasks concerning the child with the health care professionals involved. It means having to direct and maintain momentum in the day-to-day running of life. It means risking intrusion into family life and being subject to the exercise of public authority. It means having to be vigilant in claiming your child's rights to competent care and treatment because you have the lived knowledge of your child's need. It means that your home becomes divided into two zones—private and public. It means the risk of being blocked between social institutions and their sets of rules and regulations, which in turn means that your parenthood is threatened.

Next step in the process of analysis was to examine this subjective and initial interpretation by carrying out various structural analyses. The first structural analysis is a thematic analysis presenting meanings of the phenomenon professional support and the second is a further examination that answers the questions about who and in what way professionals encountered the parents.

First Structural Analysis: Unfolding Meanings of Professional Support

Subthemes and themes unfolded in this first step constituted a structure for a new, composite story (Lindahl et al., 2005, 2006) which we present in the form of a fictive, first-person voice to give the tone of a personal, but interpreted, plausible testimony. The themes work as headings in the story and are printed in bold, whereas subthemes are underlined. Quotations are used to validate our analysis.

Letting the right person into your home. When personal care assistants are employed and work in your home, they must fit in with the family's values and culture. If this happens, the staff become an essential support to child and family and it creates reciprocal trust, friendship, energy, and joy in the family. Some of the assistants have become our dear friends and remain so even after they have changed jobs or moved. We are involved in the employment process. Over the years, it has become more important to give priority to aspects such as sensitivity, interests, and our child's feelings about a person rather than to formal qualifications. The care assistants must be able to differentiate between the private and the professional in our home and respect professional confidentiality. Otherwise they become a potential threat to child and family. There is a risk that some staff may feel too much at home or try to control our home. "On one occasion a care assistant entered our bedroom at night without even knocking."

Being in need of professional support at home means having to create a smoothly running everyday life as it is a prerequisite for our family's existence. It means having control over education and the quality of bodily care. Being responsible for another person's breathing is a very serious job, therefore we must always keep a watchful eye. We must always check that everything is as it should be. "Those who cared for our child as if he were a machine were replaced."

The concept of parental responsibility is used by the authorities to suit their own purposes. When our child was cared for in hospital they relieved us of our own responsibilities—community care in contrast puts pressure on us to take on all responsibilities—so we comprehend personal relations with public authorities as paradoxical. That is why we have turned to companies providing private personal care assistants. However, you need to be critical and try to find the best—that means those companies which specialize in and advocate for families like ours.

The need to be part of fair institutions. After some time you become a parent who knows and has the strength to challenge the authorities. This may mean turning to local newspapers with your problems. But above all there is a need

to establish good relations with institutions and professionals who have special competencies. Some health professionals in hospitals sometimes regard our child as a subject for an experiment. The Child Welfare Centre is a good organization, but it does not meet our needs. However, we have benefitted from having access to Children's Rehab. We have had our reasons for doubting the professionals at the social insurance office. We have our fights there, mostly concerning the number of hours of help. We have appealed against their decisions to the county administrative court and have had our case upheld. It is more complicated with regard to the municipality's commitments. They see our child as being ill and try to control our privacy and how we care for our child. Avoiding municipal services means avoiding the exercise of authority. "They decided that I was not allowed to leave the house for more than 1 hr a day—they called it parental responsibility."

The only thing that is good about the municipal sector is the school; and school is really good for our child. Encountering the municipal authorities sometimes meant being exposed to insults and domestic transgressions in terms of being exposed to people who were sent to help us. Some of these people failed to help but instead exercised the power of their position. "Some look in drawers, wardrobes, start our computer." Some said, "there is a smell of cigarettes in your child's room."

To hand over your child's life completely to others. Our child can never be left alone as help is needed with suction, food, and mobility—that means our child's body is totally dependent on others. There must be someone present who is vigilant 24 hr a day. The ventilator treatment affects speech, making the child's voice weak, and a faltering voice reduces autonomy. Our child's illness was a critical event. We knew immediately that something was wrong so the treatment was a life-changing event where technology saved our child. This led to our child being hospitalized for a long time. "If there had been no ventilator, there would have been no child."

An infection like pneumonia is life-threatening, but on a daily basis our child seldom needs hospital care. Our child is patient and has a great will to live. Socializing with friends means building up secure relations and the ability to take part, but only on special conditions. Friends are important as they make us as parents less important. The relationship with personal assistants is good; they often become close friends. But such relations intensify vulnerability and make our child even more fragile as these people come and go. What will happen when we are no longer here?

To be relieved and given time to care for siblings. We must make our care available for everyone and be sensitive to the other children's needs and longings.

We make special arrangements, consciously plan, and try to balance the siblings' involvement between participation and time of their own. The siblings need to know that they too are seen and listened to. They usually look after and play with the child. "I arrived home from work one day and found them sitting on the roof, it was possible to get there from a window; he went over the roof carrying his brother together with the ventilator."

Siblings also protect the child and report if something is wrong with the professionals. But we do not want them to take too much responsibility. On some occasions, depending on access to care assistant support, we do things together on our own with only the siblings. That means creating quality time.

Being constantly in charge and always having the main responsibility for protecting the family. Our parenthood means being vigilant, always attentive, and keeping an eye or an ear on what is going on. This not only involves the care assistants' actions but also the staff at school, and physio- and occupational therapists. Whether you want to or not, you become a technology expert. We now know how a ventilator functions, how to change the tracheal tube, and how to assess and treat our child if there is any deterioration. Parenthood means learning how to seek knowledge. We read, ask experts, and make Internet searches. In time it means relying on your personal knowledge about your child's needs. Sometimes we long for someone who will act for us, but it has become vital to take the situation into our own hands and adopt the role of conductor of self-care. To put your tacit personal knowledge into practice when responsible for your child's condition means using your senses. "We listen to the machine and hear when something is wrong."

Even if we receive professional support from others, we must always be on watch. However, the ventilator has kept infections away from our child. Colleagues at work, friends, and contacts with families in a similar situation give rise to feelings of living in togetherness with others. We can have periods of respite care for our child, but if we both worked outside the home, our situation would be intolerable. We keep a diary, stay together, try to be open, and live a life that has something special in it. Our role means creating a safe place of our own in the presence of professionals. It means living with professionals always in the home; therefore, we have tried to divide our home into private and professional areas. Everyday life for us means routines, meeting worries, surveillance, always being in charge, and sleeping with one eye open. We suffer at times, but we have learnt to be enduring and resilient. The authorities will never be allowed to take the care assistants' working hours away from us without a fight—we have learnt to exercise our rights. We strive to live an ordinary life that other people might think is strange.

Second Structural Analysis: Revealing Who and in What Way Professionals Encounter the Parents

As there was need for a deeper understanding of data concerning questions about caring responsibilities in relation to social authorities, a second structural analysis was performed. This analysis step aimed at revealing *who* and *in what way* professionals at various institutions met the parents.

Professional support built on caring power. Caring power means that there is an extra input and flow of energy into the home, created in the encounter between professionals and family members. Caring relationships with the care *assistants*, based on reciprocal trust, create a cheerful atmosphere in the family. Some care assistants become genuine friends of the family and help the child to encounter the world outside the home. One couple said, "Those assistants have been working in our home from the start and some nights our child stays the night in their home. But he does not like staying at the respite center."

Anyone who enters the home must be able to respect the family's private space and carry out competent care with a caring attitude. That attitude involves professional discretion. *Professionals at the children's rehab* supervise arrangements in school, including contact with *physiotherapists and occupational therapists*. These professionals provide support connected to everyday living, equipment, and training. *School* is a joy in terms of relief and seeing the child happy with others of the same age. One mother said, "Some days they mix groups in school and then you sometimes hear; I joined NN's [HMV child] group today. Many children look up to him."

Specialists in hospitals also exercise caring power as they possess expert knowledge about breathing problems and technology. You learn from them and then perform self-care autonomously. However, the ventilator-assisted children are not big consumers of hospital care. Safeguarding caring power means finding a *care assistant company* that has a holistic approach—this often involves several attempts. These companies seem to be found more often within the private than public sector. Professionals at the social insurance office exercise power in that they authorize or refuse payment. *Respite care* can sometimes be a relief but, in general, home is the best place to be. Exchanging experiences with *other parents* in similar situations is a good thing. In some cases, *informal caregivers* are employed as care assistants and they create caring power.

Professional Encounters Built on Abuse of Power

Experiences of sometimes having incompetent and ignorant care assistants caring for the child at home arouse feelings of despair and anger. Some

assistants exercise power in a bullying way and try to control the family's private life. One mother narrated, "they told us, 'you have to do the dishes before putting the child to bed' . . . nothing was allowed to stay on the table, I was not allowed to have a normal house—instead I was ruled by them."

Some assistants do not respect family values leading to transgressions of private boundaries. There have also been incidents where private property has disappeared, like cigarettes and money. The home and child must then be protected, but it takes a lot of energy to start the process of giving somebody a notice of dismissal. A father said, "He [assistant] smelled strange. Hadn't been here more than an hour, it wasn't more, I went in to check—and then I couldn't wake him up."

It is surprising and remarkable that senior managers in social services make their decisions at a distance—meaning they do not meet the family, visit the home, or see the child. Nor do they know anything about the family situation. But the decisions about the number of care assistant working hours they offer as support are of crucial importance for the family's existence. This attitude represents an approach where the child becomes a legal paragraph—not a living and growing individual. Professionals at Children's Welfare Centres do their best, but the parents think that this form of caring practice is not really organized for children on ventilator treatment. All parents claimed their rights vis-à-vis the authorities. One couple had had a fight with the social insurance office; the other couples had appealed and taken their cases to higher courts.

Comprehensive Understanding and Reflections

Finally, we formulated a comprehensive understanding of the whole text by considering the parts in the preceding analytical steps. We also turned to philosophical literature for further enlightenment (Lindseth & Norberg, 2004).

The meanings of professional support are interpreted as being a lottery—where the prize is either a nightmare—or a dream fulfilled. The nightmare scenario means receiving professional support at home for your child, but being at risk of and/or exposed to malpractice and the exercise of control over family privacy. The opposite means a caring encounter characterized by a sharing and mutual relation where various occupational groups are welcomed into the home. Family unity then becomes an open system ready to embrace the professionals and their support as a part of family life. There is no hovering between these two positions, it is a case of either or.

If the parents are to receive any support from the community, there must first be an official report following approval. This investigation is carried out as a part of the responsibility of the municipal authorities and conducted by a social welfare secretary. This means that the investigator is a bureaucrat, often

with a degree in behavior/social science, but no competence within the nursing or caring sciences. However, the family can make a decision about whether they want the municipal authorities or a private organization to manage the administration of the care assistants. According to our findings the predominant attitude among the interviewees was one of distrust regarding the municipal authorities' ways of exercising power. All the interviewees were of the opinion that a holistic and caring attitude was often missing; instead, and unfortunately, there was a bureaucratic attitude. In our opinion, decision-making concerning the parents' need for professional support made at distance and without visiting the family is an example of remote-control care with no personal engagement. This makes the family invisible, reduced to a text like an item on the agenda. Foucault (1977) has described power as being exercised through the control by authorities of individuals, their activities, spaces, and bodies from a general to a very detailed level. Reflection on the parents' stories, suggests that this is what happens when the authorities or certain staff try to dominate the home area. However, the parents are not powerless, docile, or accepting of being the objects of control by the authorities. On the contrary, they are able to resist the abuse of power that threatens the child's rights.

What then generates the energy to resist? We argue that it is compassionate care for the child. This compassion generates the energy to act on behalf of the child—to literally give your child a life—and a good life too. van der Cingel (2009) pointed out that compassionate professional caring encompasses an awareness of an unequal relationship and a balancing of closeness and distance as well as the setting aside of one's own values, interests, and judgment. Roach (1995, 1997) defined compassion as an awareness and sensitivity to all living beings. Compassion implies a relationship, making room for the other and sensitivity to the other's suffering. The professionalization of caring carries a special responsibility in that the professional has undertaken a mission for which they receive payment and has the potential power to ease another's vulnerability. Home health care managers as well as personal assistants are in a position to ease suffering and respond to the fact that someone is depending on them. The Danish philosopher Løgstrup (1992) stated that power is always a part of any relationship. The difference lies in how we respond to this power; it can be misused or used to serve others. Relationships in home-care settings have been conceptualized as professional friendship (Lindahl, Lidén, & Lindblad, 2011). This friendship is connected, among other things, to an ability to balance power roles and cocreation between professionals, patients, and their near ones. The composite stories in this study present several examples of relationships between the personal assistants and the family that constitute professional friendship and compassionate care.

The findings of this study are congruent with the findings of our earlier metasynthesis study (Lindahl & Lindblad, 2011). The life situations of parents of ventilator-assisted children were thematically described as an awareness of reality and important values in life, a demanding parenthood, and being in a process of learning. Holditch-Davis, Miles, Burchinal, and Davis Goldman (2011) presented the construct of maternal role attainment (MRA) in relation to mothers of medically fragile children. MRA is understood through the concepts of identity, competence, and presence. These concepts are fruitful in understanding the meanings of parents' stories in the present study. However, they do not include the willingness to exercise power, compassionate care, and energy in directing and protecting the child's interests that were revealed in our study.

Earlier studies have shown lack of expertise in planning and providing competent care at home for technology-dependent children and their families (Boroughs & Dougherty, 2010; Noyes, 2006; Rehm & Bradley, 2005). In an editorial, Carnevale and colleagues (2008) stated that knowledge about these families' life situations is immature and fragmented. The cited studies show that parenting a medically fragile child is enriching, but often burdensome as a result of poor professional support. When Dybwik et al. (2011) interviewed family caregivers of adult or young ventilator-assisted people, they conceptualized this as fighting against a system. Life would have been much better for them if a bureaucratic community system had not given them unnecessary problems. Our findings are congruent with this research report. We see home-care managers as having a special responsibility for creating an environment conducive to fostering compassionate professional care. This is probably grounded in education, supervision, and employment structures that develop, nurture, and foster interconnectedness with families. Boroughs and Dougherty (2010) argued for a multidisciplinary perspective when managing care for ventilator-assisted children at home. Education, guidelines, home-care planning and home visits, and advocacy services for the family are suggested. We also argue that there should be a key person who coordinates the individual family's needs in a personal manner. In an editorial, Noyes (2011) argued that there is a direct correlation between a ventilator-assisted child's quality of life and the quality of care and services received.

Discussion

Critique of Method

The parents in our study comprised a small sample. As our aim was to understand the meanings of professional support as experienced by the parents—not

to describe differences or generalize research findings (Kvale, 1996)—we decided that the five couples who responded to the invitation were sufficient. A small sample also made it possible to do more detailed work on the data and the interpretations. The parents' stories are seen as dense descriptions and, as fathers often are underrepresented in research (Liamputtong, 2007), we regard our sample as more than adequate. The parents were also involved with a variety of municipal health care organizations. This means that the findings do not refer to a specific organization. When interviewing the parents, we realized that it was impossible to have a conversation where the parents described their lived experiences of professional support without at the same time talking about the meanings of being the parents of a ventilator-assisted child. Explaining the latter became important as otherwise, in their opinion, it was very difficult to reveal to us their understandings of the meaning of support. Several characteristics reflect the unique nature of families as social groups such as privacy, shared traditions, and intense involvement. Individual experiences and qualities within each family are also important, leading to families being considered one of the most closed and private of all social groups (Daly, 1992). The parents were given the interviewer's home telephone number in case they felt a need to speak more. Qualitative research often discloses moral issues. Hunt and Carnevale (2012) have developed a conceptual framework to guide qualitative research on moral experience related to families having a ventilator-assisted child. This model could be used in other areas but could be especially fruitful in further research in HMV.

How then can our findings be used in practice? One can argue that it is risky to present stories in a fictive or invented voice representing the participating couples. However, Lindseth and Norberg (2004) recommended the use of everyday language when mediating the findings. We argue that a narrative writing style affects the reader's emotions and reflections by their gaining new insights into the world, themselves, and other people. These facts hopefully make the readers, that is, various health professionals, more sensitive to the needs of families and the ventilator-assisted child and to counteract malpractice.

This study was carried out according to the basic principles of qualitative research in mind—a careful documentation of the research process, and step-by-step descriptions of the analyses, and the results derived from them. We used an audit trail (Morse, 2001) where we documented contextual data related to the data collection and decisions made during the process of analysis. The fact that both parents participated in the interviews was valuable because, in the few studies describing HMV in relation to children, fathers are often unrepresented. We consider parents of children with breathing difficulties as vulnerable and "hard to reach" as their lives are often strictly bound by everyday routines and support from others. This gives them little

free time and they are therefore difficult to access. The way we obtained informed consent enabled the parents to make a decision in private about whether to enroll in the study or not. No professionals knew whether they had agreed to participate. We consider this as an example of a sensitive data collection process, as the couples could draw their own boundaries regarding privacy (Liamputtong, 2007).

Conclusion

This text speaks of strong, stubborn, dedicated, and compassionate parents who are willing to do their utmost for their children, and then more. It seems as if dialog is missing within the health care organizations' management structure—regarding private and municipal personal care assistance—concerning the meanings that lie within concepts such as lived personal knowledge, person-centered care, and the essence of an ethics of care. Moreover, we claim, in accordance with K. Wang, Barnard, and Somerville (2007), that more education programs and workshops directed to community health care managers, personal care assistants, and parents are needed. These programs should have a comprehensive perspective that involves knowledge about financial support, physiological, emotional, and practical knowledge and skills.

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