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# A Child with Home Mechanical Ventilation Affects the Family: A Danish Study shows that well Siblings may become Shadow Children

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## ABSTRACT

**Background:** Having a child with chronic respiratory illness and home mechanical ventilation (HMV) may not only affect the ill child, but also the family, including well siblings' everyday life and physical and mental well-being. **Purpose:** To explore the perspectives of parents to a child with HMV on well siblings' lives. **Design and Methods:** A qualitative phenomenological-hermeneutic approach using semistructured interviews with eight families, that included a child on HMV and well siblings. Data were collected from March to June 2019 at a Danish University Hospital. **Results:** Three main themes emerged: Tying emotional bonds with both children, Protection of everyday life for well siblings and A different family life - sharing attentiveness. The findings showed that being a parent to an HMV child and well siblings is complex to manage, and may make parents feel inadequate towards their children. **Conclusions:** Parents feel inadequate in being parents to both the HMV child and well siblings, often transferring adult responsibilities to the well sibling, and sometimes leaving the well siblings in the shadow. **Implications:** Clinical practice needs to expand interventions to support parents and well siblings by using a more family-centred care approach, not only during admission, but also in a long-term perspective.

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## Background

Children with chronic respiratory insufficiency and in need of invasive or non-invasive ventilation are kept alive with long-term life support technologies such as ventilators and home-based surveillance provided by personal care assistants (PCAs) (Carnevale et al., 2008; Lindahl & Kirk, 2019). This kind of treatment is called home mechanical ventilation (HMV), and is a well-established treatment in many Western countries (Carnevale et al., 2008). In recent years, growing numbers of children with neuromuscular diseases e.g. are given the option of HMV owing to advances in neonatal and paediatric care, technological advances as well as development of suitable home equipment to maintain the highly specialised treatment (Cancelinha et al., 2015). HMV reduces hospital admissions, but requires a demanding, advanced home care program and changes in everyday family life. In some countries, families are provided assistance from PCAs, either for hours a day/night or 24 h a day, which can be stressful for the family (Cancelinha et al., 2015; Carnevale et al., 2006) (Lindahl & Kirk, 2019).

Life with HMV not only affects the ill child, but also parents and well siblings (Anderson & Davis, 2011; González et al., 2017; Israelsson-

Skogsberg et al., 2019; Limbers & Skipper, 2014; Williams et al., 2009). Families experience enduring emotional difficulties, social isolation, family member divisions and sibling rivalries (Mesman et al., 2013). Parents experience reduced QOL and difficulties such as poor sleep, feelings of guilt, mood swings, social isolation and fear caused by the daily threat of death (Carnevale et al., 2006; Flynn et al., 2013; Mesman et al., 2013).

Limbers and Skipper (2014) found that the health-related quality of life (HRQOL) of well siblings of children with physical chronic health conditions and illness during childhood can cause stressors and change within the family system. Well siblings' HRQOL is better than their ill sibling, but they have several risk factors associated with impaired sibling HRQOL; hence the importance of paying attention to well siblings and assessing their HRQOL (Limbers & Skipper, 2014). A systematic review found that well siblings of children with physical chronic illness are at risk of a number of negative effects; for instance, they are more likely to develop depression and anxiety (Barlow & Ellard, 2006).

Extensive literature has addressed how the impact of chronic illness can lead to a closer family relationship, but it also means loss of normality, lack of predictability and change of internal roles in the family (Alderfer et al., 2010). However, few studies have explored the impact of the additional care requirements associated with the need for HMV. According to Carnevale et al., families in general, and well siblings in particular, experience distress and enrichment on a daily basis when

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having a brother or sister on HMV (Carnevale et al., 2006). Families experience concerns, dilemmas and moral distress that need to be illuminated and discussed, but they also experience moments of deep enrichment and reward that they cannot imagine living without (Carnevale et al., 2006; Carnevale et al., 2008). Well siblings, especially older siblings, do not only feel a huge responsibility towards their HMV sibling, but also towards their parents (Lindahl & Lindblad, 2011). In addition to this, well siblings can experience concern about parental attention, shared parental love and because of this, resentment towards other family members (Lindahl & Lindblad, 2011). Well siblings of chronically ill children have over several decades been titled 'the forgotten ones' as being shadow children, the most neglected family members (Anderson & Davis, 2011; Chesler, 1987).

There is a need for increased knowledge and guidelines made for healthcare professionals to support the HMV-child's family, in particular parents and well siblings.

## Purpose

To explore the perspectives of being a parent to a child with HMV and well siblings using a qualitative approach and based upon secondary analysis of the data.

### Design and Methods.

Transcriptions of all the interview materials were analysed following a phenomenological hermeneutic approach developed with inspiration from Paul Ricoeur's theory of interpretation (Dreyer & Pedersen, 2009; Ricoeur, 1973b). The phenomenological-hermeneutic tradition is ideal for exploring the lived experiences of human life. Ricoeur argued that phenomenology and hermeneutics are co-dependent, and combining phenomenological comprehension with hermeneutic explanation facilitates an in-depth understanding of lived experiences (Dreyer & Pedersen, 2009; Ricoeur, 1973a). Following Ricoeur's thinking (Ricoeur, 1973b), interpreting a text means seeing something new in what is already taken for granted and disclosing a new sort of being-in-the-world. Thereby, researchers endeavour to explain and understand the meaning and gain a comprehensive understanding of the text, which in this case will illuminate the lived experiences of parents to a child with HMV who has well siblings (Dreyer, 2018; Dreyer & Pedersen, 2009).

### Data Collection.

Data were collected from March to June 2019 for a primary study, which aimed at exploring family life with HMV and PCAs from a family perspective. In this substudy, we report additional findings that revealed in-depth varied and usable perspectives on the lived lives of being a parent to a child with HMV and well siblings. These perspectives are

important knowledge for clinical practice on how to support parents and well siblings in families with HMV and PCAs and are presented in this article.

Data collection consisted of individual and couple/family interviews with family members about having well siblings; one family interview, one couple interview, five individual interviews with the mother only, one individual interview with a father only and two individual interviews with two children, which in all included seven mothers, three fathers and three HMV children (Table 1).

The interview guide for children and parents was divided into different research areas such as 'life as chronically ill', 'decision about respiratory assistance' and 'having PCAs at home' and 'everyday life'. The research areas were the same for all participants, but the level of abstraction was different. The included participants, parents and HMV children were interviewed about well siblings; examples of questions are to be seen in Table 2.

Data collection employing individual and couple/family interviews was inspired by Kvale and Brinkmann (Svend & Steinar, 2015) and Kampmann et al. (2017), and based on semi-structured interview guides with open-ended questions for both HMV children and parents on well siblings' lives. Every family could choose between an individual interview, or a couple/family interview, but from the same family unit. A mix of interviews provided variation to the study; the individual interviews provided a deeper understanding, while the couple/family interviews facilitated discussion and reflection between the parents, in particular.

The interviews were conducted at the Respiratory Center or the family home in accordance with the interviewees' preferences, and lasted between 46 min – 98 min. All interviews were recorded on a smartphone and transcribed verbatim by the first author.

### Sampling.

The study used purposeful sampling when recruiting participants. The overall criteria for including families with HMV were the need for respiratory assistance (invasive or non-invasive) either hours during day/night or 24 h a day and having or having had PCAs at home. Other criteria were variation in age, gender, diagnosis, ethnicity, family patterns as well as new/experienced families with HMV and PCAs at home. All children were diagnosed with chronic respiratory insufficiency and different diseases; neuromuscular diseases, lung diseases such as tracheomalacia and bronchopulmonary dysplasia, central apneas and facial anomalies.

### Settings.

The study was conducted at Respiratory Center West, Aarhus University Hospital, which is one of three centres in Denmark,

**Table 1**  
Overview of included participants.

	Child (gender)	Age	Respiratory assistance	PCAs (hours/day)	Family patterns	Siblings	Participants/Type of interview
<b>Family 1</b>	Boy	2 years	Non-invasive	24 h./social and healthcare assistants and social and healthcare helpers (no help during daytime at weekends)	Living with mother, father and sibling	Sister, 4	(1a) Mother (individual interview)
<b>Family 2</b>	Girl	14 years	Non-invasive	24 h./personal trained helpers	Living with mother, father and siblings	Sister, 18 Sister, 16	(2 a-b-c) Mother, father and girl (family interview)
<b>Family 3</b>	Boy	14 years	Non-invasive	8 h. at night-time/medical students incl. Father on the team	Living with mother, father and siblings	Sister, 12	(3 a-b) Mother and father (couple interview) (3 c) Boy (individual interview)
<b>Family 4</b>	Boy	5 years	Invasive	24 h./nurses	Living with mother, father and siblings	Sister, 14 Brother, 0	(4 a) Mother (individual interview)
<b>Family 5</b>	Boy	12 years	Non-invasive	0 h./terminated PCAs (social and healthcare workers) 1 year ago	Living with mother, father and siblings	Sister, 8 Brother, 5	(5 a) Mother (individual interview) (5 b) Boy (individual interview)
<b>Family 6</b>	Boy	8 years	Invasive	24 h./social and healthcare assistants incl. Mother	Living with mother and siblings	Brother, 12	(6 a) Mother (individual interview)
<b>Family 7</b>	Boy	4 years	Non-invasive	24 h./nurses	Living with mother, father and siblings	Sister, 5 Brother, 1	(7 a) Mother (individual interview)
<b>Family 8</b>	Girl	5 years	Invasive	24 h./social and healthcare assistants	Living with mother, father and siblings	Brother, 8	(8 a) Father (individual interview)

**Table 2**  
Interview questions about well siblings.

Main question:	Sub questions:
How do well siblings experience their life when having an ill sister/brother with HMV and PCAs?	'How is the well sibling handling life with HMV and all that comes with it?' 'What is the relationship between the siblings like?' 'What has their upbringing been like?' 'How do you spend time with the well siblings?'

which treats children < 18 years with chronic respiratory insufficiency who are candidates for HMV. The Danish government and the Danish Health Authority support home-based treatment of children, because it helps to maintain QOL and rehabilitation. However, the decision about HMV and having surveillance provided by PCAs is taken by the family and different healthcare professionals like chief surgeons, nurses, social workers and financial managers. PCAs are requested from care assistants' recruitment agencies and HMV is financed by the child's region and municipality. Families can also get financial help with reconstructing the house, transportation, nursing and helping supplies.

#### Data Analysis.

The method for analysis of the interview text was inspired by Ricoeur (1984) and, more specifically, a Nordic development of a Ricoeur-inspired method for analysis encompassing three levels: a naïve reading, a structural analysis and a critical analysis and discussion (Dreyer & Pedersen, 2009; Lindseth & Norberg, 2004). Analysis of the interviews was performed using the software program NVivo 12.0 (QSR International Pty Ltd., Victoria, Australia). To describe what the text tells about the lived experience (the interpreted meaning of all the interview texts), the interpretations will be presented as themes in the Results section in the article.

Interviews were conducted by the study's first author, and analysed by all authors, and neither authors were known to participants as care providers.

#### Ethical Considerations.

The study did not require ethical approval from the National Committee on Health Research Ethics, however, it was approved by the legal office in the Central Denmark Region. The participants were informed both verbally and in writing about the aim of the study, confidentiality, anonymisation of identity, voluntary participation and the right to withdraw from the study at any time. All participants signed a consent letter and parents signed for their children. The study adhered to requirements from the Nordic Nursing Research Foundation and the Helsinki Declaration.

#### Findings.

##### Naïve Understanding.

The naïve understanding is the first level of interpreting the text and achieving a grasp of its meaning. Parents of HMV children regard well siblings as a cornerstone in the family's well being. They speak positively about well siblings' way of coping with the home situation and acknowledge their flexibility in relation to the child with HMV, the many, often long-term hospital stays and having PCAs at home. At the same time, much parental attention was focused on the HMV child, and the family had to adjust to a different family system.

Families hold varying beliefs about the right kind of family system and parental expectations towards well siblings. Well siblings from some families are met with high parental expectations regarding how independent the child should be, such as having to take care of themselves at a young age and participating in nursing the HMV child. This means transferring adult roles and adult responsibilities to well siblings in order to maintain as normal an everyday life as possible. Given this family structure, the well sibling matures sooner than its peers. In other families, parents draw firm boundaries around their responsibility and wish to uphold these lines to a greater extent.

#### Structured Analysis.

On the basis of the naïve understanding, the aim of the structural analysis is to deepen the understanding of parents' experiences of having well siblings along with an HMV child. This part of the analysis revealed three findings: *Tying emotional bonds with both children*, *Protection of everyday life for well siblings* and *A different family life - sharing attentiveness*.

##### Tying emotional bonds with both children.

Being a parent to an HMV child could leave parents with torn feelings about their role as parents to well siblings. HMV treatment could make sharing an equal amount of affection for the children challenging. A closer tie between the parent and the HMV child could occur due to the great deal of time and attention the treatment required from the parent. Mother F4: '...he (dad) knows that he will love this child (well sibling), but for him B (child with HMV) will always come first.' The fear of what might happen to the HMV child could make separation of parent and child difficult, and negatively affect the closeness between the parent and well siblings.

Some parents experienced that having an HMV child resulted in them having a more positive relationship with well siblings. The necessity of having almost constant attention on the HMV child could be experienced as burdensome. Mother F3: *I have a more positive relationship with my daughter, because she is normal. Not that he isn't (child with HMV), but he has just been so demanding in so many ways*. The disease and HMV treatment could affect the parent-child relationship negatively, leading to a closer relationship between the parent and well sibling.

PCAs served as an extra caregiver for the HMV-assisted child. Mother F3: *B (HMV child) has always chosen me first, but he has had so many helpers/adults to go to*. Well siblings did not experience the same relationship with the PCAs, and their parents were their primary caregivers. In some families, this meant a closer tie between the parent and well sibling.

Findings could indicate that parents with an HMV child experienced feeling inadequate in their role as parents. Regarding the HMV child, the feeling of inadequacy concerned the possibility of creating a normal, free child life, with room for the child to flourish as a person and as an individual. In some families, this would relax the parents' approach as to what was allowed or not allowed for the HMV child. Mother F7: *B (HMV child) is probably a bit more spoiled, I think, as a way of compensating*. This concessional approach was a way of compensating for the many physical, psychological and social limitations the child experienced because of its illness.

The HMV child required the parents' presence in other ways than well siblings did. Mother F4: *She (well sibling) is very affected by the fact that all of the attention is on him (HMV child)*. This could leave parents with the sense that they were distributing their attention between their children unequally and that they were inadequately present in well siblings' lives.

##### Protection of everyday life for well siblings.

The HMV child needed many hospital visits, either as controls or admissions. Admission to the hospital for a substantial length of time influenced the family's everyday life, and some parents chose to bring well siblings to the hospital, whereas others completely avoided doing this. Mother F1: *I'll take care of all of this. She doesn't have to see this. It is my responsibility to take care of all of this*. Parents who chose this approach expressed the wish to protect the well siblings from any insecurity associated with a visit to the hospital. However, some parents chose to take well siblings to the hospital to visit their hospitalised sibling. They wished to protect the well sibling from imagining a situation that was worse than reality. Father F8: *...that he understands that when mom and dad suddenly are gone, it is actually okay. It is because we are doing something good for B*. Parents wished to protect the well siblings from the uncertainty of not knowing what was going on with their ill brother/sister, and to show that both parents were okay, even if they were not both at home.

For all parents, the ability to maintain a normal everyday life for well siblings when the HMV child was admitted to hospital was regarded as important, even if this meant parents placing an extra strain on themselves. By everyday life, parents referred to well siblings continuing to attend school/kindergarten/daycare and seeing other family members and friends. A way in which parents sought to maintain normal everyday life for well siblings involved dividing their resources, leaving one parent with the HMV child, and one parent with the well siblings.

The HMV child's need for tranquillity and its risk of becoming seriously ill from a simple infection meant that parents had to limit how and when well siblings were allowed to have friends over. Mother F4: *'So she is allowed to do all the things that others do. Have friends over, visit friends and have a movie night. But within limits, because there can't be too much noise. There has to be consideration'*. Parents expressed the wish to create space, physically and mentally, where siblings got to be themselves and do social, age-equivalent activities with their friends.

All families had or had had PCAs at home for up to 24 h/day. This arrangement made it possible for the HMV child to live at home instead of having to stay at the hospital, but parents experienced the constant presence of an extra adult as intrusive to well siblings' lives and to the sibling relationship. Mother F4 quotes the well sibling: *'I can't just play some silly game with my brother, because there is always someone looking at him and what I do'*. Parents expressed how the arrangement limited well siblings' creativity to invent games and their wish to play with their HMV sibling.

Parents experienced how the presence of a PCA could limit the time well siblings socialised with the rest of the family and made the child withdraw to its own room instead of spending time in the living room e.g. The older the child, the more common this was.

#### **A different family life - sharing attentiveness.**

Findings showed that parents experienced that having a child needing HMV affected the family. All the HMV child became the centre of the family, which meant that all members of the family had to adjust to it, including well siblings. Father F3: *'There was a clear difference (between the children), because we put B in a bubble.'*

Circumstances made it necessary for parents to focus much of their attention on the HMV child. This created the need for well siblings to mature earlier than their peers, and be able to take care of themselves at an earlier age. Father F3: *'She needs to take care of herself, and so she does. And she's really good at it too (laughing)'*. The well siblings' ability to take care of themselves seemed to give parents a sense of joy and release. They were aware of the requirements that were placed on their well children, but saw this as a necessity.

The extent to which the child was affected by the family's way of life seemed to decrease as the child aged. Mother F4: *'She is becoming a teenager, so she isn't any longer that affected by the fact that we spend so much time with B'. It is actually an advantage that we don't need to include her as much'*.

The parents experienced that having a child who was more mature than its peers could leave the child with a sense of loneliness. Mother F4: *'Everyone else in class has an ordinary sibling, who isn't sick. And then being the only one who is lonely. She has felt very alone in all of this'*. This was due to having to take on a different role in the family, and not being able to talk to a friend in a similar situation about how it affected their everyday life.

One parent expressed how being in a sibling group had given one well sibling a sense of connectedness with other children who also had a brother or sister with a severe disability. Mother F4: *'It was lovely for her to feel that she wasn't alone'*. The sibling group provided peers who experienced the same challenges, joys and thoughts they themselves met and felt in everyday life. Parents expressed how this could help reduce the siblings' feeling of loneliness.

Some children developed a close sibling relationship, particularly when the well sibling had spent a lot of time with the HMV child since birth. Their relationship seemed to be strengthened when the well sibling acted as a tiny adult who exhibited a great deal of care,

and was able to look after the child's respiratory needs and adjust the games to the HMV child's respiratory challenges. Mother F6: *'Hang on, the tube is up', and I just get to the trampoline, and then he puts it back in. Then B does thumbs up, and then he's ready again.'* In some families, well siblings seemed to help as an extra mother or father for the HMV child, assisting with basic nursing and practical things. Father F2: *'Both of our oldest children are good at helping her; they cook, they can help her go to the toilet, and they can do the tube feeding'*. Well siblings taking on this role were often older than the child needing care. In other families, parents had established very clear boundaries as to what was expected from well siblings, and they did not take part in the care of the HMV child.

All parents outlined how the well siblings were able to adjust to the child with HMV, which supported a closer sibling relationship. Father F8: *'They really do enjoy having each other. Because he (sibling) is a very, very caring child'*. Having a close sibling relationship was beneficial for both children, but demanded adaptability from the well sibling.

The parents expressed a sense of responsibility to support their children in having close relationships. They did this by encouraging the children to do joint activities. Mother F6: *'I think it is important that they are allowed. If we had to live and be afraid of it... we just couldn't'*. In allowing the children to play, parents had to be able to put away their fear of what might happen to the HMV child respiratorily, so that the children would get a chance to play as normally as possibly.

#### **Comprehensive Understanding.**

The final part of the analysis presented an overall, comprehensive understanding of the findings. Being a parent to well siblings and an HMV child was experienced as complex to manage. The parents nourished the wish to shield well siblings from the unpleasantness that came from the treatment of the HMV child, along with the disruption this caused in the family's everyday life. At the same time, it was seen as impossible to shield well siblings from having to take on a greater responsibility towards oneself and the family, which made the child more mature than its peers. In some families, the complexity of the situation and the many responsibilities parents to an HMV child were constantly met with gave parents a sense of inadequacy about creating a good child-life for both the ill child and well sibling.

## **Discussion**

This study showed how parents aim at protecting well siblings from the illness in order to maintain a normal family life. Other studies show how ill children strive for normalisation; they know how they are impaired but want to live as normally as possible (Pia Sander Dreyer et al., 2010a; Pia S. Dreyer et al., 2010b). When living with chronic illness in general, both children and parents try to minimise the impact of the diagnosis and normalise the illness within the context of their lives (Fay & Lesley, 2007). Therefore, it does seem understandable in our study that parents and well siblings strive to maintain a normal everyday life, though the ventilator and the related care regimen makes life more complicated. Families showed different strategies to protect well siblings due to stress from the illness. In Heaton et al.'s study (2005), siblings reported that everyday life was stressful and tense due to technology and the unpredictability of their ill sibling (Heaton et al., 2005). The analysis in our study did not show significant differences regarding the impact the illness and treatment had on well sibling's lives, which might be because of the focus of the primary study. Well siblings might have different perceptions of how it feels to have PCAs at home. Despite differences in age, gender e.g. the study showed how all parents experienced PCAs as intrusive to well siblings' everyday life.

Our study showed how limited parental attention affected well siblings, e.g. so that they matured at an earlier state than their peers and took on adult responsibilities. According to Lindahl and Lindblad (2011) well siblings want to help and give their parents a break, but that can result in sleep disruption or limited social activities, and

stressing the need for siblings to balance their involvement and having time on their own. Well siblings spend less time with their parents and experience loss of attention which can make them feel neglected, ignored, isolated and lonely in the family. These experiences can lead to jealousy, disgust and conflicts, and end in sibling rivalry (Alderfer et al., 2010; Anderson & Davis, 2011; González et al., 2017; Israelsson-Skogsberg et al., 2019; Williams et al., 2009). Parents felt guilty when well siblings had to learn to come second (Deavin et al., 2018; Lindahl & Lindblad, 2011), and the risk of becoming 'shadow children' increased (Jensen, 2011). Studies with other children with chronic or mental illness have shown how well siblings are being overshadowed and can become secondary victims (Barak & Solomon, 2005) as well as how they feel the imbalance in parental attention and sharing of love (Carnevale et al., 2006; Deavin et al., 2018).

As a new perspective, we found that some parents experienced a more positive relationship with the well sibling if they had a child with HMV and PCA; this might be because of a positive adjustment to the problem and parents being able to pay well siblings more attention (Keilty & Daniels, 2018). Oppositely some parents experienced a closer relationship with the HMV child and found it difficult to be present in a sufficient way for both children. Knecht et al. (2015) showed how this unequal distribution of affection could leave the well sibling with externalising behaviour such as jealousy and envy (Knecht et al., 2015). A meta-analysis on siblings of children with different chronic illnesses found a statistically significant and negative effect of having a sibling with chronic illness. Internalising behaviours such as anxiety and depression were associated with larger negative effects than externalising behaviours (Sharpe & Rossiter, 2002). Research indicates that parent and family factors are strong predictors of how well siblings handle having a brother or sister with HMV (Giallo & Gavidia-Payne, 2006), showing that family or parent resilience affects the well sibling's resilience.

The Danish Health Authority, provides recommendations about including relatives (Smith, 2012). In Norway, Sweden and Finland, legislation exists that obliges healthcare professionals to document in the medical journal whether there are well siblings as relatives which ensure the needed support (Smith, 2012). Documented information from parents and/or siblings is important to support a family-centred care approach (Park et al., 2018) during admission and in a long-term perspective.

#### **Methodological Reflections.**

Combining semi-structured individual and couple/family interviews strengthened the study. Well siblings' perspectives were not the main research question, but a sub-question; however, the parents' narratives provided in-depth varied reflections and discussions about well siblings, which gave us an understanding of the importance of the topic. However, it might have strengthened the study if well siblings' perspectives had been the main focus of our research, and if HMV children also provided narratives regarding their well siblings.

The included participants reflect variation with respect to age, gender, ventilation, PCAs and family patterns and thus ensure nuances, which is a strength of the study. Using purposeful sampling posed the risk that only resourceful families were included; however, they were selected because they had expressed diverse experiences and feelings towards having a child with HMV. Due to ethical considerations the analysis does not include family characteristics, since it would affect the anonymisation of data and therefore impact the protection of the participants. At the same time, we sought a broad perspective on being a parent to both a HMV child and well siblings. Our purpose was not to compare our participants due to the different sampling criteria, but to explore the perspectives of parents to a child with HMV on well siblings' lives by a phenomenological-hermeneutic approach.

Using Ricoeur's phenomenological-hermeneutic approach to the text ensures analytical rigour. The data set consisting of nuanced answers to open-ended questions and a Ricoeurian interpretation made

the meanings and main themes clear to us. The trustworthiness and transparency of the study are reflected in a clear description of the study's method and data analysis, which also are represented in tables. Furthermore, all authors contributed to analysing the data set and had several meetings during the process to discuss and validate the analysis.

#### **Implication for Clinical Practice.**

This study shows that it is important for healthcare professionals to pay more attention to well siblings of an HMV child, and how parents are managing their role as parents. These findings about siblings' perspectives bring important evidence-based knowledge to clinical practice, which should be transposed into national guidelines and recommendations. Clinical practice needs to expand interventions to support parents and well siblings by using a more family-centred care approach, not only during admission, but also in a long-term perspective.

Further research into siblings' own perspectives is needed to improve their lives and protect them from becoming shadow children. This study shows how parents may experience being inadequate in their role as parents and knowledge about how healthcare professionals can support the parents' needs.

#### **Limitations to this study.**

Data collection was restricted to a small sample of parents of children on HMV and their child. Well siblings of children on HMV were not interviewed as this was not the aim of the primary study. However through analysis of data important knowledge about well siblings emerged leading to this article.

The study might have been more in-depth if the primary research question had related to well siblings, and not been an additional finding. It could have influenced responses regarding the age of the well siblings, regarding families with PCAs versus none, and regarding families with a child who required invasive versus noninvasive mechanical ventilation. Interviews were not conducted with well siblings, but it would be relevant in further clinical research.

Perspectives of participants may be influenced by characteristics of the Danish health care system, e.g., provision of PCAs, and, therefore may not be representative of other geographic areas.

#### **Conclusion**

The study provides new knowledge about how being parents to an HMV-child and well children is a challenging task and impacts the whole family, often leaving parents with a feeling of being inadequate in their parenthood. The inside parent-perspective, which this study gives, shows how the different family life impacts well siblings, creating the need for them to take on more responsibility for themselves and their family, leaving them in the shadow of the HMV child.

#### **Author contributions**

Anette Bjerregaard Alrø was responsible for the drafting of the manuscript and the study design. Anette contributed the majority of the writing and analysis in this manuscript. The other authors contribution to the manuscript were responsibility for the study conception, and they also made critical revisions to the paper. Linea Høyer has been associated with the research project during her last semester at the nursing education.

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#### **Declaration of Conflicting Interest.**

The authors have no conflicting interests regarding the research, authorship and/or publication of this article.

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