



Review Article

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Impact of Caring for Home Mechanically Ventilated Children on Families - A Review of the Literature

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Abstract

Background: Despite extensive research regarding mechanical ventilation and ventilator weaning, not all patients can be weaned off their mechanical support. This results in an increasing number of mechanically ventilated children being cared for at home. However, this not only has an impact on the children themselves, but also on the families who provide care for the ventilated children.

Aim: To explore the impact of caring for a child under home mechanical ventilation on family members.

Methods: We conducted a review of the literature. A formative search was carried out in PubMed and CINAHL in July 2023. We only considered original empirical research and reviews that included children under 18 years of age on home mechanical ventilation. Screening and data analysis were independently carried out by two reviewers.

Results: A total of 231 studies were obtained, of which 15 were included. The review contains seven qualitative and five quantitative studies as well as three reviews. The analysis revealed a predominantly negative experience of family members in the care for children under home mechanical ventilation.

Different burdens were identified and sorted into five main clusters. These are entitled burdens for the entire family system, dependence of the family, different roles of parents, burdens for siblings, and multiple care needs.

Discussion: The care for children under home mechanical ventilation is complex and has a major impact on the families, who play a central role as caregivers. While current research and professional caregivers mainly focus on the ventilated child, there is only little evidence and hardly no development of interventions to meet family members' needs.

Conclusion: In order to ensure high-quality care for children under home mechanical ventilation in the future, it is crucial to strengthen and empower families. This also requires increased support from specially qualified healthcare professionals such as advanced practitioners.

Keywords: Artificial respiration, home mechanical ventilation, Home Care, Child, Infant, Adolescent, Family, Burden, Experience

Abbreviations: HCP- Healthcare professional; HMV- Home mechanical Ventilation; MV- Mechanical Ventilation.

Introduction

Mechanical ventilation (MV) is considered a key intervention for critically ill patients in life-threatening situations. More and

more studies and guidelines are available that concern not only mechanically ventilated adults [1,2] but also children [3]. Despite this growing interest, for example in the predictors of weaning fail-



ure [4-6], not all children are successfully weaned from ventilation. Various studies highlight extubation or decannulation failure rates between 2 - 20 % [7-10]. As a result, some patients that cannot be weaned from ventilatory support gradually transition from acute MV to prolonged MV.

In recent decades, new facilities and structures have been developed globally for these patients, enabling them to be cared for at home. Accordingly, there is a continuous increase in the number of adults [11-13] and children [14-17] under home mechanical ventilation (HMV).

Home care is particularly important for children. It allows them to [partially] participate in everyday life, grow up in a familiar environment, and have important family members available [18]. In order to make all this possible, the children need caregivers. Parents and siblings usually take on this role. In addition to the opportunities for the children, it is also important to reflect on the consequences for the families.

Therefore, the aim of this review is to explore the impact of caring for a child under HMV on family members.

Methods

A formative literature search was conducted in PubMed and CINAHL in July 2023. For this purpose, we combined the two components 'care' and 'home mechanical ventilation' and their respective synonyms. Original empirical studies and reviews on the care of children under HMV were included. Studies in clinical settings and on individuals aged 18 years or older were excluded. The screening was conducted independently by two reviewers (LB, FS). The results are grouped thematically and presented narratively.

Results

A total of 231 studies were obtained, of which 36 were screened in full text and 15 were finally included. Seven qualitative and five quantitative studies as well as three reviews were considered. After data extraction, we formed five clusters that summarize the impact of HMV children's care on families. These clusters are presented below.

Burdens for the Entire Family System

Children requiring HMV have a major impact on families' everyday lives and their physical and psychological well-being [19]. The HMV child becomes the focus of the family and changes the dynamic, and relatives have to adapt [20,21]. The life of the family differs significantly from that of other families in terms of everyday life and the social environment [20]. Social activities are significantly restricted by the complex therapy regime of the child. Simple activities such as shopping or meeting up with friends are challenging. Every trip outside the home must be well organized, as a missing item in the emergency bag or an insufficiently filled oxygen bottle may lead to life-threatening consequences for the child [22]. As a result, families have to spend hours planning and packing or even cancel family events or other activities altogether [20]. Furthermore, parents struggle physically and mentally with practical mat-

ters such as maintaining control and ensuring the treatment and care for their child [20]. These tasks are physically and mentally demanding for parents, as they are permanent and involve a high level of responsibility [22]. Mothers in particular describe the disruption of daily life due to scheduling conflicts, lack of normality, care deficits, and mental health problems [23].

Dependence of the Family

In addition to the child's dependence on the ventilator, families are also dependent due to various aspects [22]. Parents of HMV children spend an average of nine hours a day caring for their children [24]. They are grateful for the help of healthcare professionals (HCP) but feel that their privacy is disturbed by their presence [22,25]. Being dependent on HCPs may be stressful and frustrating for families [20]. The necessary technologies also lead to substantial changes in the home. Parents may try to hide or integrate devices into their rooms [e.g. oxygen concentrator, respirator, monitor], but they require a lot of space. Due to these changes, families experience their living environment as alienating [22].

Different Roles of Parents

When caring for a HMV child, parents act in different roles [22]. They are no longer just parents, but also caregivers, managers, therapists, and technicians. Parents become experts, as they are responsible for the complex care for their child [22,26]. They are expected to be both parents and caregivers. This duality is difficult for parents, especially in drawing clear boundaries between them [27]. By taking on contradictory roles, they also feel that their own identity is being torn apart [22].

Burdens for Siblings

Not only the parents, but also the siblings of the HMV child are affected. Parents aim to establish an emotional bond with the HMV child. However, it is often challenging to be equally available and supportive for the healthy children [20]. Siblings report an imbalance concerning parental attention [22]. The HMV child has also an impact on the physical and mental well-being of healthy siblings [21]. They sometimes demand a break and distance from the HMV child. Siblings want to spend time alone with their parents that is exclusively theirs [28]. Finally, siblings often face a high level of responsibility. The early confrontation with the severe health condition of the HMV child can overburden them [21].

Multiple Care Needs

Families are facing difficult access to therapeutic and qualified care services [29], inadequate facilities to recover and relax [30,31], unmet care needs [19,29,31], bureaucratic barriers [22], long periods of waiting for medical aid prescriptions [22] and financial difficulties [29,30]. Parents experience a lack of support from the wider family, the healthcare system, and the social network. Some family members and friends do not support the care of the HMV child because they are afraid of the technical equipment or do not want to cause any problems [23]. Parents often feel left alone in their roles and the associated challenges, they long for further professional support [22]. The lack of home nursing care due to parental exhaus-

tion and the lack of possible support services are declared as two main reasons for hospital readmission [32].

Discussion

The results of this review emphasize that caring for long-term ventilated children at home has a major impact on families. The literature refers to comprehensive care needs. Children with HMV lead to a strain on the entire family system as well as dependency of the family. In addition, relatives and siblings take on new roles and conflicts may arise in different situations. This demonstrates the complex impact of caring for an HMV child at home.

It is therefore highly recommended to consider the effects on relatives, even if home care may result in clear benefits for long-term ventilated children. In this regard, research already highlighted the experience and needs of relatives. What is still missing are approaches, quality improvement projects, or intervention bundles to meet these needs in a sufficient manner. Families often feel left alone and lack a contact person or guide in the care process.

As a consequence, parents often become leaders themselves and are not cared for. They are facing a previously unimaginable situation and are forced to change roles. This change occurs suddenly and unexpectedly, and parents are not adequately prepared for the transition process.

This leads to the issue of how the care of HMV children should be organized at all. Many studies refer to the concept of person-centered care and focus primarily on the affected children. The crucial question here is whether the parents should also be cared for and whether existing structures are suitable for this. Various studies are

already suggesting that family-centeredness should be considered as the care model of choice in this context (e.g. 33).

In summary, a system of care has been established that enables children under HMV to be cared for at home. However, this results in obvious consequences for relatives. These need to be given greater attention in the future.

Conclusion

Providing care for long-term ventilated children at home results in complex implications for families. The present review provides a differentiated understanding of the situation of these families. In order to face their burdens, family caregivers need to develop a long-term and coordinated care plan with a multidisciplinary team [34]. In this regard, the transition from patient-centered care to family-centered care needs to be considered [33,35]. In addition, periods of recovery are crucial for parents and siblings [36].

To provide and strengthen high-quality care of HMV children and their families, HCPs are of central importance. On the one hand, they are required to have a wide range of skills [e.g. clinical, technical, social]. On the other hand, they need to provide sufficient guidance and instructions to the family members, as these are the primary caregivers [34]. In order to ensure this, HCPs need specialist qualifications. Derived from the identified needs of families in this review, Figure 1 summarizes the requirements and tasks of HCPs in caring for families and children under HMV. At this point, we highly recommend advanced practitioners with a master's degree to guide families within the process of caring for HMV children and meet the diverse needs of all people involved.

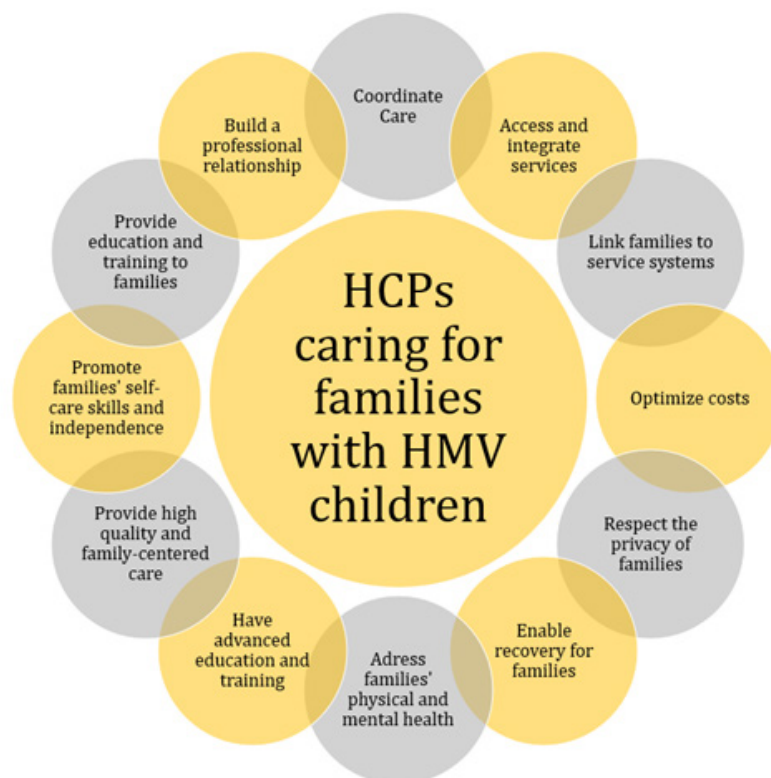


Figure 1: Requirements and tasks for HCPs in the care for families with HMV children

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None.

Conflict of Interest

Authors declare that they have no conflict of interest.

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