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Section 13: The published experience and outcomes of family caregivers when a child is on home mechanical ventilation

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Introduction

This section will review the available literature regarding the experience and outcomes of family caregivers of children requiring home mechanical ventilation (HMV), with an aim of providing Canadian-specific pediatric practice recommendations around long-term home ventilation for children and youth with respiratory failure and hypoventilation. There is a growing appreciation of the positive and negative consequences of a family providing care to a child requiring HMV. It is clear that society relies on family caregivers of children on HMV to provide highly skilled and vigilant care in their homes up to 24 hours per day. In their survey of caregivers of medically complex children that included children dependent on technology, Carter and colleagues\textsuperscript{1} found that providing care at home normalized family life in such activities as meal times and sleep routines. However, family functions are affected by financial and time constraints, impact on siblings and their mental health, social isolation and caregiver burnout.\textsuperscript{2}

Following the first wave of discharges from hospital to homecare for ventilator-dependent children, Kirk\textsuperscript{3} published an overview of the existing literature that examined the experiences of families caring for a technology-dependent child at home. The author\textsuperscript{3} reported that there is evidence that family caregivers experienced social isolation as they were found to be virtually house bound due to their extraordinary caregiving responsibilities. Sleep deprivation and other negative health outcomes owing to the family caregivers needing to provide care through the night or their overriding worry for their child, was also located as a theme among many of the studies. Daytime exhaustion and poor coping were also described along with reports of anxiety, anger, guilt and frustration. The daily emotional strain of caring for a child requiring HMV cannot be underestimated, as families strive to achieve a balance between their exceptional circumstance and normalcy.

Literature review: Methodology

Search of the literature

Databases were searched for articles indexed as of August 24, 2015 and included: OvidSP, MEDLINE (from 1946), EMBASE (from 1980). A combination of controlled vocabulary and free text terms were used to generate a high-sensitivity search that would locate any study reporting on outcomes in family caregivers of children on HVM. In addition, a hand search of relevant citations from article bibliographies was also completed.

Study selection

Eligibility criteria for inclusion in the review:

1. Full-text reports published in peer-reviewed, English-language journals
2. Study sample included\textsuperscript{*} family caregiver(s) (e.g., mother, father, grandparent, foster parent) and/or significant others (e.g., siblings and grandparents) of children on HVM
3. Study reported on any outcome among the family caregivers
4. Study designs of all types, excluding case reports.

\textsuperscript{*}Count of family caregiver (FC) of children on HVM was explicit in description of study sample, even when full study sample may have been heterogeneous

Review process

Each database was searched to perform initial screening of articles for relevance using study titles and abstracts. Full texts and their reference lists were reviewed for all studies that reported outcomes in family caregivers of children on HVM.

Results

A total of 1098 studies were retrieved with a total of 25 independent studies and 1 metasynthesis that met eligibility criteria. Given that the studies varied highly in terms of their methods and measurement, this review is presented as a narrative.
Metasynthesis of qualitative studies

A metasynthesis (i.e., a systematic approach to the analysis and synthesis of findings of qualitative studies) of qualitative studies from 1998–2006 sought to answer ‘what is the family members’ experience of everyday life when a child is dependent on a ventilator?’ Twelve studies met eligibility criteria for inclusion and findings are based on a data set representing 91 HMV children, 24 siblings, 60 fathers, 190 mothers, and 2 grandparents. Findings were structured into themes according to the child’s, siblings’, and parents’ experiences, along with the meaning of space and place. Among its findings:

Siblings took on exceptional roles and caregiving responsibilities in the home: Siblings were described to have participated directly in the work of caring for their sibling on HMV (e.g., providing nursing and technical care). Siblings also carried out domestic responsibilities typically associated with adults (e.g., supervising other siblings) and tried to give their parents a break or cover for them while they were away at work. A theme of siblings ‘living with a loss of personal attention’ was also found across the studies. The authors suggested that support systems and formal (e.g., young carers’ groups) and informal (e.g., overnights with friends) peer support are important considerations in planning services for families of children on HMV.

Living in an awareness of reality and of important values of life: Studies described the experience of family caregivers living with the awareness that the HMV child is fragile and resultant uncertainty about the future. Families are also reported to ascribe positive, often spiritual meaning, to the child’s death. In the context of a demanding parenthood for caregivers of children on HMV, it is notable that in these studies, none of the parents reported regret or doubts about their decision to have their child on HMV.

A demanding parenthood: The studies reported on the highly skilled and vigilant caregiving assumed by parents of children on HMV. The nature of the child’s healthcare needs required parents to carefully manage many details 24 hours per day, all while planning ahead for the unexpected. The parents, due to nighttime caregiving needs of the child, also frequently reported sleep disruption along with overwhelming tiredness and exhaustion. Moreover, it has been described that some parents feel conflicted as they are required to maintain constant vigilance and perform physical life-sustaining tasks that made them feel more like nurses than parents. Social isolation and loss of income were reported in the context of a demanding parenthood for caregivers of children on HMV.

Being in a process of learning: Parents described being motivated to learn, especially close to the time of discharge, so that they could safely care for their child at home. They also described that there was a tremendous amount to learn about how to collaborate and work with others, such as hospital providers and school personnel, who helped care for their child on HMV.

On the meaning of space and place: The care of a child on HMV placed unusual demands on families to accommodate the child, their equipment and associated personnel, in the physical layout of the home. It was found that some families experienced the demands of caregiving to be even higher as the child aged, in part due to physical limitations in the home environment (e.g., lacking lifts, elevators). Some families in the studies gave the child’s equipment a prominent place in the home, while others were reported to hide or camouflage equipment so that it would not overwhelm the look and feel of small spaces.

While the metasynthesis by Lindahl and Lindblad provides insight into the day-to-day experiences of family caregivers of children on HMV, it is notable that in these studies, none of the parents reported regret or doubts about their decision to have their child on HMV.

Independent studies

Twenty-five individual studies not cited in the review paper (above) are summarized below. These studies included 723 family caregivers of children on HMV. Of the independent studies, 17 were conducted in the United States, 4 in the UK/Europe, 3 in Canada and 1 in Japan. Two major outcome types emerged: (1) health and related outcomes of the family caregivers (FCs) and (2) family functioning and related outcomes. As such, the outcomes from each study were categorized into the following subcategories for each of these major themes:

1. Physical and mental health, including quality of life (QoL), caregiver burden, stress and anxiety, social isolation.
2. Family function, including normalization, caregiver competence, parent/professional relationships.

The studies were highly varied in terms of methods and measurement and most had a cross-sectional design using mixed methods that included questionnaires and interviews, or were qualitative studies using in-depth interviews. Only 1 was an intervention study, and only 2 employed a control group. Many described FCs of children on HMV among larger samples of children with other complex conditions (e.g., using other technologies or having other chronic health conditions). Most studies described the experiences of mothers with few reporting on the experiences of other FCs. Many studies used validated measures, but the use of the same measures was seldom repeated. The most common measure, the Center for Epidemiological Studies Depression Scale (CES-D), was applied in 5 studies.

Outcomes in family caregivers: Physical and mental health

The evidence suggests that FCs of children on HMV were at a higher risk of depression, especially when supports such as care coordination and homecare nursing levels were minimal or lacking. A factor compellingly associated with increased depression was poorer sleep quality in FCs of children on HMV when compared to FC of otherwise healthy children. Self-reported shorter sleep times have been associated with greater daytime sleepiness and lower daytime functioning (p < 0.05) when night nursing was not
adequate. The studies were limited by reliance on subjective measures of sleep. In the 1 intervention study, a resourcefulness training intervention, which included in-person teaching of 8 resourcefulness skills using the acronym RESOURCE to prompt recall of social (help-seeking) and personal (self-help) skills, was used. The intervention was found to be acceptable and feasible in a pilot study with 22 mothers of children on HMV. The participants engaged in a 4-week, nurse-led cognitive behavioral education-based intervention that demonstrated positive impact at 6 weeks follow-up on mental health, including medium effects on negative emotions (d = 0.52) and small effects on depressive cognitions (d = 0.22).

In a study examining health promotion activities and lifestyle among FCs of children on HMV (n = 38), the healthiest behaviors were observed for substance use (e.g., smoking) and safety (e.g., drinking alcohol), and the worst behavior scores were found for items pertaining to nutrition, exercise, relaxation and general health promotion (Personal Lifestyle Questionnaire (PLQ)). Overall health promotion correlated with improved functional status of the child (r = 0.46, p < 0.01) and parental coping (r = 0.40, p < 0.05).

**Health-related QoL**

Qualitative studies that examined aspects of QoL reported that parents were happy about having their child at home despite the difficulties they faced. This appraisal was largely because parents, rather than focusing on the negatives, focused on the positive aspects of their lives. Agazio described that parents felt an overall sense of well-being with having their child at home. This was due to being well-prepared and having planned ahead for the physical needs of their child. In studies that reported on caregiver QoL using validated measures, many negative aspects of emotional (frustration, anxiety, sadness, hopelessness) and physical (tiredness, feeling weak) health were reported. Greater physical and mental health (p < 0.01) were associated with higher scores for social support, self-esteem and psychological stability.

**Caregiver burden**

Studies have described the high cost associated with HMV along with many parents having to quit their job or reduce their work as a result of the demands of caring for their child. Increased responsibilities, physical demands and the burden of having to care and coordinate care for the child was also reported. Having to be available 24 hours a day was especially difficult for many parents and 1 study even reported that mothers felt there were demands and expectations of ‘extraordinariness’ placed on them. On the other hand, having reliable family support and having knowledgeable and helpful healthcare staff reduced some of the burden of care. During a 6-month period, a videophone was used to provide respiratory care specialists’ resources to primary care physicians and their pediatric patients. This reduced the net number of hours spent by both patients and physicians in unscheduled medical care by 95 hours over this 6-month period.

**Stress and anxiety**

Studies that examined stress and anxiety in FCs reported that the technical and physical aspects of caring for the child were associated with increased anxiety, especially when the child first came home. Additional expenses associated with HMV (e.g., loss of income and increased out-of-pocket expenses) were also associated with increased stress. One study found that increased stress about the ill child's condition was found to be related to increased sleep disruption. Blucker described that coping efforts, such as developing social relationships and engaging in activities that promote individual self-identity were associated with less distress and with more optimal physical health. On the other hand, in children with underlying complex chronic healthcare needs (e.g., neuromuscular diseases), Mah found no difference in stress between FCs with children on HMV compared with FCs of children not on HMV.

**Social isolation**

Many families expressed increased feelings of social isolation, which was often associated with not having enough home healthcare help and lack of community services. In 1 study, FCs reported that they found it hard to talk to others about their situation. A pilot study by Miyasaka observed that having a videophone for parents to access healthcare gave parents the additional benefit of gaining peer support. Presumably, such interventions would be easier to deploy currently, given the wide availability of voice-over-Internet software.

**Outcomes in family caregivers: Family functioning and related outcomes**

**Family function**

Mixed findings were reported for family functioning. Toly found that greater depressive symptoms correlated with poorer family functioning. Kuster and colleagues have also reported that 82% of parents described problems in family daily activities. Agazio reported that many aspects of couples’ relationships had to be re-adjusted as a result of having a child on HMV. This included re-acquainting and redefining themselves as couples, re-aligning household and healthcare responsibilities and adjustments for siblings due to less attention. However, having the child at home had positive effects on many families and siblings as it helped family members to be more understanding and compassionate and HMV enabled the child to be at home with the family before dying.

**Normalization**

Most studies found that with effort, families were able to achieve a sense of normality in their routine. Metasynthesis findings pointed to the family home feeling like a public rather than private place as professionals were
in the home up to 24 hours per day.\textsuperscript{4} Furthermore, it was reported that, after the termination of homecare nursing, families expressed appreciating a return to privacy.\textsuperscript{16} Toly found that normalization was correlated negatively with mother’s depressive symptoms and positively with the child’s functional status and family functioning ($p < 0.01$).\textsuperscript{24}

**Caregiver competence**

The majority of FCs felt confident and competent in caring for their child and for emergencies, especially after time, when they became experts on caring for their child.\textsuperscript{4,13,15,16,19,20} Findings of the metasynthesis suggested that parents were ‘astute to learn their child’s unique cues and individualized responses,’ thus enabling them to become the best people to care for and teach others about all of their child’s needs.\textsuperscript{4} In contrast, Dybvik\textsuperscript{14} and Margolan\textsuperscript{18} reported parents believed they only had ‘some’ competence\textsuperscript{18} and FCs often felt they lacked competency and continuity in care.\textsuperscript{14} Notably, the use of simulation-based education was described in 1 retrospective study as helpful for enabling confidence and competence among FCs of children on HMV when preparing for discharge.\textsuperscript{27}

**Parent/professional relationships**

There were mixed feelings on the part of FCs about the relationships they had with professionals. Many parents described that they worked hard at improving them,\textsuperscript{4,19} but still reported conflict, lack of understanding, poor communication and inadequately prepared professionals.\textsuperscript{14,17–19,24} Toly\textsuperscript{24} described that many parents reported having difficulty finding adequately prepared nurses while other parents felt there was inadequate communication between agencies\textsuperscript{19} and a lack of understanding and involvement from the community healthcare system.\textsuperscript{14} Parents also felt that the polarization along jurisdictional lines between and among providers created barriers in communication, collaboration and conduct of responsibilities.\textsuperscript{6} Conversely, many parents expressed feeling comfortable and happy with the skills of home caregivers\textsuperscript{10,18} and, when homecare nursing was terminated, they missed the homecare provider’s expertise, emotional support and personal contact.\textsuperscript{16} Some parents rated the care providers’ social skills higher than did their adolescents on HMV.\textsuperscript{28}

**Discussion**

It is evident that FCs experience a variety of outcomes impacting their health and family functioning. In terms of physical and mental health, commonly reported themes include high demands\textsuperscript{7,17} and the stress associated with caring for a child on HMV.\textsuperscript{15,16} The financial burden associated with the child on HMV contributes significantly to these stresses.\textsuperscript{15,17,21,22} FCs experience elevated levels of depression\textsuperscript{7,8} associated with poorer sleep quality as well as anxiety around the care of their child.\textsuperscript{9,10,23,24} Many families also report challenging encounters with members of the healthcare team, hospitals and agencies involved in their child’s care. FCs express that there is often a lack of communication, understanding, coordination and cohesion between parents and healthcare providers.\textsuperscript{14,18,19,24,29}

On the other hand, despite the numerous difficulties family caregivers face, many family caregivers are positive and happy about having their child at home.\textsuperscript{13–16} FCs work hard to normalize their home environments, which contributes to the positive aspects of their caregiving experiences.\textsuperscript{14,15,23}

**Limitations**

Many of the studies have reported on the experiences of family caregivers through the use of author-generated surveys or other subjective, unstructured methods, leaving these studies prone to self-report bias. A large variety of questionnaires has been used and repeated measures have rarely been carried out. In addition, only 1 pilot intervention study has been published. Many studies are at risk for participation bias. For example, in the study by Mah,\textsuperscript{21} the non-participant rate of eligible FCs was >50%. Blucker\textsuperscript{5} also acknowledged that it was surprising to find that the prevalence of family caregivers in their sample who met criteria for a major depressive disorder was lower than the national prevalence rate for adults in the United States and speculated that responses were colored by concerns that their responses could be viewed by the attending physician, leading to negative perceptions of the family by the healthcare team (i.e., social acceptability bias). FCs who did experience considerable psychological distress may have been underrepresented at clinic visits.\textsuperscript{5} Only 1 study has reported on including FCs who spoke any language other than English.\textsuperscript{12}

Studies also lacked details with respect to the sociodemographic and clinical characteristics of the sample. This review suggests that there are caregiver (e.g., age, education, income, number in household), child (e.g., age, length of time on HMV, number of hours of ventilator use per day, number of comorbid conditions) and environmental (e.g., number of homecare hours, frequency of equipment alarms, distance from hospital or HMV program) factors that may influence the experience of FCs of children on HMV. In future studies, these characteristics should be described more fully so that results may be interpreted in the context of the many variables of interest. Additional studies are needed to better inform the development of targeted interventions and inform health service delivery providers and integrated health policy to support and enhance the valuable contributions of the FCs of children on HMV.

Despite these limitations, the studies have provided a reasonable overview of the experiences of FCs of children on HMV. Much of the data derived from these studies resonates with clinicians, researchers and others who have experience caring for children on HMV and their families. The qualitative methodologies described in the metasynthesis by Lindahl and Lindblad\textsuperscript{4} has generated data that provides a rich understanding of the experiences of FCs when a ventilator-dependent child is cared for at home. A major strength of these studies is a description of the experience of individual family members (e.g., parents, siblings)
and the family as a unit. Collectively, these findings can help healthcare providers and others involved in the care of the child on HMV to determine ways in which the home care experience for FCs can be targeted and improved.

Research questions

Based on this review of the literature and expert consensus, the following questions need to be addressed, particularly in the Canadian context, regarding FCs of children on HMV:

1. What aspects of the FC experience best predict a positive QoL?
2. What interventions can improve mood, sleep and daytime function among FCs of children on HMV?
3. What is the right model of respite care: type (regulated, unregulated, both), amount (hours per day, week, daytime, nighttime) and place (in-home, out of home) to optimize health and family function among FCs of children on HMV?
4. Which social support programs (e.g., peer support) are the most feasible, acceptable and effective for FCs (e.g., siblings and parents) of children on HMV?
5. How can funding systems be better organized to recognize and reward the contributions of FCs of children on HMV (e.g., self-directed funding packages)?
6. What would assist FCs of children on HMV in securing and maintaining gainful paid employment?
7. What are the characteristics and circumstances that enable resiliency in FCs (to successfully use their strengths and overcome their vulnerabilities) when managing the care of a child on HMV?
8. What is the long-term experience of FCs of children who are on HMV?

Recommendations for the published experiences and outcomes of family caregivers when a child is on long-term mechanical ventilation at home

1. Family caregivers should receive initial and ongoing psychosocial assessments as well as both instrumental and psychological supports related to the burden and costs (financial, emotional) associated with caring for a child on HMV. (Consensus)
2. Family caregivers should be assigned a ‘key worker’ or another accountable individual to provide professional care coordination and case management, to ease the daily workload of caregiving. (Consensus)
3. Care of the child on HMV includes routine assessment of the health and well-being of family members including parents, siblings and others involved in the child’s care. If there are concerns regarding patient safety due to issues in the family, child protective services must be contacted. (Consensus)
4. As the use of HMV advances, family caregivers should receive personalized services using novel technologies, including high-fidelity simulation for training purposes, that promote confidence, competence, enhanced problem solving and optimal family function. (Consensus)
5. Technology-enabled video monitoring, or other technology-enabled modalities and support, should be used for communication with the healthcare team to reduce family caregiver anxiety, provide symptom support, promote trouble-shooting of equipment challenges and reduce unscheduled provider visits. (Consensus).

Disclosure statement

No potential conflict of interest was reported by the author(s).

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