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Caring for children with new medical technology at home: parental perspectives

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ABSTRACT

Objectives This qualitative descriptive study explores the experiences of family caregivers (FCs) of children with medical complexity who are initiated on new medical technology in the hospital and transition to new daily life at home. The study aims to investigate FCs' response and readiness for medical technology use, the value of education and transition support and the challenges associated with managing new medical technology in the home.

Study design A qualitative descriptive approach was used to conduct and analyse 14 semistructured interviews with a group of FCs composed of 11 mothers and 3 fathers. Content analysis was used to analyse transcripts of the caregiver interviews. The study was conducted at a tertiary paediatric hospital in Toronto, Canada.

Results Our study revealed three main themes: FC's response and readiness for medical technology use, the value of education and transition support for initiation of new medical technology and the challenges associated with managing new medical technology in the home. FCs expressed emotional distress related to coping with the realisation that their child required medical technology. Although the theoretical and hands-on practice training instilled confidence in families, FCs reported feeling overwhelmed when they transitioned home with new medical technology. Finally, FCs reported significant psychological, emotional and financial challenges while caring for their technology-dependent child.

Conclusions Our study reveals the unique challenges faced by FCs who care for technology-dependent children. These findings highlight the need to implement a comprehensive education and transition programme that provides longitudinal support for all aspects of care.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Family caregivers of technology-dependent children with medical complexity experience several challenges in their transition home from hospital, especially related to medical technology complications.

WHAT THIS STUDY ADDS

- ⇒ A training programme that combines theoretical and hands-on learning can increase family caregivers' confidence in managing medical technology at home.
- ⇒ Family caregivers of children who are initiated on medical technology in hospital desire having more robust support following their discharge home as they adapt to new life.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ There is a critical need to develop comprehensive education programmes for family caregivers whose children are initiated on medical technology in hospital.
- ⇒ Educational and psychosocial supports should be available during the disclosure of the need for medical technology, training process, transition home and postdischarge period.

INTRODUCTION

Children with medical complexity (CMC) are a growing population due to advancements in medical care and home technologies without which they would not have survived previously.[1–3] CMC are a group of diagnostically heterogeneous children whom are united by multiple chronic conditions, significant functional limitations and dependence on technology.[4] CMC and their family caregivers (FCs) endure enormous challenges, including prolonged hospitalisations, poor care coordination and caregiver burden.[4–6] Due to their underlying medical fragility, CMC often are frequent users of the healthcare system and experience significant morbidity and mortality.[3–7]

Families of CMC have reported that transitioning from hospital to home with technology-dependent children can be demanding because of the involvement of multiple healthcare providers and services.[8 9] This transition experience is especially heightened by the addition of new medical technology such as tracheostomies, ventilators and feeding tubes. A substantial amount of emergency department visits and hospital encounters in CMC are related to medical technology complications soon after technology initiation.[10–12] It has been postulated that several technology-related complications could be prevented or managed at home with appropriate support and action plans.

Previous research has shown that interventions aimed at enhancing the competency and confidence of FCs in managing new medical technology resulted in improved overall experiences of FCs and reduced psychological distress.[13 14] For instance, a discharge coaching model for CMC decreased hospitalisation and overall cost per patient, thereby signalling that discharge interventions in this population have the potential for system-wide improvement.[15]

To improve the quality of life of technology-dependent CMC and their FCs, there is a critical need to gain a deeper understanding of whether innovation in education is meeting their needs with medical technology. This study has been conducted as part of a larger prospective observational study to evaluate the impact of a training programme called Connected Care on acute healthcare utilisation and the experiences of technology-dependent CMC, their families and home healthcare providers. The aim of this qualitative study was to explore FCs' experiences with caring for CMC who are initiated on medical technology during a hospital admission. We sought to understand their experiences undergoing the training programme in hospital as well as throughout the process of being discharged and transitioning to new daily life at home.

METHODS

Study design

We conducted a qualitative descriptive study using semistructured interviews with FCs. Data were collected between December 2020 and May 2022. A subset of primary FCs already enrolled in a prospective, observational study to evaluate the Connected Care Program were invited to participate in this qualitative study via phone call. FCs were eligible for study inclusion if they[1] had CMC who were newly initiated (in-hospital) on new medical technology such as enterostomy tubes, respiratory technology and vascular access (eg, peripherally inserted central catheter (PICC line), port-a-catheter)[2]; could read, write and understand English and[3] provide informed consent for study participation. The definition of CMC for study inclusion is a child with complex chronic conditions and/or neurologic impairment requiring specialised care, substantial healthcare needs, functional limitations and high healthcare resource utilisation.[3] The maximum variation sampling technique was used to ensure representation from FCs of CMC across a range of social strata with diverse child and family characteristics. Written voluntary consent was provided before study enrolment. Participants were informed that they have the right to withdraw from the study at any time without penalty.

Connected Care Program

The Connected Care Program is located at Canada's largest paediatric hospital, The Hospital for Sick Children, and was developed to support transitions from hospital to home and improve paediatric homecare for CMC, their families and healthcare providers.[16] Please refer to online supplemental file 1 for a full description of the Connected Care Program.

Data collection

Health records were retrospectively reviewed for study participants' children for the following: child's age, gender, single primary medical diagnosis and medical technology/technologies initiated. A demographic questionnaire was administered to FCs to collect their age, gender, level of education, employment status and average distance to hospital. Qualitative data collection included individual semistructured interviews that were scheduled 3–6 following discharge from hospital with new technology. Interview guides were developed iteratively by the research team after a review of relevant literature and consultation with content experts (see online supplemental file 2). The interview guide explored the experiences and perspectives of FCs' regarding their (1) responses to the first disclosure of medical technology, (2) experiences in managing the care for a child dependent on medical technology, (3) knowledge, impacts, facilitators and barriers of education programming and (4) access and usefulness of supports in managing care for their child with new medical technology beyond discharge/in homecare. Interviews were conducted by a female medical student with formal training in qualitative research (NP). There was no relationship established prior to study commencement. The interviews were conducted online via Zoom Video Communications teleconference platform or by phone as per participant preference.

Patient and public involvement

Patients were not involved in the design and/or conduct of this study.

Data analysis

Interviews were recorded, transcribed verbatim and deidentified by a professional transcriptionist. Qualitative data analysis software (NVivo V.12 Plus) was used for data and coding management. Conventional content analysis was used to analyse the transcripts.[17] The inductive, four-step content-analysis process was conducted to identify, code and categorise predominant themes from the text. First, all the transcripts were read several times by three independent reviewers (AS, NP and RA) to identify initial patterns and recurring categories. Second, two reviewers independently coded all the interview transcripts (AS and NP). This step involved the creation of several codes and their application over the volume of interviews by two independent reviewers. Third, similar codes were grouped into categories and subthemes and later categories and subthemes were grouped under major themes. Finally, the main themes and subthemes were discussed among the reviewers (AS, NP and RA) until agreement on the themes was achieved and reflected the entire data set. Methodologic rigour was established through prolonged engagement and peer debriefing, and according to The Consolidated Criteria for Reporting Qualitative Research (online supplemental file 3). After 14 interviews, recruitment was closed because data saturation was reached, defined as the point when additional data did not lead to the emergence of new themes.[18] Transcripts were not returned to participants; however, they were provided a description of the coding framework.

RESULTS

A total of 34 eligible participants were approached by the study team, of which 14 FCs of CMC agreed to participate. The 20 participants who declined participation in the study reported that they did not have time for an interview (n=13), or they did not want to participate in additional research-related activities (n=7). The demographic information for the FCs is shown in table 1. Of the 14 semistructured interviews conducted, 3 were with fathers and 11 were with mothers. Each of these interviews lasted between 30 min and 60 min. The demographic and clinical information for the children of participating FCs is also shown in table 1.

Framework for experiences of FCs of children with new medical technology at home

Based on the content analysis, three overarching themes emerged from the interviews[1]: FCs' response and readiness for medical technology use[2]; the value of education and transition support for initiation of new medical technology[3]; the challenges associated with managing new medical technology in the home. The themes and subthemes are outlined in summary (table 2). Please refer to online supplemental file 4 for the full table 2 with illustrative quotes.

Table 1 Demographic and clinical characteristics of family caregivers and their children (N=14)

Characteristics of family caregivers	N (%) or mean±SD
Caregivers	
Female	11 (78.6)
Male	3 (21.4)
Caregiver age (years)	38.3±6.5
Highest educational level	
Secondary education	4 (28.6)
Postsecondary education	9 (64.3)
Prefer not to answer	1 (7.1)
Employment status at the time of the study	
Employed	7 (50.0)
Unemployed	5 (35.7)
Receiving disability or retirement pension	2 (14.3)
Average distance to hospital one way (km)	71.8±67.8
Characteristics of child participants	
Children	
Female	11 (78.6)
Male	3 (21.4)
Age (years)	
<6	8 (57.1)
6–12	2 (14.3)
13–18	4 (28.6)
Primary diagnosis	
Musculoskeletal disease	4 (28.6)
Central nervous system disease	9 (64.3)
Respiratory disease	1 (7.1)
Medical technology initiated	
Enterostomy tubes	8
Vascular access device	5
Respiratory device	4

*The number of medical technologies initiated does not total N=14 as some participants were started on more than one technology.

FCS' RESPONSE AND READINESS FOR MEDICAL TECHNOLOGY USE

FCs' initial reaction to first disclosure by the healthcare team

Most FCs reported experiencing emotional distress in response to the first disclosure of their child's need for medical technology. Some expressed feeling nervous and emotional while others felt shocked and scared by the idea of their child being dependent on medical technology. Many felt hesitant about the decision to proceed with medical technology because of the fear associated with caregiving responsibilities and risks. Even knowing they would receive education, some FCs felt that they would not be capable of managing the technology. Some of those who were initially hesitant about starting their child on technology noted feeling reassured and more accepting of the technology following additional discussions with the healthcare team.

FCs' attitude towards participating in training program

Nearly all FCs expressed feeling very anxious about the prospect of learning how to use the technology. Some initially expressed not wanting to do the training altogether, believing that they would not be capable of learning to manage at home. They expressed fear related to the learning process and undertaking tasks normally done by healthcare professionals. One FC whose child previously had a tracheostomy had panic attacks from the thought of having to complete tracheostomy changes. Another FC noted feeling like she was not able to absorb

Table 2 Themes and subthemes

Themes	Subthemes
Family caregivers' reaction and preparedness towards the first disclosure of the need for medical technology	1.1 Family caregivers' initial reaction to first disclosure by the healthcare team
	1.2 Family caregivers' attitude towards participating in training programme
The value of education and transition support for initiation of new medical technology	2.1 Experience of learning medical technology
	2.2 Access to education and transition support for medical technology management
The challenges associated with managing new medical technology in the home	3.1 The initial transition home
	3.2 Difficulties dealing with emergencies and medical complications
	3.3 Increased emotional and financial burden among family caregivers

the information well during training because she was so overwhelmed by her child's admission.

THE VALUE OF EDUCATION AND TRANSITION SUPPORT FOR INITIATION OF NEW MEDICAL TECHNOLOGY

Experience of learning medical technology

FCs felt that the education they received played a significant role in improving their knowledge of medical technology. They received both theoretical knowledge of the skills and hands-on training using mannequins, both of which provided the opportunity to learn various scenarios associated with technology as well as potential complications that could arise. Some FCs appreciated that the educational material was provided in plain language without medical jargon. FCs also noted that the nurse educators who were teaching provided them the flexibility to learn at their own pace and the opportunity to ask as many questions as they needed. Many FCs appreciated the registered nurses and respiratory therapists for providing supplemental information and training support at the bedside.

A few FCs provided suggestions to improve the overall learning experience including adjusting the speed of sessions according to participant level of understanding and learning pace as well as the development of additional training materials and recorded sessions in the take-home education package for quick reference. A few FCs reported that the educational material was too long with too much content to absorb in one session.

Access to education and transition support for medical technology management

Most FCs reported adequate access to education and training support. Many received virtual follow-up visits from the programme, which helped them in understanding the use of supplies in the home environment and responding to medical complications in real time. However, some FCs felt that the programme was not accessible to their partners and extended family members due to restrictions imposed by the COVID-19 pandemic. One FC mentioned it was difficult to participate in training because additional caregivers were not allowed in hospital during the pandemic to care for her son, making it challenging to participate in the classes. Another FC expressed wishing there was more flexible access to enable others at home also access to the programme. FCs suggested expanded access with virtual sessions to be available to other groups of FCs such as partners, siblings, grandparents as well as patients (ie, medically complex children) if they were willing to learn. To improve transition support, some FCs who did not receive them suggested the implementation of standardised longitudinal follow-up visits from members of the training programme following discharge to ensure FCs are coping well.

THE CHALLENGES ASSOCIATED WITH MANAGING NEW MEDICAL TECHNOLOGY IN THE HOME

The initial transition home

FCs reported feeling stressed by the process of transitioning their child from hospital to home with new technology. They highlighted that returning home was a sudden change as they had been accustomed to a hospital environment where there is constant nursing care and support from the healthcare team. An added challenge at home was safety and FCs worried about ensuring that siblings did not disrupt or interfere with the medical technology. Furthermore, a couple of FCs noted that they had difficulty ordering supplies or accessing different equipment at home compared with what they received training within hospital, making the transition more stressful. Some FCs felt they did not have adequate support at home on their first day of discharge.

A few FCs mentioned strategies that they used to stay organised at home after discharge such as following a timetable, setting up stations for feeding, stocking up equipment and dividing responsibilities among FCs at home. Even with these strategies, most FCs felt overwhelmed by the demands of managing the technology. For instance, one FC stated being overwhelmed because she had to spend an entire day observing her child to ensure that they did not pull out their tubes or throw up after feeding.

Difficulties dealing with emergencies and medical complications

FCs also recounted their experiences of managing emergencies and medical complications at home. Common scenarios discussed included site infections, equipment malfunction or difficulty with technology insertion/replacement. FCs reported feeling stressed and frustrated while trying to navigate these situations. A few FCs expressed not having adequate experience with tasks that are required to manage certain complications. Additionally, they expressed the need for more support in making the decision when to seek emergency care, especially given the distance that they live from the hospital. Many FCs mentioned that they do not have a clear point of contact for emergencies after discharge. They suggested that the hospital should provide clear contact information and/or set up a virtual platform to connect healthcare providers directly to FCs in such situations.

Increased emotional and financial burden among FCs

FCs also highlighted the exhaustion associated with the care of children with medical technology. CMC require intense care demands throughout the day and night including dressing changes, equipment and supply cleaning and purchasing, medication administration and troubleshooting. Some FCs report experiencing burnout as a result. FCs also emphasised the difficulties of attending hospital appointments, especially when they have several in 1 week or have to travel long distances to the hospital.

FCs also expressed psychological and emotional challenges associated with the care of a child with medical technology. Some report not getting adequate support from their partners or family members because they are fearful of taking on the responsibility, work full-time or did not receive training. Some FCs expressed their frustration and desire to escape the responsibility of caregiving for a mental break. FCs also highlighted the financial burden associated with the care of a child with medical technology. One FC noted having to borrow money from friends and family as having their child at home on medical technology put them into a financial crisis.

DISCUSSION

This study enhanced the current understanding of FCs' needs and experiences of caring for technology-dependent CMC. Previous research has focused largely on FCs' experiences and challenges associated with the care of children that are already using medical technology.[6 19–21] Our study is unique in that we outline the challenges faced by FCs from when they first learn about the need for medical technology in hospital to when they learn to care for their child's new device in transition to home and experience new daily life.

In response to the first disclosure of their child's need for medical technology, most FCs reported experiencing fear and distress as well as hesitation to proceed with the decision to initiate the technology. This is consistent with previous research highlighting the emotional distress and decisional conflict experienced by families involved in the decision-making process about initiating medical technology for their child.[22 23] When making the first disclosure of a child's need for medical technology, it is critical for clinicians to recognise the psychological bearing this has on FCs. Findings from studies that examine caregiver experience in this decision-making process can inform how first disclosures should be facilitated. Importantly, caregivers appreciate clinicians who provide communication that is compassionate, transparent and frequent.[24] FCs undergoing the decision for paediatric home ventilation have expressed the benefit of connecting with other FCs in similar situations.[25] Caregivers have also highlighted the value of including external sources of supports in these discussions outside the healthcare team, including extended family members, religious leaders and primary care providers.[22 26 27]

Overall, there is a pressing need to provide robust psychological and emotional support during the process of communicating a child's need for technology. Importantly, our study cohort highlighted that undergoing the training was an emotional and stressful experience itself. Thus, training for clinical educators to support learners in stressful contexts and access to psychosocial supports should be available to FCs as an integral part of their training as well. FCs also highlighted how important it is for them to have education that is a combination of didactic and hands-on, personalised, and appropriately paced. They shared the need to further extend classroom-based education to ensure practice at the bedside, access to support in first 24 hours at home, and ongoing virtual care to help with equipment troubleshooting and managing complications. Other specific recommendations made by FCs in our study included a more robust education on types of available supplies, improved access to the education programme (ie, partners and patients themselves when applicable) and implementing a check-in by a healthcare provider in the first-week postdischarge.

FCs communicated that virtual approaches to providing education before (to other family members not at the hospital) and after discharge was highly desired. Similarly, Ravid *et al* implemented a pilot intervention involving a 'multidisciplinary discharge videoconference' for CMC.[28] The participating physicians and FCs found the intervention acceptable due to a variety of benefits including the development of a shared understanding of the patient's care plan, remote physical assessment by the primary care provider, transparency, humanisation of the care handoff and increased primary care provider comfort with the care of CMC.[24] Our programme's early experience with delivery of virtual visits after discharge for FCs of technology-dependent CMC is similar, and those in this study who received this service in addition to their baseline education greatly appreciated the ease of access and ongoing support of their competencies. Thus, follow-up in the form of virtual care is now standard of care for children initiated on technology and followed in the training programme in our hospital.

Our study highlighted the impact of the Connected Care Program on FCs' knowledge of medical technology and overall readiness to transition home. Despite the support provided to FCs by the training programme, it is clear from our findings that day-to-day life continues to be stressful for FCs given the intensive nature of managing medical technology at home. FCs in our study reported several psychological, emotional and financial challenges while caring for their technology-dependent child. It is well documented in the literature that caring for technology-dependent children can lead to adverse physical and mental health impacts on caregivers.[29–31] FCs of children who depend on medical technology are at risk of acute and chronic sleep deprivation, psychological distress and impaired daytime functioning that may threaten their capacity for sustained caregiving.[6] In fact, the prevalence of psychosocial stress in FCs of CMC, who are frequently dependent on medical technology, is among the highest of all studied paediatric populations.[32] This psychosocial stress was exacerbated during the COVID-19 pandemic.[33 34] Taken together, our study highlights the distress experienced by FCs at the time of technology initiation as well as during the transition home and adaptation to new daily life. Thus, beginning at the initiation of technology and at follow-up visits, it is critical for healthcare providers to question families about their needs and risk factors for psychosocial stress. This is an important step in facilitating the provision of appropriate education and related interventions, specifically focused on providing psychosocial support and access to specialised hospital and community resources.

Study limitations

There were some notable limitations to the study. The study included a sample size of 14 FCs (11 mothers and 3 fathers). While data saturation was reached, the small sample size limits the generalisability of the findings. Thus, experiences and perspectives of these caregivers may not be representative of all FCs of CMC. The participants were recruited from a larger prospective observational study, and only those who agreed to participate were included in the qualitative study. It is possible that those who chose to participate may have different experiences or perspectives compared with those who declined, introducing selection bias. The study was conducted at a tertiary paediatric hospital in Toronto, Canada. The sample may not be representative of the broader population of FCs of CMC, particularly in terms of cultural and socioeconomic diversity. The findings may be influenced by cultural, socioeconomic and healthcare system factors unique to the study setting. Therefore, caution should be exercised when applying the study findings to other populations or contexts.

Furthermore, the data collected in the study relied on self-reported experiences of the FCs. There is a possibility of recall bias or social desirability bias, where participants may provide responses that they believe are expected or favourable. The study focused on the experiences of FCs from the time their child was initiated on medical technology in the hospital to the transition to home. Thus, the study does not provide insights into long-term experiences or the effectiveness of the Connected Care Program in the broader context of paediatric homecare. The study did not include a comparison group of FCs who did not receive the Connected Care Program. Without a control group, it is difficult to determine the specific impact of the programme on the caregivers' experiences and outcomes. The study was conducted during the pandemic and participants were interviewed via videoconferencing rather than in person, which may have limited the rapport established by the interviewer during the interview. Finally, the study primarily focused on the perspectives of FCs and did not include perspectives from other key stakeholders, such as healthcare professionals or home healthcare providers. Including multiple perspectives could have provided a more comprehensive understanding of the challenges and support needs during the transition from hospital to home with new medical technology.

Despite these limitations, the study provides valuable insights into the experiences and challenges faced by FCs of CMC and highlights the need for comprehensive education and support programmes for these caregivers. The small sample size, limited generalisability, reliance on self-report data and absence of perspectives from other stakeholders are important limitations to consider when interpreting the findings. Further research with larger and more diverse samples is needed to validate and expand on these findings.

Conclusion

FCs provided unique insights into their experiences of going home with new medical technology. FCs reinforced and highlighted the need to implement a comprehensive education and transition programme that provides longitudinal support for all aspects of care. This includes support during the disclosure of the need for medical technology, learning to manage the technology, coordinating transition home and postdischarge follow-up. Future research should include the codevelopment and implementation of these identified opportunities for improvement to ensure a more integrated and holistic support programme for FCs of CMC going home with newly initiated medical technology.

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Contributors RA and JO conceptualised and designed the study, and critically reviewed and revised the manuscript for important intellectual content. SC, KK, EC and JO were involved in the study design and critically reviewed and revised the manuscript for important intellectual content. NP, SM, MA designed the data collection instruments, and collected data. RA provided oversight for all of the data collection. NP and AS analysed the qualitative data independently and discussed it with RA to agree on the major themes and categories. AS and NP co-wrote the initial draft of the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work. RA accepts full responsibility for the work and/or conduct of the study, had access to the data and controlled the decision to publish.

Competing interests No, there are no competing interests.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

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