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Bringing it all home: the experience of family caregivers caring for children with new medical technology at home

Short title: Bringing it all home

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ABSTRACT:

Objectives*:* A novel education program that provides personalized, competency-based training using simulation was introduced for family caregivers (FCs) of children with medical complexity (CMC) being initiated on new medical technology in the hospital. This study explored FCs' experiences from the time their child was initiated on medical technology in the hospital to when they were discharged home and transitioning to new daily life.

Study design: A qualitative descriptive approach was used to conduct and analyze 14 semi-structured interviews with a group of FCs composed of 11 mothers and 3 fathers. Content analysis was used to analyze transcripts of the caregiver interviews. The study was conducted at a tertiary pediatric 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 realization 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 program that provides longitudinal support for all aspects of care.

What is already known on this topic:

- Family caregivers of technology-dependent CMC experience several challenges in their transition home from hospital, especially related to medical technology complications

What this study adds:

- A training program 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 programs 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 post-discharge period

Introduction

Children with medical complexity 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 hospitalizations, 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 hospitalization 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 program called Connected Care on acute healthcare utilization 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 program 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 semi-structured interviews with FCs. Data were collected between December 2020 and May 2022. Institutional research board approval was obtained [Research Ethics Board number 1000064641]. 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 (e.g., 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 specialized care, substantial healthcare needs, functional limitations, and high healthcare resource utilization.[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 enrollment. 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 pediatric hospital, The Hospital for Sick Children, and was developed to support transitions from hospital to home and improve pediatric homecare for CMC, their families and healthcare providers.[16] Please refer to Supplementary Material 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 an average distance to hospital. Qualitative data collection included individual semi-structured 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 Supplementary Material 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.

Data Analysis

Interviews were recorded, transcribed verbatim, and de-identified by a professional transcriptionist. Qualitative data analysis software (NVivo 12 Plus) was used for data and coding management. Conventional content analysis was used to analyze the transcripts.[17] The inductive, 4-step content-analysis process was conducted to identify, code, and categorize 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, 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 sub-themes and later categories and sub-themes were grouped under major themes. Finally, the main themes and sub-themes were discussed among the reviewers (AS, NP, RA) until agreement on the themes was achieved and reflected the entire dataset. Methodologic rigor was established through prolonged engagement and peer debriefing, and according to The Consolidated Criteria for Reporting Qualitative Research (Supplementary Material 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 semi-structured interviews conducted, 3 were with fathers and 11 were with mothers. Each of these interviews lasted between 30 and 60 minutes. The demographic and clinical information for the children of participating FCs is also shown in Table 1.

Framework for Experiences of Family Caregivers 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 sub-themes are summarized in Table 2 with illustrative quotes.

1. Family Caregivers' Response and Readiness for Medical Technology Use

1.1 Family caregivers' 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.

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

2. The value of education and transition support for initiation of new medical technology

2.1 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.

2.2 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 program, 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 the program 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 program. FCs suggested expanded access with virtual sessions to be available to other groups of FCs such as partners, siblings, grandparents as well as patients (i.e., medically complex children) if they were willing to learn. To improve transition support, some FCs who did not receive them suggested the implementation of standardized longitudinal follow-up visits from members of the training program following discharge to ensure FCs are coping well.

3. The challenges associated with managing new medical technology in the home

3.1 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. Further, a couple of FCs noted that they had difficulty ordering supplies or accessing different equipment at home compared to 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 organized 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.

3.2 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.

3.3 Increased emotional and financial burden among family caregivers

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 emphasized the difficulties of attending hospital appointments, especially when they have several in one 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 recognize 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 pediatric 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, personalized, 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 program (i.e., partners and patients themselves when applicable) and implementing a check-in by a healthcare provider in the first-week post-discharge.

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, humanization of the care handoff, and increased primary care provider comfort with the care of CMC.[24] Our program'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 program 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 program, 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 amongst the highest of all studied pediatric 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 specialized hospital and community resources.

Study Limitations

There were some notable limitations to the study. Firstly, it was conducted with a focus on an education and capacity building program (Connected Care Program) within a single setting, which could limit the transferability of the findings to other institutions. However, this study may provide insights into other hospitals providing care for technology-dependent CMC with similar programs. Secondly, this 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. Lastly, the participants in this qualitative study do not necessarily represent the breadth of all family experiences and temporally the study was influenced by pandemic related restrictions in service levels and policies that may not apply in a different context. However, the purposeful sampling allowed us to capture perspectives of a variety of the demographic, geographic, and sociocultural groups.

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 program 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 post-discharge follow-up. Future research should include the co-development and implementation of these identified opportunities for improvement to ensure a more integrated and holistic support program for FCs of CMC going home with newly initiated medical technology.

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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 1 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

Table 2. Themes and Sub-themes with Illustrative Quotes

Themes	Sub-themes	
1. 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	*"Oh, I cried. I cried and cried and cried because I do not like central venous lines. They freak me out. They're big and bulky, and it lies right into the child's heart." (SK-25)* *"It was sort of very shocking. Just overall, it was very emotional, it was something difficult to see, even though we knew that he needed it." (SK-55)* *"I was nervous, because I thought it was like a big deal. And also maybe even like something like electric, you know, connecting to his body. So I was a little bit nervous, scared." (SK-51)* *"So they suggested putting in a permanent port. And I was very against it because a close family friend actually had a stem cell treatment, ended up getting an infection and passed away from it. So knowing the risk associated with it, I just wasn't willing to treat to deal with that kind of high level risk…It's not for the faint of heart. And it's not it's not without risk." (SK-B41)* *"The GJ tube bothered me but not as much as the trach did 'cause it was more in your face…It was really hard like I had to literally overcome fears because I didn't want to go in near it 'cause in my words I was grossed out by it." (SK-7)* *"Yeah, at first when they were teaching me how to do the flush, I was very scared. I was nervous. I was really nervous because I don't want to cause my son to have an infection." (SK-25)* *"…but at first the purpose for it wasn't very well explained. And so at first it felt like we were jumping from she was just not eating and we just had to get her back to eating. But she had done just fine before this medication change to like suddenly needing a G-tube, but it felt it felt rushed…It felt like it was coming into left field, and so we were pretty like uncertain and even resistant to it*

		for the first few days before it got explained well, and then it was fine." (SK-21)
	1.2 Family caregivers' attitude towards participating in training program	*"At first, I didn't want to learn, but not everyone is entitled to nursing (at home), so the nurses told me you have to learn how to do it because they may not be around cause something could happen like X goes into distress or anything. So you have to learn. So I was like forced to learn. Even though I didn't want to, I had to." (SK-7)* *"We're mere mortals, right? We're not medical professionals. To insert something into someone else's body like an NG Tube…the thought of it is a little scary and there's a lot more comfort knowing that medical professionals going to do it, someone who has inserted many in their lives. I don't want to be the one holding him down to do it. It's such an uncomfortable experience, right? What if I do it wrong? What if I stick it down as long? So many fears." (SK-55)* *"So, I was doing a lot of trach changes at 3 1/2 years. But I really blocked this memory, and it was very hard for me to start changing the trach again. Every time…even the thought of it I would be having a panic attack. I was very, very nervous about the trach changes…So the part of taking care of the trach wasn't so bad. But actual trach changes were the worst to learn." (SK-1)* *"There were certain points during the class where I would just break down and start crying because it's just so much." (SK-25)*
2. The value of education and transition support for initiation of new medical technology	2.1 Experience of learning medical technology	*"I think the training was good in the sense that the information was readily available. The tools were there, the tools that were needed that X would be using were present. So I think for families, it's a comfort thing, right? Being discharged after a big procedure, stresses are high. I just believe that thorough training is important; that all the appropriate equipment was there which it was. The lady who did the training for us was fantastic. She was in no rush, we had as much time as we needed. I think the program in that sense was set up quite well for us." (SK-29)* *"But I received all the training that I needed and then we were at the hospital a little bit*

		longer so every time RT came with the helping me out, telling me, and refreshing my memory. So I was very, very comfortable going home." (SK-1) *"…for me, it was really great. Because initially, it's a slide presentation about what the technology is, why he needs it, why other kids use it, quite a bit of background. And then they sort of go through it with the slides. What is happening when you're flushing, why you need to flush it, And then I need to try actually doing it on this doll." (SK-55)* *"Well, everything about it is helpful in the sense of how to properly care for your kid, right? So the fact of just knowing what to look for, knowing how to properly use it, knowing how to properly clean it, and looking for the signs of infection are the main important things. So it was all well covered. She demonstrated everything quite well, and the brochure that she left with us was great."(SK-29)* *"She knew we were a little bit slow and hesitant. I think I initially booked for an hour. We went well over that time, went over like two hours. She was kind and very accommodating." (SK-B35)* *"So the classes were very helpful. Like absolutely awesome, I think those classes are amazing because even though I've done it in the past, I needed to refresh my memory. It was very helpful 'cause I got to do everything on a little doll. And then once I did everything I remembered, I know how to do that. So the part of taking care of the trach wasn't so bad." (SK-1)* *"I think it would be nice to have like a visual or pamphlet, or something just in case something were to happen, I know we have the write-up of it but just, a quick reference or even something to be like, oh, you want to go back through the training and make sure we remember everything." (SK-23)* *"Oh, it was a lot to be honest. At one point like, in one session, I feel like as a mom, you know, you're already in different environments. Right? So grabbing all that information in one session, to be honest, was a lot."(SK-1)*

	2.2 Access to education and transition support for medical technology management	*"I think the pandemic has given us the opportunity to like Zoom, for instance…Just like, send an email, hey, I'm having a complication. Then, they're like, hey, I got a Zoom link let me have a peek. Do you know what I mean? Troubleshoot it with those families online and then they can be like, yeah, this is something that you should probably make your way down to X for." (SK-29)* *"It seems like they train the parents, and unfortunately with COVID, I know there's, a limit. But, even like, if they could do like virtual classes for like, you know, like say for my sister or for X, so, they'd know a little bit more about it." (SK-23)* *"The other thing that was done that I wish was that every month, every at least three months, someone can check up on you, you know what I mean? Hey, how are you doing? How's everything doing? Do you need any help? Like, how do you feel about it… just making sure the parent is not overwhelmed. You know, I mean, and also the parent is still on the same page with the training or updated and just keep on trial that the parent is doing well with a child. (SK-51)* *"Having somebody come in and actually take a look, make sure that you do it right, in the first weeks…Because you want to get a second opinion, from a professional. Me, being like the first time doing this. You always have this question in the back of your head, did I do anything right? And like I would then look over the checklist over the checklist once or twice or three times, making sure that you do it right." (SK-B35)*
3. The challenges associated with managing new medical technology in the home	3.1 The initial transition home	*"Yeah, it's one it's definitely a totally different thing when you're in the hospital setting, But just coming home it was it was a nightmare." (SK-B41)* *"…like he's just home from the hospital. I don't know, like, you don't even, like you go from having 24/7 care. Like anything happens like a nurse runs in, so when you're at home and it's like, okay, like I know, they gave me all the information of who to call and what to call like, you're like, 'am I calling the right person, who am I like who supposed to reach out to?" (SK-B41)*

		"The other challenge at home was I have another 18 month old Another child that I was afraid would kinda grab at it. And so we had to make arrangements for that which she was always higher up that he couldn't reach her but sometimes we would hold her and then my other child could probably come in and pull the tube out…That fear was was there. Keep him away. So always under 24/7 kind of being aware of his presence near the baby. That was a challenge for us." (SK-B35) *"And we were told that the (homecare) nurse would come on the daily to do the hep-locking and to change his bandage on a weekly basis. We were told that that same day that we got home supplies would be delivered. Yeah, well fast forward to the day after we were home and I'm waiting for the hep-locks, no contact with anybody. We didn't get any materials and we didn't get any nursing care. So the entire time that he was home with the line, we didn't have a nurse come at all, because there was a nursing shortage." (SK-B41)* *"So what was eight to 10 hours, like just looking during the day, just making sure it is not pulling anything that he's not touching and making sure he's not throwing up. Making sure that the tube is not out. I was going so crazy about it to be honest." (SK-51)*
	3.2 Difficulties dealing with emergencies and medical complications	*"I think that probably the one thing that we felt unprepared for was how frequent infections could be. So I think that it would be helpful to have a little bit more information. Since the G-tube was inserted, [child] has had three site infections. For us, it feels like a massive failure in terms of managing even though we're doing everything we should be doing." (SK-21)* *"Yeah, like I've never done a cap change before. Then, one day he needed it to be done, I couldn't flush his line and I couldn't get blood return because the cap was still f***** up. So I turned to my husband, I was like, I've got to do it. I've seen it done 1000 times. I can do it. I was just really nervous about it because what if I mess up." (SK-25)*

		"Whereas, I wish there was a direct line to someone on call…I know there's a lot of kids that have PICC lines at X, but someone part of the discharge team that we could call and say this is the scenario we're running into right now, can we troubleshoot this with you? Or should we come down? Just because we live at a great distance, a couple of hours away, right? So, for us to go down and go to the emergency room and have them check it, and then it'd be something so simple. That's four hours, and the gas involved in the time and dragging me out in the middle of the pandemic and stuff." (SK-29) *"Yeah, like I've never done a cap change before. Then, one day he needed it to be done, I couldn't flush his line and I couldn't get blood return because the cap was still f***** up. So I turned to my husband, I was like, I've got to do it. I've seen it done 1000 times. I can do it. I was just really nervous about it because what if I mess up." (SK-25)* *"like nobody was answering that was on top of the stress like I couldn't get ahold of anyone. It's like press zero if you if it's urgent I kept pressing zero and I would get voicemail no matter what I did I would get voicemail." (SK-B41)* *"I do wish, as I said before, if we had someone more direct to reach out to that was part of that team of people who did the training. That were part of the discharge, I think that would be more helpful for someone like me, I can troubleshoot and we can figure it out." (SK-29)*
	3.3 Increased emotional and financial burden among family caregivers	*"I get up at 6:00 o'clock. Then it's either me or the nurse that starts the feed, it depends. If the nurse is here, because we only have her for four nights, then she starts the meds and his feed. When she's not here, it's all up to me. And she will do the diaper change also. But I get up and I'll do the sponge bath for him before he goes to school. I do the trach care when she's not here because I'm usually sleeping. So I have to do the trach care so the dressing and change the inner cannula, and then I dressed him up. And I put him to the wheelchair, and then I have to prepare his feed for lunch for the school and make sure that he has all his emergency app*

		which is the trach and the G tube line with him. Make sure that his backpack is filled with catheters, suction catheter, and Younkers, syringes, dressings, and then he also needs his oxygen tank with him and oximeter, and of course his suction machine and a ventilator. Then we wait for the school nurse to show up and then she goes on the bus with him and she goes to school with SK1." (SK-1) *"I think we're probably pretty burnt out. I think that would be fair to say that we're very burnt out. And also it's worth it. So you know SK-21 is so much healthier with her technology than without it that it's worth it to do it and we're burnt out." (SK-21)* *"My life changed a lot too. I was always a caregiver because X was always disabled but before he didn't require 24 hour watch. I could leave him with one of my son's or my daughter-in-law. I could be gone all day and she could be taking care of him like a regular child. With X having a tracheostomy, I can only leave him with a nurse or another person who's trained. (SK-1)* *"I always feel like I'm running around like a chicken with their head cut off. I'm running from one area to another area, maintain a household, cook, clean and watch him. So it's just like, my sanity is when I go to bed at night. That's my time. But during the day it's literally chaos. Like if he's throwing up, then I have to think "why are you throwing up, was it too much feed?". You know you're always questioning and second guessing yourself. It's a lot of work, it really is." (SK-7)* *"It's parents like me that are falling through the cracks, and it's just like, we're just waiting for mom to have a mental break for her to just lose her mind. It's gotten close. It's really close to the point where I just want to put my kid in his room with his toys, close the door, and just sit outside for 20 minutes." (SK-25)* *"Where do I start? We don't have enough funding. There's nothing for caregivers. For example, I'm a single parent. I can't work really. It's very difficult for me to find employment and there's no financial support*

		for caregivers. Zero. Then another thing, medical supplies are very expensive. I still cannot get the grants for medical supplies. It takes forever and we left the hospital in May. In order to get medical supplies, I have to borrow money from my family and max out my credit cards." (SK-1)

Contributors Statement Page

Dr Reshma Amin and Dr Julia Orkin conceptualized and designed the study, and critically reviewed and revised the manuscript for important intellectual content.

Stephanie Chu, Krista Keilty and Dr Eyal Orkin were involved in the study design and critically reviewed and revised the manuscript for important intellectual content.

Natalie Pitch, Sam Mekhuri, Munazzah Ambreen designed the data collection instruments, and collected data. Dr Reshma Amin provided oversight for all of the data collection.

Natalie Pitch and Anam Shahil analyzed the qualitative data independently and discussed it with Dr Reshma Amin to agree on the major themes and categories.

Anam Shahil and Natalie Pitch 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.

Description of the Connected Care Program

The Connected Care Program is located at Canada's largest pediatric hospital, The Hospital for Sick Children, and was developed to support transitions from hospital to home and improve pediatric homecare for CMC, their families and healthcare providers. After discharge from hospital, these CMC are cared for by FCs and some receive provincially or privately funded home care services. The program was iteratively developed with guidance from patients, FCs, providers, and policy makers with expertise in the care and transition of CMC to home and community care. To support FCs whose children are initiated on medical technology in hospital, the Connected Care Program provides FC and homecare provider education prior to discharge. The novel training program combines theoretical content with the application of knowledge and skills using simulation to support FCs as they prepare to transition home. It leverages a standardized evidence-based curriculum that is delivered by hospital-based pediatric nurses who have extensive experience with clinical teaching and management of medical technology.

The specific teaching received by FCs depends on the technology used by their children but can include nasogastric tube care, tube feeding, tracheostomy care, suctioning, central venous line care, among other types of care. FCs learn how to manage the technology, manage potential equipment failure or malfunctioning, and identify scenarios that require emergency care. It is delivered one-on-one in a safe 'home like' learning environment away from the child's bedside that limits interruptions and is personalized to meet the unique learning needs of families. In addition, services include scheduled nurse and/or respiratory therapist-led virtual visits after discharge with FCs. There is also 24/7 access to nurse-led consultations by text, talk or video for homecare nurses of CMC for questions about medical technology education and practice. This approach aims to promote access to innovative education supports in transition from hospital to home and build competence and confidence in FCs and homecare providers (i.e., nurses) to safely manage the child's new medical technology at home.

Connected Care Study Guide – Family Caregiver Experience

Part 1: Pre-hospital preparedness

1. Let's talk about when you were in the hospital – can you tell me about the technology that your child was started on?

2. Can you tell me about your experience learning to care for your child's new medical technology?
    a. [Can prompt]: Can you elaborate on what you learned?
    b. [Can prompt]: Did you receive teaching in the hospital, or at bedside, or in a classroom?
    c. [Can prompt]: Was the teaching in one session or split across sessions?
    d. [Can prompt]: What was most helpful about the training that you received?
    e. IF VIRTUALLY:
        i. [Can prompt]: What was it like to receive the training through zoom?
        ii. [Can prompt]: Do you think it would have been different to have the training in person?
        iii. [Can prompt]: Were you watching or were you able to practice with a mannequin?
    f. [Can prompt]: Was there anyone else in your household that received the training?

3. Before you left the hospital, did you feel like you had enough training before you went home?
    a. Did you feel like you had enough practice and had the tools to succeed?
    b. Now that you've gone home, do you feel like there was anything missing from the training you received?

4. What didn't go well in preparing for your child's care at home?
    a. Do you think there was anything else that could have made you more confident?

Part 2: Home readiness experience

5. Let's talk about after you were discharged from the hospital - Can you tell me about an average day in your life caring for your child using a medical technology at home?
    a. How does your new medical new technology fit into your day?
    b. How do you stay organized with all that you have to handle?
    c. How are you managing or coping?

6. Which aspects of your CCP training are you using on an average day?
    a. Is there any extra training or preparation you could have had in the hospital that would make a day like this a bit easier?

Part 3: Access and supports

7. Now let's talk about your supports at home – how is it going with your home care nurses?
    a. Do you think they feel comfortable caring for your child?
    b. Are you confident in their skills as they care for your child's technologies?
    c. Have you had any issues with your homecare support, such as cancelled shifts or nurses falling asleep during their night shift?

8. Connected Care offers home care nurses access to call them 24/7. Do you know if your home care team used this service?
    a. Can you tell me about any of your nurse's experiences communicating post-discharge with the 24/7 hotline or by e-mail or over the phone? Are you aware of any?
    b. Have you spoken with your homecare nurses about their experience? Were you aware of the program (prompt Connected Care live)?

9. Let's talk about your life at home. Often children recently discharged from hospital with new medical technologies may experience trouble or complications with the technology. Can you tell me if you have experienced this and what happened?
    a. [*Can prompt*] Did you need to go to the hospital?
    b. [*Can prompt*] What was your experience finding education and resources? Did you feel that your needs were identified and met?
    c. Which materials or resources were especially helpful for you?
    d. Which of the connected care materials did you make use of? If any, do you have any feedback to share about these?
    e. Is there anything that would have been helpful that you didn't have?
    f. Do you feel prepared for handling emergencies?

10. Apart from the complications we discussed, have you experienced any other 'bad days' with the technology? Perhaps where your child had a medical emergency or an equipment failure or just a day that went sideways.
    a. Is there anything that would have helped you get through this day?
    b. Help us understand how we can better support families who are caring for a child with a new medical technology at home?

11. We are coming to the end of the interview, do you have any additional questions or thoughts?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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

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

Short title: Caring for children with medical technology at home

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ABSTRACT:

Objectives*:* This qualitative descriptive study explores the experiences of family caregivers (FCs) of children with medical complexity (CMC) 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 analyze 14 semi-structured interviews with a group of FCs composed of 11 mothers and 3 fathers. Content analysis was used to analyze transcripts of the caregiver interviews. The study was conducted at a tertiary pediatric 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 realization 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 program that provides longitudinal support for all aspects of care.

What is already known on this topic:

- Family caregivers of technology-dependent CMC experience several challenges in their transition home from hospital, especially related to medical technology complications

What this study adds:

- A training program 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 programs 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 post-discharge 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 hospitalizations, 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 hospitalization 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 program called Connected Care on acute healthcare utilization 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 program 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 semi-structured interviews with FCs. Data were collected between December 2020 and May 2022. Institutional research board approval was obtained [Research Ethics Board number 1000064641]. 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 (e.g., 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 specialized care, substantial healthcare needs, functional limitations, and high healthcare resource utilization. (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 enrollment. 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 pediatric hospital, The Hospital for Sick Children, and was developed to support transitions from hospital to home and improve pediatric homecare for CMC, their families and healthcare providers. (16) Please refer to Supplementary Material 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 an average distance to hospital. Qualitative data collection included individual semi-structured 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 Supplementary Material 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 de-identified by a professional transcriptionist. Qualitative data analysis software (NVivo 12 Plus) was used for data and coding management. Conventional content analysis was used to analyze the transcripts. (17) The inductive, 4-step content-analysis process was conducted to identify, code, and categorize 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, 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 sub-themes and later categories and sub-themes were grouped under major themes. Finally, the main themes and sub-themes were discussed among the reviewers (AS, NP, RA) until agreement on the themes was achieved and reflected the entire dataset. Methodologic rigor was established through prolonged engagement and peer debriefing, and according to The Consolidated Criteria for Reporting Qualitative Research (Supplementary Material 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 semi-structured interviews conducted, 3 were with fathers and 11 were with mothers. Each of these interviews lasted between 30 and 60 minutes. The demographic and clinical information for the children of participating FCs is also shown in Table 1.

Framework for Experiences of Family Caregivers 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 sub-themes are outlined in summary Table 2. Please refer to Supplementary Material 4 for the full Table 2 with illustrative quotes.

1. Family Caregivers' Response and Readiness for Medical Technology Use

1.1 Family caregivers' 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.

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

2. The value of education and transition support for initiation of new medical technology

2.1 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.

2.2 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 program, 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 the program 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 program. FCs suggested expanded access with virtual sessions to be available to other groups of FCs such as partners, siblings, grandparents as well as patients (i.e., medically complex children) if they were willing to learn. To improve transition support, some FCs who did not receive them suggested the implementation of standardized longitudinal follow-up visits from members of the training program following discharge to ensure FCs are coping well.

3. The challenges associated with managing new medical technology in the home

3.1 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. Further, a couple of FCs noted that they had difficulty ordering supplies or accessing different equipment at home compared to 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 organized 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.

3.2 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.

3.3 Increased emotional and financial burden among family caregivers

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 emphasized the difficulties of attending hospital appointments, especially when they have several in one 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 recognize 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 pediatric 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, personalized, 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 program (i.e., partners and patients themselves when applicable) and implementing a check-in by a healthcare provider in the first-week post-discharge.

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, humanization of the care handoff, and increased primary care provider comfort with the care of CMC. (24) Our program’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 program 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 program, 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 amongst the highest of all studied pediatric 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 specialized 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 generalizability 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 to those who declined, introducing selection bias. The study was conducted at a tertiary pediatric 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.

Further, 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 favorable. The study focused on the experiences of family caregivers 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 pediatric 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 program 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. Lastly, 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 programs for these caregivers. The small sample size, limited generalizability, 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 upon 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 program 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 post-discharge follow-up. Future research should include the co-development and implementation of these identified opportunities for improvement to ensure a more integrated and holistic support program for FCs of CMC going home with newly initiated medical technology.

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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 1 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

Table 2. Themes and Sub-themes

Themes	**Sub-themes**
1. 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 program
2. 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
3. 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

Contributors Statement Page

Dr Reshma Amin and Dr Julia Orkin conceptualized and designed the study, and critically reviewed and revised the manuscript for important intellectual content.

Stephanie Chu, Krista Keilty and Dr Eyal Orkin were involved in the study design and critically reviewed and revised the manuscript for important intellectual content.

Natalie Pitch, Sam Mekhuri, Munazzah Ambreen designed the data collection instruments, and collected data. Dr Reshma Amin provided oversight for all of the data collection.

Natalie Pitch and Anam Shahil analyzed the qualitative data independently and discussed it with Dr Reshma Amin to agree on the major themes and categories.

Anam Shahil and Natalie Pitch 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.

Description of the Connected Care Program

The Connected Care Program is located at Canada’s largest pediatric hospital, The Hospital for Sick Children, and was developed to support transitions from hospital to home and improve pediatric homecare for CMC, their families and healthcare providers. After discharge from hospital, these CMC are cared for by FCs and some receive provincially or privately funded home care services. The program was iteratively developed with guidance from patients, FCs, providers, and policy makers with expertise in the care and transition of CMC to home and community care. To support FCs whose children are initiated on medical technology in hospital, the Connected Care Program provides FC and homecare provider education prior to discharge. The novel training program combines theoretical content with the application of knowledge and skills using simulation to support FCs as they prepare to transition home. It leverages a standardized evidence-based curriculum that is delivered by hospital-based pediatric nurses who have extensive experience with clinical teaching and management of medical technology.

The specific teaching received by FCs depends on the technology used by their children but can include nasogastric tube care, tube feeding, tracheostomy care, suctioning, central venous line care, among other types of care. FCs learn how to manage the technology, manage potential equipment failure or malfunctioning, and identify scenarios that require emergency care. It is delivered one-on-one in a safe ‘home like’ learning environment away from the child’s bedside that limits interruptions and is personalized to meet the unique learning needs of families. In addition, services include scheduled nurse and/or respiratory therapist-led virtual visits after discharge with FCs. There is also 24/7 access to nurse-led consultations by text, talk or video for homecare nurses of CMC for questions about medical technology education and practice. This approach aims to promote access to innovative education supports in transition from hospital to home and build competence and confidence in FCs and homecare providers (i.e., nurses) to safely manage the child’s new medical technology at home.

Connected Care Study Guide – Family Caregiver Experience

Part 1: Pre-hospital preparedness

1. Let’s talk about when you were in the hospital – can you tell me about the technology that your child was started on?

2. Can you tell me about your experience learning to care for your child’s new medical technology?
    a. [Can prompt]: Can you elaborate on what you learned?
    b. [Can prompt]: Did you receive teaching in the hospital, or at bedside, or in a classroom?
    c. [Can prompt]: Was the teaching in one session or split across sessions?
    d. [Can prompt]: What was most helpful about the training that you received?
    e. IF VIRTUALLY:
        i. [Can prompt]: What was it like to receive the training through zoom?
        ii. [Can prompt]: Do you think it would have been different to have the training in person?
        iii. [Can prompt]: Were you watching or were you able to practice with a mannequin?
    f. [Can prompt]: Was there anyone else in your household that received the training?

3. Before you left the hospital, did you feel like you had enough training before you went home?
    a. Did you feel like you had enough practice and had the tools to succeed?
    b. Now that you’ve gone home, do you feel like there was anything missing from the training you received?

4. What didn’t go well in preparing for your child’s care at home?
    a. Do you think there was anything else that could have made you more confident?

Part 2: Home readiness experience

5. Let’s talk about after you were discharged from the hospital - Can you tell me about an average day in your life caring for your child using a medical technology at home?
    a. How does your new medical new technology fit into your day?
    b. How do you stay organized with all that you have to handle?
    c. How are you managing or coping?

6. Which aspects of your CCP training are you using on an average day?
    a. Is there any extra training or preparation you could have had in the hospital that would make a day like this a bit easier?

Part 3: Access and supports

7. Now let’s talk about your supports at home – how is it going with your home care nurses?
    a. Do you think they feel comfortable caring for your child?
    b. Are you confident in their skills as they care for your child’s technologies?
    c. Have you had any issues with your homecare support, such as cancelled shifts or nurses falling asleep during their night shift?

8. Connected Care offers home care nurses access to call them 24/7. Do you know if your home care team used this service?
    a. Can you tell me about any of your nurse's experiences communicating post-discharge with the 24/7 hotline or by e-mail or over the phone? Are you aware of any?
    b. Have you spoken with your homecare nurses about their experience? Were you aware of the program (prompt Connected Care live)?

9. Let's talk about your life at home. Often children recently discharged from hospital with new medical technologies may experience trouble or complications with the technology. Can you tell me if you have experienced this and what happened?
    a. [*Can prompt*] Did you need to go to the hospital?
    b. [*Can prompt*] What was your experience finding education and resources? Did you feel that your needs were identified and met?
    c. Which materials or resources were especially helpful for you?
    d. Which of the connected care materials did you make use of? If any, do you have any feedback to share about these?
    e. Is there anything that would have been helpful that you didn't have?
    f. Do you feel prepared for handling emergencies?

10. Apart from the complications we discussed, have you experienced any other 'bad days' with the technology? Perhaps where your child had a medical emergency or an equipment failure or just a day that went sideways.
    a. Is there anything that would have helped you get through this day?
    b. Help us understand how we can better support families who are caring for a child with a new medical technology at home?

11. We are coming to the end of the interview, do you have any additional questions or thoughts?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Table 2. Themes and Sub-themes with Illustrative Quotes

Themes	**Sub-themes**	
1. 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	*"Oh, I cried. I cried and cried and cried because I do not like central venous lines. They freak me out. They're big and bulky, and it lies right into the child's heart." (SK-25)* *"It was sort of very shocking. Just overall, it was very emotional, it was something difficult to see, even though we knew that he needed it." (SK-55)* *"I was nervous, because I thought it was like a big deal. And also maybe even like something like electric, you know, connecting to his body. So I was a little bit nervous, scared." (SK-51)* *"So they suggested putting in a permanent port. And I was very against it because a close family friend actually had a stem cell treatment, ended up getting an infection and passed away from it. So knowing the risk associated with it, I just wasn't willing to treat to deal with that kind of high level risk…It's not for the faint of heart. And it's not it's not without risk." (SK-B41)* *"The GJ tube bothered me but not as much as the trach did 'cause it was more in your face…It was really hard like I had to literally overcome fears because I didn't want to go in near it 'cause in my words I was grossed out by it." (SK-7)* *"Yeah, at first when they were teaching me how to do the flush, I was very scared. I was nervous. I was really nervous because I don't want to cause my son to have an infection." (SK-25)* *"…but at first the purpose for it wasn't very well explained. And so at first it felt like we were jumping from she was just not eating and we just had to get her back to eating. But she had done just fine before this medication change to like suddenly needing a G-tube, but it felt it felt rushed…It felt like it was coming into left field, and so we were pretty like uncertain and even resistant to it for the first few days before it got explained well, and then it was fine." (SK-21)*

	1.2 Family caregivers' attitude towards participating in training program	*"At first, I didn't want to learn, but not everyone is entitled to nursing (at home), so the nurses told me you have to learn how to do it because they may not be around cause something could happen like X goes into distress or anything. So you have to learn. So I was like forced to learn. Even though I didn't want to, I had to." (SK-7)* *"We're mere mortals, right? We're not medical professionals. To insert something into someone else's body like an NG Tube…the thought of it is a little scary and there's a lot more comfort knowing that medical professionals going to do it, someone who has inserted many in their lives. I don't want to be the one holding him down to do it. It's such an uncomfortable experience, right? What if I do it wrong? What if I stick it down as long? So many fears." (SK-55)* *"So, I was doing a lot of trach changes at 3 1/2 years. But I really blocked this memory, and it was very hard for me to start changing the trach again. Every time…even the thought of it I would be having a panic attack. I was very, very nervous about the trach changes…So the part of taking care of the trach wasn't so bad. But actual trach changes were the worst to learn." (SK-1)* *"There were certain points during the class where I would just break down and start crying because it's just so much." (SK-25)*
2. The value of education and transition support for initiation of new medical technology	2.1 Experience of learning medical technology	*"I think the training was good in the sense that the information was readily available. The tools were there, the tools that were needed that X would be using were present. So I think for families, it's a comfort thing, right? Being discharged after a big procedure, stresses are high. I just believe that thorough training is important; that all the appropriate equipment was there which it was. The lady who did the training for us was fantastic. She was in no rush, we had as much time as we needed. I think the program in that sense was set up quite well for us." (SK-29)* *"But I received all the training that I needed and then we were at the hospital a little bit longer so every time RT came with the*

		helping me out, telling me, and refreshing my memory. So I was very, very comfortable going home." (SK-1) *"…for me, it was really great. Because initially, it's a slide presentation about what the technology is, why he needs it, why other kids use it, quite a bit of background. And then they sort of go through it with the slides. What is happening when you're flushing, why you need to flush it, And then I need to try actually doing it on this doll." (SK-55)* *"Well, everything about it is helpful in the sense of how to properly care for your kid, right? So the fact of just knowing what to look for, knowing how to properly use it, knowing how to properly clean it, and looking for the signs of infection are the main important things. So it was all well covered. She demonstrated everything quite well, and the brochure that she left with us was great."(SK-29)* *"She knew we were a little bit slow and hesitant. I think I initially booked for an hour. We went well over that time, went over like two hours. She was kind and very accommodating." (SK-B35)* *"So the classes were very helpful. Like absolutely awesome, I think those classes are amazing because even though I've done it in the past, I needed to refresh my memory. It was very helpful 'cause I got to do everything on a little doll. And then once I did everything I remembered, I know how to do that. So the part of taking care of the trach wasn't so bad." (SK-1)* *"I think it would be nice to have like a visual or pamphlet, or something just in case something were to happen, I know we have the write-up of it but just, a quick reference or even something to be like, oh, you want to go back through the training and make sure we remember everything." (SK-23)* *"Oh, it was a lot to be honest. At one point like, in one session, I feel like as a mom, you know, you're already in different environments. Right? So grabbing all that information in one session, to be honest, was a lot."(SK-1)*

	2.2 Access to education and transition support for medical technology management	*"I think the pandemic has given us the opportunity to like Zoom, for instance…Just like, send an email, hey, I'm having a complication. Then, they're like, hey, I got a Zoom link let me have a peek. Do you know what I mean? Troubleshoot it with those families online and then they can be like, yeah, this is something that you should probably make your way down to X for."* (SK-29) *"It seems like they train the parents, and unfortunately with COVID, I know there's, a limit. But, even like, if they could do like virtual classes for like, you know, like say for my sister or for X, so, they'd know a little bit more about it."* (SK-23) *"The other thing that was done that I wish was that every month, every at least three months, someone can check up on you, you know what I mean? Hey, how are you doing? How's everything doing? Do you need any help? Like, how do you feel about it… just making sure the parent is not overwhelmed. You know, I mean, and also the parent is still on the same page with the training or updated and just keep on trial that the parent is doing well with a child.* (SK-51) *"Having somebody come in and actually take a look, make sure that you do it right, in the first weeks…Because you want to get a second opinion, from a professional. Me, being like the first time doing this. You always have this question in the back of your head, did I do anything right? And like I would then look over the checklist over the checklist once or twice or three times, making sure that you do it right."* (SK-B35)
3. The challenges associated with managing new medical technology in the home	3.1 The initial transition home	*"Yeah, it's one it's definitely a totally different thing when you're in the hospital setting, But just coming home it was it was a nightmare."* (SK-B41) *"…like he's just home from the hospital. I don't know, like, you don't even, like you go from having 24/7 care. Like anything happens like a nurse runs in, so when you're at home and it's like, okay, like I know, they gave me all the information of who to call and what to call like, you're like, 'am I calling the right person, who am I like who supposed to reach out to?"* (SK-B41)

		"The other challenge at home was I have another 18 month old Another child that I was afraid would kinda grab at it. And so we had to make arrangements for that which she was always higher up that he couldn't reach her but sometimes we would hold her and then my other child could probably come in and pull the tube out…That fear was was there. Keep him away. So always under 24/7 kind of being aware of his presence near the baby. That was a challenge for us." (SK-B35) *"And we were told that the (homecare) nurse would come on the daily to do the hep-locking and to change his bandage on a weekly basis. We were told that that same day that we got home supplies would be delivered. Yeah, well fast forward to the day after we were home and I'm waiting for the hep-locks, no contact with anybody. We didn't get any materials and we didn't get any nursing care. So the entire time that he was home with the line, we didn't have a nurse come at all, because there was a nursing shortage." (SK-B41)* *"So what was eight to 10 hours, like just looking during the day, just making sure it is not pulling anything that he's not touching and making sure he's not throwing up. Making sure that the tube is not out. I was going so crazy about it to be honest." (SK-51)*
	3.2 Difficulties dealing with emergencies and medical complications	*"I think that probably the one thing that we felt unprepared for was how frequent infections could be. So I think that it would be helpful to have a little bit more information. Since the G-tube was inserted, [child] has had three site infections. For us, it feels like a massive failure in terms of managing even though we're doing everything we should be doing." (SK-21)* *"Yeah, like I've never done a cap change before. Then, one day he needed it to be done, I couldn't flush his line and I couldn't get blood return because the cap was still f***** up. So I turned to my husband, I was like, I've got to do it. I've seen it done 1000 times. I can do it. I was just really nervous about it because what if I mess up." (SK-25)*

		"Whereas, I wish there was a direct line to someone on call…I know there's a lot of kids that have PICC lines at X, but someone part of the discharge team that we could call and say this is the scenario we're running into right now, can we troubleshoot this with you? Or should we come down? Just because we live at a great distance, a couple of hours away, right? So, for us to go down and go to the emergency room and have them check it, and then it'd be something so simple. That's four hours, and the gas involved in the time and dragging me out in the middle of the pandemic and stuff." (SK-29) *"Yeah, like I've never done a cap change before. Then, one day he needed it to be done, I couldn't flush his line and I couldn't get blood return because the cap was still f***** up. So I turned to my husband, I was like, I've got to do it. I've seen it done 1000 times. I can do it. I was just really nervous about it because what if I mess up."* (SK-25) *"like nobody was answering that was on top of the stress like I couldn't get ahold of anyone. It's like press zero if you if it's urgent I kept pressing zero and I would get voicemail no matter what I did I would get voicemail."* (SK-B41) *"I do wish, as I said before, if we had someone more direct to reach out to that was part of that team of people who did the training. That were part of the discharge, I think that would be more helpful for someone like me, I can troubleshoot and we can figure it out."* (SK-29)
	3.3 Increased emotional and financial burden among family caregivers	*"I get up at 6:00 o'clock. Then it's either me or the nurse that starts the feed, it depends. If the nurse is here, because we only have her for four nights, then she starts the meds and his feed. When she's not here, it's all up to me. And she will do the diaper change also. But I get up and I'll do the sponge bath for him before he goes to school. I do the trach care when she's not here because I'm usually sleeping. So I have to do the trach care so the dressing and change the inner cannula, and then I dressed him up. And I put him to the wheelchair, and then I have to prepare his feed for lunch for the school and make sure that he has all his emergency app*

		which is the trach and the G tube line with him. Make sure that his backpack is filled with catheters, suction catheter, and Younkers, syringes, dressings, and then he also needs his oxygen tank with him and oximeter, and of course his suction machine and a ventilator. Then we wait for the school nurse to show up and then she goes on the bus with him and she goes to school with SK1." (SK-1) *"I think we're probably pretty burnt out. I think that would be fair to say that we're very burnt out. And also it's worth it. So you know SK-21 is so much healthier with her technology than without it that it's worth it to do it and we're burnt out." (SK-21)* *"My life changed a lot too. I was always a caregiver because X was always disabled but before he didn't require 24 hour watch. I could leave him with one of my son's or my daughter-in-law. I could be gone all day and she could be taking care of him like a regular child. With X having a tracheostomy, I can only leave him with a nurse or another person who's trained. (SK-1)* *"I always feel like I'm running around like a chicken with their head cut off. I'm running from one area to another area, maintain a household, cook, clean and watch him. So it's just like, my sanity is when I go to bed at night. That's my time. But during the day it's literally chaos. Like if he's throwing up, then I have to think "why are you throwing up, was it too much feed?". You know you're always questioning and second guessing yourself. It's a lot of work, it really is." (SK-7)* *"It's parents like me that are falling through the cracks, and it's just like, we're just waiting for mom to have a mental break for her to just lose her mind. It's gotten close. It's really close to the point where I just want to put my kid in his room with his toys, close the door, and just sit outside for 20 minutes." (SK-25)* *"Where do I start? We don't have enough funding. There's nothing for caregivers. For example, I'm a single parent. I can't work really. It's very difficult for me to find employment and there's no financial support*

		for caregivers. Zero. Then another thing, medical supplies are very expensive. I still cannot get the grants for medical supplies. It takes forever and we left the hospital in May. In order to get medical supplies, I have to borrow money from my family and max out my credit cards.” (SK-1)