

**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	<p><i>“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)</i></p> <p><i>“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></p> <p><i>“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)</i></p> <p><i>“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)</i></p> <p><i>“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)</i></p> <p><i>“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)</i></p> <p><i>“...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)</i></p>

	1.2 Family caregivers' attitude towards participating in training program	<p><i>"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)</i></p> <p><i>"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)</i></p> <p><i>"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)</i></p> <p><i>"There were certain points during the class where I would just break down and start crying because it's just so much." (SK-25)</i></p>
2. The value of education and transition support for initiation of new medical technology	2.1 Experience of learning medical technology	<p><i>"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)</i></p> <p><i>"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</i></p>

		<p><i>helping me out, telling me, and refreshing my memory. So I was very, very comfortable going home.” (SK-1)</i></p> <p><i>“...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)</i></p> <p><i>“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)</i></p> <p><i>“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)</i></p> <p><i>“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></p> <p><i>“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)</i></p> <p><i>“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)</i></p>
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	2.2 Access to education and transition support for medical technology management	<p><i>"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)</i></p> <p><i>"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)</i></p> <p><i>"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)</i></p> <p><i>"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)</i></p>
3. The challenges associated with managing new medical technology in the home	3.1 The initial transition home	<p><i>"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)</i></p> <p><i>"...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)</i></p>

		<p><i>“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)</i></p> <p><i>“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)</i></p> <p><i>“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)</i></p>
	3.2 Difficulties dealing with emergencies and medical complications	<p><i>“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)</i></p> <p><i>“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)</i></p>

		<p><i>“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)</i></p> <p><i>“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)</i></p> <p><i>“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></p> <p><i>“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)</i></p>
	3.3 Increased emotional and financial burden among family caregivers	<p><i>“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</i></p>

		<p><i>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></p> <p><i>“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)</i></p> <p><i>“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></p> <p><i>“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)</i></p> <p><i>“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)</i></p> <p><i>“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</i></p>
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