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## Caring for Technology-Dependent Children at Home: Problems and Solutions Identified by Mothers

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### 1. Introduction

The population of children who are dependent on life-sustaining medical technology in the United States is over 600,000 and continues to grow (U.S. Department of Health and Human Services, 2013). Technology-dependent children have complex, chronic conditions and are dependent on technology such as mechanical ventilation, intravenous nutrition or medication, respiratory support or nutritional support to live (Toly, Musil & Carl, 2012a; Spratling, 2015). Advances in medical technology allow technology-dependent children to live longer. Yet, the care associated with technology significantly impacts individual family members and family life on a daily basis over an indefinite period (Toly et al., 2012a; Caicedo, 2014; Caicedo, 2015).

Following the technology-dependent child's discharge to home, families begin to adjust to the change imposed by caring for a child with these complex care needs by creating a new "normal." This new normal requires that the parent respond to the situation and adapt their lifestyle to accommodate the healthcare needs of the child (Toly et al., 2012a; Knafl & Deatrck, 2003). This process, referred to as normalization in the literature, begins with accepting the reality of the child's condition and the potential lifestyle and family changes needed to manage the child's condition (Deatrck, Knafl, & Murphy-Moore, 1999; Knafl et al., 2013). When normalization is present, parents feel competent in caring for the complex healthcare needs of their children and incorporating the medical management into their family lifestyle and routines (Deatrck et al., 1999; Knafl et al., 2013; Rehm, 2005). These families adopt unique solutions for solving the problems they experience and adjust the environment to provide their children with as many everyday childhood experiences as a typical, normally developing child (Leyenaar, O'Brien, Leslie, Lindenauer, & Mangione-Smith, 2017). Families caring for a technology-dependent child at home must learn to restructure goals based on balancing daily family life with their children's required medical

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technology to keep the child stable and healthy while concomitantly maintaining a functioning family (Toly et al., 2012a; Toly, Musil & Carl, 2012b). When parents feel like they fully understand their children's medical condition, they perceive the condition management as less burdensome and have greater confidence in their parenting skills (Deatrack et al., 1999; Sav et al., 2015; Smith, Cheater, & Bekker, 2015).

Other families struggle in their normalization efforts and experience unresolved problems in the day-to-day medical management of their children's condition (Gonzalez et al., 2017; Knafl & Deatrack, 2003). Parents face challenges in balancing normalcy, family life, household needs, and medical care or treatment needs of their technology-dependent child. The constant change in the care needs of the technology-dependent child and unpredictability of the child's health status can lead parents to focus on the child's health schedule and routine to the detriment of other family roles and responsibilities (Leyenaar et al., 2017; Smith et al., 2015).

### 1.1 Study Purpose

The purpose of this study was to identify the day-to-day management problems and solutions employed by mothers of technology-dependent children. At this time, there is little information to assist parent caregivers with the day-to-day management problems they might experience while caring for their technology-dependent children at home (Dybwik, Tollali, Nielsen, & Brinchmann, 2011). Thus, exploring management problems and solutions to these problems is warranted.

## 2. Methods

### 2.1 Design

This research was one component of a larger, mixed method, institutional review board (IRB) approved study that examined the relationship between the technology-dependent children's severity of illness, the mothers' normalization efforts and depressive symptoms with family functioning in mothers caring for technology-dependent children at home (Toly et al, 2012a). In this report, a qualitative, descriptive design was employed to analyze the open-ended question regarding normalization.

### 2.2 Sample

A convenience sample of 101 mothers ( 18 years old) that was comprised of primary female caregivers (biological, foster, adoptive mother or grandmother) who cared for technology-dependent children 16 years of age at home and were able to speak and read English participated in the larger study (Toly et al, 2012a). The technology-dependent children were classified using the Office of Technology Assessment criteria (OTA, 1987): Group 1-mechanical ventilation; Group 2-intravenous nutrition/medication; Group 3-respiratory or nutritional support. Mothers of children with cancer or in the terminal stages of illness were excluded due to potential grief reactions that may be experienced with these diagnoses.

### 2.3. Measures

This report includes only responses to the qualitative portion of the mixed method study and an investigator-developed demographic questionnaire to describe the technology-dependent child and characteristics of the children's mothers. The open-ended question posed to the mothers was, *"Tell me a story about a problem you had caring for your child with special technology needs while still maintaining a normal family life and how you solved it. For example, how did you go about doing an activity that you had previously done prior to bringing your child home from the hospital while still meeting your child's needs for caregiving?"*

### 2.4. Procedures

**2.4.1. Subject screening and recruitment**—Staff members from pediatric specialty clinics at a large, Midwest children's hospital (e.g., Pulmonology, Gastroenterology, Otolaryngology, Pediatric Surgery, and Preterm Infant Follow-Up) identified the study participants. Introductory letters describing the study and requesting that the child's primary female caregiver contact the researcher, were mailed to potential participants. A research team member contacted those who did not contact the study office within two weeks to follow up. Data collections were scheduled for a private place of the mothers' choosing, such as their home, public library, or the clinical research unit.

### 2.5 Data collection

All data were collected during face-to-face interviews for the larger study (Toly et al, 2012a). After informed consent was obtained from participants, code numbers were assigned to maintain confidentiality. Participants were given a \$15 gift card following completion of the interview. This report includes only responses to the open-ended qualitative question and the investigator-developed demographic questionnaire.

### 2.6. Data analysis

Responses to the open-ended qualitative question were audio recorded and transcribed verbatim. Data analysis was performed using descriptive content analysis that included both quantitative and qualitative components (Neuendorf, 2002; Sandelowski, 2000). Two of the authors independently read participants' transcripts and marked them with key words and phrases. A list of codes was then developed using inductive analysis within each case as well across cases. These codes were then categorized to identify major themes and sub-themes then cross-checked for agreement. Then, quantitative content analysis was performed. These analyses included summing the frequency of participant responses for each theme/subtheme to describe data patterns (Sandelowski, 2000). Qualitative content analysis also was performed. These analyses included interpretation of the data contents (Sandelowski, 2000). Discrepancies in coding were resolved by discussions about participant transcripts until consensus was reached. The authors then selected illustrative quotes from the transcripts. Qualitative rigor was maintained throughout the analysis as described by Lincoln and Guba (1985), including the steps of trustworthiness: credibility (data collection by unstructured interviews), transferability (thick description) as well as confirmability (multiple researchers, audit trail) (Elo et al., 2014).

### 3. Results

#### 3.1. Sample characteristics

##### Sample Description

**Mothers.:** A total of 101 mothers met inclusion criteria (Table 1). The mothers ranged in age from 21 to 66 years old ( $M=37.87$ ,  $SD=9.42$ ) with duration of caregiving for the child at home following the child's initiation of lifesaving medical technology between 2-161 months ( $M=56.447$ ,  $SD=45.$ ). A majority of the mothers were White, Non-Hispanic, the biological mother, married or partnered, with at least some college or a baccalaureate degree. About half had a yearly family income of \$60,000.

**Children.:** The age of the technology-dependent children in the study sample (Table 2) ranged from 6.75 to 202 months ( $M=77.97$ ,  $SD= 53.25$ ). The most common technology used was gastrostomy tube, followed by tracheostomy tube, oxygen via tracheostomy collar, and nasal oxygen. Neuromuscular dysfunction (43.56%) was the most common main diagnosis of the children, followed by respiratory dysfunction (21.78%). Neuromuscular dysfunction was twice as prevalent as respiratory dysfunction.

#### 3.2 Major Themes

With respect to frequency, the interview data revealed six major themes regarding problems identified by mothers caring for technology-dependent children at home (Table 3). Further, seven major themes were unveiled regarding solutions to resolve these problems (Table 4).

**3.2.1 Identified Problem Themes.—**The major themes related to identified problems were 1) medical supply or equipment barrier, 2) personal balance, 3) disruption of family routine, 4) healthcare service scheduling, 5) safety, and 6) healthcare financing.

##### Specifics Relevant to Identified Problems

**Medical Supply or Technological Equipment Barrier.:** A medical supply or equipment barrier was the most common identified problem in the interviews. Almost half of the mothers (39.6%,  $n=40$ ) reported a problem with transporting the child and their medical technological equipment. In particular, the technological equipment was reported to be heavy and burdensome to transport outside the home. One mother said, "*[technology-dependent child] had a large ventilator that was not portable, so it was difficult to leave home with the child; difficult for [child] to participate in family activities.*" One mother reported, "*[An] overwhelming amount of equipment, made it difficult to transport [technology-dependent child],*" while another said "*we started off with a double-stroller to put everything on one side, but then we had to transfer everything into the car...it would take us a long time to go places*".

One mother said she had a problem packing up the needed technological equipment for twins who needed oxygen and tube feedings.

"You needed a second hand just to carry oxygen and worry about getting them in and out of the car...And we had to take the pulse ox machines...Then they'd move

their feet; it [pulse oximeter] was going off and then you're like, 'why is it going off? Is there something wrong? Is their oxygen in? Are they okay?' They also needed tube feedings...trying to go out and be back for the feeding, because they're not taking anything by bottle. And if you go out for the whole day event, you have to take all of the feeding tube stuff, all of your Kangaroo Pumps and your formula, and the stethoscope to check placement, and the syringes and the meds. Going out for a day, you need a U-Haul truck to take everything”.

**Personal balance.:** Personal balance was the second most commonly identified problem by 34.65% (n=35) of mothers. This included balancing the care of their technology-dependent children with the many other facets of their lives such as supervision of their well children, managing the activities of their well children and the relationship with their significant other as well as their work life and social life. One mother said,

*“I think it’s important for family or a mother who has a child with special needs to have an outside life, but it’s very hard to hold down a job when you have a child like this because of being in the hospital a lot. I personally stay there. I don’t go home. You lose your job a lot”.*

Another mother said the problem she encountered was, *“Trying to provide care for [child] while working full time”*. One mother expressed the personal balance required to take care of her child’s care needs as well as her own needs while getting ready for work,

*“The biggest challenge that I had to really overcome was pretty much setting up a routine for us and making sure, that all his needs were met, that mine were met, and then we got up in enough time, we went to bed in enough time when we had to get up early to go to work...we weren’t just, you know, frazzled.”* Others mentioned difficulty balancing their social life, *“It was difficult having visitors or friends over when medically caring for my child, because the visitors felt uncomfortable, so they stopped coming over”*.

**Disruption of family routine.:** Disruption of family routine was the third most common problem reported by the mothers. Over a quarter of them (25.74%, n=26) reported a problem incorporating the technology-dependent child’s needs into family routines. One reported a disruption in the care of her well children,

*“To maintain a normal family life was...I kind of had to neglect one of them to take care of the other one at some point. Most of the time everything was smooth, but there were times where [technology-dependent child] needed something, so I had to put [well child] off to help the other one”*.

Another added,

*“You know unfortunately when you have other kids [well children], they kind of go by the way side because you’re dealing with a very emergent situation...we tried managing our lifestyle as a family unit, even though we all were in different places at different times.”*

One mother said it was difficult to do certain activities together as a family,

“We don’t really do any other stuff apart from her and so sometimes those things that other families consider normal, aren’t normal for us, and then our whole life I guess has just been adapting to [technology-dependent child] and her needs”.

For one family, caring for a technology-dependent child meant that the father quit his job to stay home and care for the child while the mother worked outside the home,

“He got to stay home and handle everything but...it was very difficult for him to become a stay-at-home dad, and he told me...he had to learn how to take care of her and try and maintain a household during the day, which typically is not what he was used to. Sort of added a lot of stress to the family.”

**Healthcare Service Scheduling.** Healthcare service scheduling was a problem for almost a quarter of the mothers (23.76%, n=24). The scheduling issues mentioned were related to home health nursing coverage and scheduling the technology-dependent child’s needed healthcare treatments. Several mothers reported that it was problematic when the homecare nurses did not show up for the night shift or called off unexpectedly. One mother said,

“I work full-time and my husband works full-time. Sometimes the nurses call off of night shift but he needs care throughout the night...and then I sleep near his bed, and I have to get up and suction him”.

Other mothers commented on the problem of scheduling their technology-dependent children’s required treatments. One mother said,

“So the hard thing is every hour he needs to have water pushed through his Mickey Button [gastrostomy tube]. The hard thing is to try to make sure we can be there to give his fluids. We’ve done a lot of adjusting.”

Another stated,

*“The main problem has been doing things as a family including [technology-dependent child] with her pump and so forth and balancing a schedule with children at three different ages and three different activities. Traveling with the pump was not very easy...So I would often have to choose between attending an activity or sticking to a program.”*

Other mothers reported difficulty finding reliable respite care for their technology-dependent children so they could get out of the house with their significant other or other family members.

“It’s just hard when you’ve got to find somebody that knows how to take care of your child or that’s going to take care of your child the way you want your child taken care of...My siblings are scared to take care of him...It hurts a lot when you don’t have your siblings there for you. It may take a lot of stress off a person. I really don’t have the sibling support that I want to have, but I manage.”

Another mother was concerned about scheduling and the administration of required healthcare services for her technology-dependent child at school,

“[Specifically related to his gastrostomy tube] I put together all of his meds and syringes and how we do it and usually go on the first day of school and go over it with the nurse...the first days are a little hectic. So that always makes me nervous because they’re getting too much information all at once...So I try and be available that first day of school while they’re giving his meds if they want. As [technology-dependent child] gets older, it’s nice because he knows after his breakfast, he gets his meds.”

**Safety:** Safety was another problem reported by 13.86% (n=14) of mothers. Safety issues included preventing the equipment tubing from wrapping around the child at night, making sure that they hear ventilator alarms or receive timely healthcare attention as well as issues related to equipment that may place the child at risk for a decline in health status.

One mother reported that her young children, including her well children, were curious about the medical technological equipment and tried to pull it out.

“[Technology-dependent child] is a twin, so her twin was very disturbed by the fact that she had a nasogastric [NG] tube and constantly wanted to pull it out, which made it very difficult for us to ever leave them alone [together] because the NG tube did get taken out quite a few times, and trying to put that NG tube back in is a very scary thing. It was very difficult and added a lot of stress to the family. Even with a G tube, a Mickey button, didn’t make things any easier because we still had to watch that she or her brother didn’t pull the tube out”.

Another safety issue was related to the tubing for the gastrostomy tube feeding. Several mothers reported that the tubing ended up wrapping around their children at night while they slept. One mother said, *“We were having a problem with her having the tubing wrap around her neck when she woke up in the morning, and she was just a baby, so she rolled.”*

Another safety issue related to the tubing was that it could become dislodged.

“It’s a very tedious, stressful situation. We constantly have to make sure that the extensions to the G tube and J tube are either disconnected or remove them so that she can be reconnected in the car...that they’re tucked away and out of the way so they don’t get caught on things...on some piece of furniture or something and then that loosens the G/J tube”

**Healthcare financing:** Healthcare financing was a problem for 8.91% (n=9) of mothers. The healthcare financing problems include health insurance barriers, affordability of necessary tools such as vans that can accommodate medical equipment, financial issues related to medical care, and financial issues as a result of out-of-pocket medical care expenses.

One mother said that even though her child receives the Medicaid Waiver, *“He can’t get a new wheelchair, because they say he doesn’t qualify for one yet. Can’t get anybody from [nursing service program] to come ...as soon as they realize where we live [rural area] they haven’t come back...”*

Another stated,

“If I need something for his wheelchair they’ll say, ‘Here are 3 different places you can call’, but then I call and they say, ‘you have to have a physical therapist do an evaluation before we can do that’. I then try to get a physical therapist and they say ‘we can’t give you a physical therapist because of where you live’ or ‘you have to have a referral from this doctor or that doctor’. It’s a constant runaround. If I did not do the best I could to care for my child, he would...be in assisted living or not be here.”

One mother was troubled that the care they received was based on the type of insurance,

“Parents like in my situation should have more access to things that need to be given to their children. It shouldn’t matter you know ‘what type of insurance do you have?’ because we don’t ask for our children to have special needs”.

### Specifics Relevant to Identified Solutions

**Flexibility.:** Flexibility was the most frequently identified solution for 39.6% (n=40) of mothers caring for a technology-dependent child at home. Flexibility included some kind of adjustment or accommodation such as family adjustment, change in the family’s schedule or child’s medical technological equipment, activities, sleeping arrangements, experimentation/ risk taking with technological equipment or treatments, providing adaptations to accommodate the technology-dependent child in settings outside the home and parental career adjustments.

Mothers described the adjustments their family made to solve some of the problems they encountered while caring for their technology-dependent children, “*Other families are making sacrifices to accommodate familial needs all the time, and we’re no different from that*”. Another said, “*You just learn to adapt just so life can be as normal as you can when you have a child that has the specialties of equipment that you want to make sure that he’s normal and your life is normal.*”

Mothers also described flexibility in terms of changing their schedule to meet the needs of their children during the night shift when there was no nursing coverage,

“I was left without any coverage for the night shift between five and six days a week, depending on the week...what I did is I just changed my schedule around so I could stay up and do what needed to be done for her at night”.

Another mother handled lack of night shift coverage differently because both she and her spouse worked outside the home during the day,

“But there’s a risk going on there...I mean we can’t not go to sleep. If we were to choose to stay awake, the next day would be of no use to us. So, we take that risk. I’m certainly not talking about life and death risks, but because it is possible that he might need to be suctioned at night...I will stay up to provide some of the meds and treatments that he needs. Typically, I go to sleep by midnight, and he gets one or two things. He’s supposed to get one or two things in the middle of the night, but we just forego those because they’re not essential to his health ... They’re more



maintenance type things. Then my husband will get up earlier, typically around 4:00 am and provide some of his earlier care... I sleep near his bed.”

Some mothers reported that the solution for lack of night nursing coverage was changing their sleeping arrangements.

“We moved [technology-dependent child] into this addition...Our bedroom was down this hallway... We used a baby monitor to listen for his ventilator, which goes off. I was in Nursing School all day and I come home and I had no nurses at night, so trying to watch [technology-dependent child] at night, Nursing School during the day, I’m tired. I wake up to the sound of the vent on the baby monitor, but for some reason it’s turned lower than normal...I was asleep, so I didn’t hear it for a while. So when I did wake up and realize that’s his vent alarm going off and getting to his room, he has coded. I now sleep in his room. Ever since that happened, I don’t trust the baby monitor. I have a futon in his room and that’s where I sleep.”

Other mothers related how they had to adjust their career to meet the care needs of their technology-dependent children,

“We needed health insurance, so we [mother and spouse] couldn’t afford to lose our jobs...My husband went to second shift...so we were able to keep working without being at the mercy of a nurse if they called off and we took some control back into our own lives. That’s how we problem-solved to keep managing to work but have a family life.”

Sometimes flexibility with meeting employment responsibilities meant making adjustments with the technological equipment,

“I was wondering how I was going to be able to care for [technology-dependent child] and work [at a day care center] at the same time with all the needs that she had. So, I told my boss about the situation and she actually called the home care nurse for me, and she comes to the daycare and brings the equipment and provided it there [too], so she had two machines.”

Mothers addressed the need to leave the house for family activities,

“With the trach we have special equipment that we have to take with us whenever we go grocery shopping, even to church on Sunday, visiting friends. We have to take a suitcase with suction machines, an Ambu bag, extra trach, plastic gloves, a jug of water, all the essentials. It’s almost like packing a picnic basket. It’s essential-[technology-dependent child] needs it. There’s no way around it... We go through a checklist before we leave and then we just attach it to the back of her wheelchair and out the door we go.”

**Reliance on Family/Friends.:** Almost a third of mothers (29.7%, n=30) identified relying on family and friends as a solution for the problems encountered caring for a technology-dependent child at home. This included immediate and extended family support, social/friend support, community support (church, school), and support from their co-workers or boss.

Mothers often mentioned helpful assistance from their spouse/partner or other extended family members. One mother stated,

*“My grandparents helped us financially because my husband stayed home from work to be with me until I was okay to be alone. So it took a couple of months, but I finally was able to say, ‘Okay, I can do this.’”* Another said, *“I had to train family members to watch him, take care of him and know his needs and everything, because you can’t just go off and leave him with just a neighbor down the street”.*

Others found a group of other mothers with special needs children was helpful to address problems and concerns they encountered. One mother reported,

*“Networking with other parents...you have to find a group of moms...A lot of moms are out there and they know where, how to get information for their children and where to get it from, and you just all share your information together.”*

Another said,

*“You have to be very creative at [amusement park, zoo, museum] when you have a child who is on a ventilator... You have to work with the organization and find out where the First Aid Stations are...that is truly helpful. You don’t think about the First Aid Stations as being that user-friendly but those people have been trained to be very accommodating to persons who have disabilities in their families...they’re wonderful.”*

**Organization/Advance Planning.:** Organization and advance planning was identified as a combination solution for 28.71% (n=29) of mothers caring for technology-dependent children. This solution included being proactive, organizing daily life and the care of the technology-dependent child and following routines. Some mothers relayed what it is like going out to dinner as a family. *“We had to take three different bags along with us to go to dinner... It took lots of planning, lots of packing and a lot more time.”*

Many mothers found that organization and developing a routine was key,

*“It was getting a routine together for us so that our mornings, you know, went a little bit more smoothly. Making sure that he got fed, changed, washed before it’s time for me to go”.*

Another said,

*“...Being ready and organized...but we’ve focused on as long as [technology-dependent child’s] stuff is organized, then that makes the rest of the house to some degree organized. So we’ve integrated just making sure that we’re very organized, making sure that the other kids know that [technology-dependent child] is going to have emergencies, she is going to be sick, they’re going to be sick; everyone has a different degree of sickness”.*

Some mothers found organization strategies that helped them to accurately administer the numerous medications and treatment their children needed,

“I have a board that has all of [technology-dependent child’s] medications up, so I can check off which ones we’ve given for every day...The other thing we did when [child] was on a lot of meds, is my husband and I would draw up the meds in the syringes and then label them and put them in plastic bags with the day or the week on there, so then we were able to have the meds already in a bag, so we weren’t trying to draw the meds up while you’re trying to feed them and go about your normal day. It’s already right there just to pull out of the bag and go”.

Another mother described advance planning prior required for a vacation,

“I never attempted in the 10 years the [technology-dependent child] has been trached to travel by air. I called on the home equipment people who gave me suggestions...she’s like ‘I’ll get you the extra vent that you can put in a box and UPS it out there along with any supplies you need like sterile water, oxygen, heavy stuff.”

**Creativity/Improvisation.:** Close to one third of mothers (27.72%, n=28) identified creative, improvised solutions to equipment challenges or barriers including home-made devices or schedules for healthcare treatments. These solutions were discovered using trial and error to accommodate the necessary technological equipment and streamlining the child’s care delivery with the goal of keeping the technology-dependent child safe.

One mother described transporting the equipment, *“It helps having things portable so you can take the equipment with you and have her [technology-dependent child] able to go different places...go out to the park or to church.”* Another said, *“We bought a water camel which holds a small tank, and we have a backpack now for a small tank.”*

Many mothers described ingenious solutions to problems with the equipment and ways to keep their children safe with the equipment. One said, *“We had a friend of ours (welder) to make what we called the cart. It was two pieces with a quick disconnect”.* Another mother was concerned about protecting the Mickey button gastrostomy tube from being pulled out, *“when he played sports he covers his G tube to protect it. I use a big elastic thing that just wraps around him. It protects it so it doesn’t get pulled out.”*

Other mothers described improvisation while traveling with the family, *“We needed to hang her bag somewhere with her pump so we didn’t have to travel with the pole...so the removable hooks [e.g., by 3M] we just keep those with us at all times”.*

One mother created a coat that she could easily get on and off her technology-dependent child who is in a wheelchair,

“I developed a coat on my own. It’s a piece of print material...I cut holes and Velcro with cotton around it so I just have this slip-on that slips over his head and we tie it in a couple of places and it covers him from head to toe in the wheelchair...no pushing him forward to yank it across.”

**Advocacy.:** Twenty mothers (19.8%) indicated that advocacy was a solution to a problem they faced while caring for their technology-dependent children. This included advocating

for their children's needs, educating others about the child's condition and family needs and advocating for proper medical equipment and care costs to health insurance agencies. One mother talked about being an advocate for her child with the school staff,

“The schools don't have a nurse full-time, and so how comfortable would they be [with my child]? The night before Kindergarten, I was worried about his G-tube. So I typed up a letter of introduction, which turned out to be more of a small book, several pages about [technology-dependent child] and specific instructions. I also attached some medical information, places they could go for more information”.

Another mother used advocacy for her child with insurance companies to avoid additional hospitalizations and disruptions to her family life,

“There was a problem with his trach. I was trying to get coverage from insurance. They cover you to change the trach once a month, but in this case, he had pseudomonas growth so we need to change his trach twice a month so we could try to prevent the pseudomonas growth. It was very hard trying to get approval for the second trach, but if they will, it is cheaper. They can pay \$70 for another trach or pay thousands for hospitalization. They understood when we started going a lot to the hospital. It's better for me, for my family because we live far away from the hospital...there are times that in one or two weeks I could not see my [well child].”

One mother had to advocate for her daughter regarding her schooling,

“They [school administrators] made it impossible for [technology-dependent child] to attend the desirable school and they said that we had to go back to the other school. I was very offended because you know they came out with the “No Child Left Behind”. It [other school] clearly was encumbering my daughter. It was ‘take it or leave it-that is what we have to offer’. So, I got the School Board involved. It turned out that the school just wanted to save money by hiring a school nurse instead of paying for the agency nurse. It ended up that the Medicaid Waiver agreed to pick up the charge for the agency nurse to go along to the other school [to manage the trach and G-tube]. They were being negligent with my daughter's education because they thought it would cost them money.”

**Healthcare Provider Support.:** Fewer mothers (12.87, n=13) mentioned healthcare provider support as a solution. It included emotional support and respite care from home healthcare nurses, team decision making and team planning for back-up healthcare plans. Mothers relayed that the assistance of home healthcare nurses was helpful so that they could also maintain other family activities. One said, “*We had home nursing... while we were preparing for the festivities*”. Another mother stated, “*I could never do what I do without my nurses.*” The assistance from the nurses was reported to be essential for day-to-day errands, traveling or family outings.

“Vacation or traveling or just day to day running errands is hands down the biggest obstacle. So we've recruited help-a nurse. As much as we wanted to incorporate [technology-dependent child] in the family outings, we have reconciled that maybe it's just not possible. We have had to set that idea aside of doing everything as a

family and we have a nurse who comes to stay with her for family parties. On family outings, we are actually going to bring our nurse with us on little road trips.”

**Change in Perspective.:** Few mothers 5.94 (n=6) described a change in perspective as a solution. It included voicing acceptance of the technology-dependent child’s state of health, positively reframing the situation, hopefulness and belief in a higher power. One mother stated, *“Roll with the punches; don’t view it as a problem”*.

Another said,

*[Technology-Dependent Child’s] life and his illness could be looked at as negative. I look at them as difficult. Everybody has difficulties in their life, and I see opportunity in the job to teach me and my other children how to function and live joyfully in the midst of difficulties. That’s my job.”*

#### 4. Discussion

The problems identified by mothers of technology-dependent children in this study tended to be quite challenging for a parent caregiver to address, extremely cumbersome at times, co-existent, and costly. The six problem themes could be grouped as stressful situations and characterized as all requiring special skills, special knowledge, and a positive attitude to deal with effectively and efficiently. For example, keeping the technology-dependent child’s appointment schedule is a major feat and involves a high degree of skill at scheduling from mothers because the appointments are ongoing and needed in the overall monitoring of the child’s wellbeing. Trying to balance the child’s frequent appointments with family life requires that the child’s parent caregivers be knowledgeable about strategically integrating everyday life experiences into a fairly pre-set appointment schedule. Maintaining a positive attitude when caregiving conflicts and complications occur is pivotal to parent caregivers remaining hopeful and focused on long-term positive outcomes for the child and family.

The seven solution themes reflect creative problem solving and can be characterized as highly organized. The mothers’ solutions associated with their children’s problems tended to be creative, flexible, proactive, and resourceful. Parent caregivers were proactive in terms of advocating for resources to meet their children’s needs, and learning how best to make situations work so that their children could have a normal childhood; a major component of normalization (Deatrick et al., 1999; Knafl et al., 2013). They were also willing to take advantage of offers of assistance from family and friends and to use respite care when necessary. Overall, the mothers from this study appeared to be experts at juggling life events so that their technology-dependent children could be included in as many family activities as possible.

This study provided some new insights into the problems and solutions that mothers use to manage daily care of a child who is dependent on technology for survival. Past research regarding the problems parent caregivers encounter during the day-to-day management of technology-dependent children includes time demands, social isolation, lack of personal and career growth, financial issues, anxiety, depression, emotional stress and loss of privacy (Toly et al., 2012b; Caicedo, 2014; Dybwik et al., 2011; Falkson, Knecht, Hellmers, &

Metzing, 2017; Gonzalez et al., 2017; Lindahl, 2010). In this study, the most frequently reported but least previously referenced problems were medical supply and technological equipment problems and healthcare service scheduling.

Families often use specific normalization strategies unique to their lifestyles and needs to solve these problems. Frequently reported solutions to everyday management difficulties have been family support, health care provider support, social support, positive perceptions, hopefulness, establishment of routines, and organization (Edelstein, Schippke, Sheffe, & Kingsnorth, 2016; Kepreotes, Keatinge & Stone, 2010; Lindahl, 2010; Smith et al., 2015; Wang, Lin, Lee, & Lee, 2016). This study added three solutions that had not been previously identified: flexibility, advocacy and creativity/improvisation.

As identified in other studies, time demands, disruptions of routines, and scheduling conflicts are common problems experienced by parent caregivers of technology-dependent children. Time demands related to care routines limit the family's participation in school, employment, and social activities. School days are often challenging because there is less time to deal with technological equipment and administration of various treatments in the morning (Heaton, Noyes, Sloper, & Shah, 2005), especially if there are other children in the home. Incorporation of the time schedules required for the management of the child's technological needs may lead some families to forgo participation in school, employment and social activities (Gonzalez et al., 2017; Heaton et al., 2005).

Finding personal balance is challenging. Parents may need to make the difficult choice to change their career aspirations as well as quit or be fired from a job due to the care their technology-dependent children requires and the need for greater flexibility with their time (Gonzalez et al., 2017; Kirk & Glendinning, 2004). Other parents decrease their hours of employment to meet the care needs of their children (Glendinning, Kirk, Guiffrida, & Lawton, 2001). Also, parents felt the technology was not flexible, rather it was heavy, cumbersome and difficult to use (Lindahl, 2010). These are not easy choices and impact the family in imperceptible and dramatic ways that can have a big impact on the security of the family and well-being of all members.

Establishing social support networks help parents cope with their children's complex, chronic condition (Smith et al., 2015). Social support groups provide families with medical care and normalization resources (Edelstein et al., 2016; Emiliani, Bertocchi, Poti, & Palareti, 2011; Knafl, Darney, Gallo, & Angst, 2010; Popp, Robinson, Britner & Blank, 2014). Social support groups typically include families who have children with similar medical conditions that provide an opportunity to keep their children involved in social activities (Edelstein et al., 2016). Extended family members often step in to help when there are problems balancing the needs of members of the technology-dependent child's immediate family.

Adjustment of roles and responsibilities is one solution for the organization of family schedules and family life balance (Leyenaar et al., 2017). Families frequently have disruptions in child/family routines and needed to continuously make choices as to priorities (Knafl et al., 2013). Families who are proactive in managing their children's condition share

responsibility for care routines (Smith et al., 2015). Families who have routines are more likely to be organized and plan ahead (Leyenaar et al., 2017, O'Brien, 2001). Parents engage in usual parenting activities and participate in normal activities by maintaining a routine (Lee & Rempel, 2011), however it was apparent that flexibility and adaptability are key normalization strategies.

Changes in perspective or reframing the situation were among the least identified strategies for mothers in this study. Parents recognize that their children have different lives from others and describe recognition of the difference as a balancing act (Lee & Rempel, 2011). These parents adjust to new ways of living by reexamining their beliefs and values and by changing the order of priorities (Kepreotes et al., 2010). Parents who accept their children's health may be better able to envision a positive future (Kepreotes et al., 2010).

There is understanding that the whole family experiences a significant emotional impact and lifestyle change when implementing and administering daily medical care for a technology-dependent child (Toly et al., 2012a; Brenner et al., 2015; Falkson et al., 2017). The psychosocial impact on families and caretakers of technology-dependent children is described and understood throughout the literature (Toly & Musil, 2015; Edelstein et al., 2016; Gonzalez et al., 2017; Wang et al., 2016). Though psychosocial problems result from daily medical management, the problems with the medical technology equipment and care regimens are not described in depth. The problems mentioned in the literature do not focus on issues directly related to medical technology, medical procedures or medical care. The common day-to-day challenges and solutions for managing medical equipment and care regimens can be shared with families before they take children home from the hospital. Having a resource to call to troubleshoot malfunctions or challenges is useful, and may be one of the major benefits of participation in face-to-face or virtual support groups. Parent caregivers are often hesitant to tinker with the technology, but making them aware that many parents like themselves have devised creative and innovative approaches to managing equipment challenges, and that they can do the same, can bolster their confidence. Planned follow up appointments and adequate home care services also facilitate successful daily care management.

The mothers took situations "one day at a time" yet were simultaneously thinking about the future. From statements made by mothers, they seemed to quickly learn from past experiences with their children and as a result, were competent at being proactive and making sure that negative experiences were avoided in the future. Even in challenging situations, mothers maintained a positive outlook on life events and were optimistic about the future.

When a technology-dependent child's situation involved something that could have led to a safety concern, mothers clearly articulated what was needed to resolve the events leading up to and/or involved in the situation. This was particularly apparent when mothers discussed their children's heavy and burdensome yet much needed equipment. No matter how complex the situation became, few mothers verbalized that solutions could not be found.

## 5. Limitations

A major limitation of this study was that participants were solely mothers from one geographic region of the United States, which limits generalizability. Additionally, a couple of mothers identified no problems and no solutions to the open-ended question. The investigators would have liked to follow up with these mothers to see if things were going so smoothly, that no problems existed or whether they had potentially addressed all of the problems they encountered successfully and then forgot about those past experiences.

This project had a number of strengths, the greatest of which is the robust sample size from which we were able to examine the problems and solutions faced by these mothers. Although it is important to use care when applying percentages to thematic analyses, the fact that 40% of participants spoke about flexibility as a key solution highlights its importance. Flexibility is a theme that particularly resonates with the descriptions of how caregivers manage the day-to-day moments of life with a child dependent on technology.

## 6. Conclusion

Mothers of technology-dependent children and their children are highly resilient at dealing with life events in complex situations. These parent caregivers are experts at problem solving and adapting in challenging situations and need to be respected for these sophisticated capabilities. Health caregivers would be wise to listen carefully to what parents of technology-dependent children report about their activities of daily living to best recommend useful strategies verbalized by these seasoned maternal parent caregivers.

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**Table 1.**

## Demographic Characteristics of Mothers (N=101)

	n (%)
<b>Marital Status</b>	
Married	72 (71.28)
All others	29 (28.71)
<b>Mother's Relationship to child</b>	
Biological mother	86 (85.14)
Adoptive mother	8 (7.92)
Foster mother	5 (4.95)
Grandmother	2 (1.98)
<b>Mother's Education</b>	
Did Not Complete HS, Graduate	7 (6.93)
HS Graduate/Vocational Training	24 (23.76)
Partial College	31 (30.69)
Baccalaureate Degree	20 (19.8)
Graduate School	10 (9.90)
Missing	1 (.99)
<b>Race/Ethnicity</b>	
White, Hispanic/Latino	6 (5.94)
African American	17 (16.83)
White, Non-Hispanic	74 (73.26)
Asian	2 (1.98)
Bi-Racial	2 (1.98)
Missing	1 (.99)
<b>Total Yearly Family Income</b>	
<\$20,000	12 (11.88)
\$20,001-\$40,000	24 (23.76)
\$40,001-\$60,000	15 (14.85)
\$60,001-\$80,000	29 (28.71)
>\$80,001	20 (19.80)

**Table 2.**

## Descriptive Characteristics of Children (N=101)

	n (%)	M	SD
Child Age (months)	101 (100)	77.97	53.25
<b>Technology Usage</b>			
Nasogastric Tube	1 (.99)		
Gastrostomy Tube	88 (87.12)		
Intermittent intravenous infusion	6 (5.94)		
Continuous intravenous infusion	1 (.99)		
Intravenous infusion of total parenteral nutrition	3 (2.97)		
Nasal Oxygen	18 (17.82)		
Oxygen via tracheostomy collar	23 (22.77)		
Oxygen via continuous positive airway pressure	2 (1.98)		
Continuous positive airway pressure without oxygen	2 (1.98)		
Tracheostomy Tube	31 (30.69)		
Mechanical Ventilation	17 (16.83)		
<b>Main Diagnosis</b>			
Respiratory Dysfunction	22 (21.78)		
Digestive Dysfunction	17 (16.83)		
Metabolic Dysfunction	4 (3.96)		
Neuromuscular Dysfunction	44 (43.56)		
Circulatory Dysfunction	6 (5.94)		
Renal Dysfunction	2 (1.98)		
Cystic Fibrosis	6 (5.94)		

**Table 3.**

Problems: Definitions and Frequencies (N=101)

<b>Theme</b>	<b>Definition</b>	<b>Participants who Reported n (%)</b>
Medical supply or technological equipment barrier	Inclusive of transportation of child and medical technology, heavy and burdensome medical equipment, faulty medical equipment, unfamiliarity with medical equipment, noisy medical equipment, missing or poorly fitting medical equipment, reordering medical equipment or supplies	40 (39.60)
Personal balance	Inclusive of juggling the supervision of well siblings, personal lives of well siblings, childcare balance, relationship balance, work balance, social life balance	35 (34.65)
Disruption of family routine	Barriers to incorporation of the technology-dependent child's care into family routines, family adaptation issues, family member adjustment issues, learning to take turns providing medical treatment/care	26 (25.74)
Healthcare service scheduling	Issues related to scheduling appointments, seeing consistent healthcare provider, homecare scheduling	24 (23.76)
Safety	Issues related to keeping the technology-dependent child safe while using technological equipment, hearing ventilator alarms, proper connection and function of technological equipment, prompt delivery of medical care at appropriate times	14 (13.86)
Healthcare financing	Inclusive of health insurance barriers, affordability of transportation (wheelchair accessible van) that accommodates medical equipment, financial issues related to cost of technology-dependent child's medical care	9 (8.91)
No identified problem	Mother unable to identify problems with day-to-day management of technology-dependent child	1 (.99)

**Table 4.**

## Solutions: Definitions and Frequencies (N=101)

<b>Theme</b>	<b>Definition</b>	<b>Participants who Reported n (%)</b>
Flexibility	Inclusive of family adjustment; changes in family schedule, activities, sleeping arrangements; adjustment in type of technological equipment used, adjustment in timing of medical care or treatments, parental career adjustment and making accommodations for the child with medical technology in typical settings	40 (39.60)
Rely on family/friends	Inclusive of immediate family support, extended family support, social/friend support, community support (e.g., church, school), support from others with technology-dependent children and support from co-workers/boss	30 (29.70)
Organization/advance planning	Inclusive of being proactive, organizing daily life and care for the child, following routines	29 (28.71)
Creativity/improvisation	Inclusive of handmade products to resolve equipment barriers; creative schedules for delivery of needed medical care treatments; experimentation with products or techniques that promote the child's safety.	28 (27.72)
Advocacy	Inclusive of advocating for child's needs, proper medical equipment and healthcare costs; educating others about child's condition and family needs.	20 (19.80)
Healthcare provider support	Inclusive of emotional support and respite care from home healthcare nurses; healthcare provider support.	13 (12.87)
Change in perspective	Inclusive of accepting the technology-dependent child's state of health; reframing the situation positively; hopefulness; belief in a higher power.	6 (5.94)
No solution	Mothers who described problems, but unable to verbalize solutions to the stated problem.	4 (3.96)