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Living in a house of cards: Family experiences with long-term childhood technology dependence

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Abstract

Families' experiences of providing long-term home care for the child who is technology dependent were explored via parental interviews. Families identified frequent change, uncertainty, and unpredictability in their lives, a phenomenon described as "living in a house of cards." Attempts to increase stability involved the use of vigilance, advocacy, and reframing. Areas of challenge, change, and growth included making sense of life, managing daily life with technology, and maintaining a functioning family. Increased understanding of family experiences with long-term childhood technology dependence can provide nurses with additional strategies for providing optimal care to this population.

BECAUSE OF IMPROVED health care technology and treatment, more children with severe chronic conditions are surviving for longer periods of time, including those who are technology dependent. Children who are dependent on technology use a medical device to compensate for the loss of a vital body function and require substantial and ongoing nursing care to avert death or further disability (Office of Technology Assessment [OTA], 1987). Increased numbers of children who are technology dependent are now being cared for at home by parents and other caregivers. Although the actual number of children who are technology dependent and living at home is unknown, an estimated 6.5% of children in the United States are classified as having a disability (Newacheck & Halfon, 1998). Little is known about the long-term effects on families when caring for a child who is dependent on technology. Most of the research to date on family experiences with childhood technology dependence has focused on the safety and cost-effectiveness of home care and the initial transition phase from hospital to home (Aday, Aitken, & Wegener, 1988; Frates, Splaingard, Smith, & Harrison, 1985; Hazlett, 1989; Leonard, Brust, & Sielaff, 1991; Quint, Chesterman, Crain, Winkleby, & Boyce, 1990; Smith, 1995; Youngblut, Brennan, & Swegart, 1994). Several recent studies (Coffman, 1995; Murphy, 1997; Patterson, Jernell, Leonard, & Titus, 1994) have also considered the aspect of parent-professional relationships, with the conclusion that control, trust, and competence are critical issues in family adaptation and adjustment to long-term care of the child who is technology dependent.

Technology can certainly prolong the life of an individual with a chronic or life-threatening health problem; however, the financial, psychological, and emotional burden of caring for this family member at home may be overwhelming (Kirk, 1998; Lynch, 1990; Smith, 1996). The daily, unrelenting care demands of a child who is technology dependent, the continual uncertainty related to the future, the financial burden, and the lack of support systems such as counseling or respite care can be devastating to a family (Cohen, 1995; Fleming et al., 1994; Teague et al., 1993; Youngblut et al., 1994; Wegener & Aday, 1989). Some families may manage well at first. Evidence of overwhelming stress may not appear until months or even years later when the strains of caregiving within the context of other developmental transitions become too difficult to bear (Diehl, Moffitt, & Wade, 1991; Frates et al., 1985; Patterson, Leonard, & Titus, 1992). Other families develop effective strategies that enable them to continue to deal with the experience of having a child who is technology dependent as a family member (Hamlett, Walker, Evans, & Weise, 1994; Petr, Murdock, & Chapin, 1995; Scharer & Dixon, 1989; Smith, 1996).

The purpose of this study was to examine the experience of providing long-term home care for the child who is technology dependent from the family's point of view. Specific research questions for the study included (1) What does it mean to families to have a child member who is technology dependent? and (2) How do families that include a child who is technology dependent adapt to and manage daily life? The results reported here are part of a larger naturalistic study of the phenomenon of long-term childhood technology dependence (O'Brien, 1996). The sensitizing theoretical framework for the study was Kazak and Christakis' (1994) systems and social-ecological model, which is a synthesis of family systems theory, and Bronfenbrenner's (1979) model of the ecology of human development.

Research design and method

A descriptive, naturalistic design was used to answer the research questions of this study. Specifically, interpretive interactionism (Denzin, 1989) was used to guide the research design and data analysis processes. This qualitative method is used in research to examine the relationship between personal problems and the public policies and services created to address those problems.

Sample and setting

A purposive sample of 15 families, which included a child who was technology dependent, was obtained through family response to an introductory letter about the study distributed by health care agencies, social service agencies, and parent support groups. The child who was technology dependent was 3 to 12 years of age, had been dependent on technology and living at home for at least 1 year, and was medically stable at the time of the study. The sample selection continued until there was evidence of thick data description and no new data were being obtained. A total of 11 mothers and 4 parent couples (mother and father) were interviewed, and all chose to be interviewed in their homes. One family who had originally indicated interest in the study decided not to participate because of ongoing issues related to the pending adoption of the child who was technology dependent.

The demographic characteristics of the children who were technology dependent and their families varied considerably. One exception was race: All of the parents were European-American, and all of the children who were technology dependent were also European-American with the exception of one African-American child.

All of the children in the study ($N = 16$) were technology dependent as defined by the Office of Technology Assessment (1987), with 12.5% dependent on ventilators, 12.5% receiving prolonged intravenous nutritional support, and 75% needing other technologies such as tracheostomy, frequent suctioning, oxygen, or gastrostomy feedings. Over half (56%, $n = 9$) were dependent on more than one technology, and all had multiple chronic conditions. Reasons for dependence on technology varied from complications of prematurity and congenital defects such as spina bifida, to sequelae from acquired diseases (e.g., meningitis) and trauma. Ten of the children in the study were boys and 6 were girls. The children had been technology dependent and cared for at home for time periods ranging from 2 to 9 years, with an average of 5.84 years of home care while dependent on technology. All except two attended school outside of the home for at least part of the day.

Of the 15 families who participated in the study, 11 (73%) consisted of 2 biological parents, the child who was technology dependent, and 1 or more siblings. The total number of children in each family ranged from 1 to 5, with a mean of 3.27 children per family. Parents ($N = 28$) ranged in age from 26 to 52 years ($M = 36.9$). All parents had graduated from high school, with 57.1% ($n = 16$) of the parents having at least a college degree. Eleven of 15 mothers were employed outside of the home, with 4 employed on a full-time basis. Twelve of 13 fathers were employed full-time, and 1 was unemployed. All families lived in the U.S. Midwest, with many of the families (53.3%, $n = 8$) residing in urban or suburban areas.

Although all of the families received health care benefits for the child who was technology dependent through Title XIX (i.e., Medicaid), 80% received additional financial assistance to keep their child at home. Additional sources included private insurance coverage and/or financial assistance from state-funded programs for the disabled. Most families (80%, $n = 12$) used home health care services to assist them in providing care for their child. The number of care hours provided by home health personnel ranged from 3 to 18 hours per day.

Data collection

Family experiences with childhood technology dependence were explored via unstructured parental interviews. Sociodemographic data also were obtained from participants. Study procedures and instruments were evaluated in pilot home visits/interviews with 2 families who met all criteria and were included as participants in the final study.

Interviews were initiated with the grand tour question (Spradley, 1979), "How would you describe what having a child who is technology dependent in your family means to you and to your family as a whole?" Additional questions were used as probes to elicit further information. Questions in later interviews became more focused as the ongoing processes of data collection and analysis began to form the parameters of the study (Denzin, 1989; Lofland & Lofland, 1984).

Data collection and analysis procedures

After receiving approval from the Institutional Review Board for the Protection of Human Subjects, data were collected over a 7-month period. Informed consent was obtained from all participants. Interviews were audiotaped, and other observations were audiotaped as field notes in narrative form. The duration of the home visit, which included the interview and a participant observation component not addressed in this article, ranged from 3 to 7 hours, with a mean visit time of 4.2 hours. Most parent interviews took place while their child was sleeping, at school, or being cared for by another qualified provider.

All audiotaped materials were transcribed verbatim into typewritten format as soon after data collection as possible. Descriptive statistics were used to describe the sample as a whole, and demographic data were incorporated into the qualitative analysis where appropriate.

Transcribed data were analyzed by using the interpretive process outlined by Denzin (1989). This process includes the components of bracketing, construction, and contextualization. Initially, data were bracketed in an attempt to isolate, define, and analyze the key elements of the families' experiences. Construction involved classifying and ordering the phenomena to search for recurring patterns and to examine how the key elements related to each other. Data analysis techniques such as first-level coding and development of pattern codes (Miles & Huberman, 1994) were used during these phases of analysis. Finally, contextualization, a resynthesis and interpretation of the main themes, was undertaken so that what was learned about the phenomenon of family experiences with childhood technology dependence could be given meaning within the social environment in which it occurred.

The criteria of credibility, transferability, dependability, and confirmability were used to evaluate the trustworthiness, or rigor, of this study (Lincoln & Guba, 1985). Strategies used to assure rigor included (1) prolonged engagement with and observation of participants, (2) triangulation of sources and methods, (3) validation of data and interpretations with the informants during the course of the study, (4) verbatim transcription and professional member checking with transcripts, (5) purposive sampling, and (6) thick descriptions of the sample, setting, and data.

Results

Each family who participated in this study had a unique experience, yet when these experiences were compared, certain commonalities emerged. Families identified frequent change and unpredictability, phenomena that were described as “living in a house of cards,” as characterizing their lives. Areas of challenge, change, and growth identified by families included the dimensions of making sense of life, managing daily life with technology, and maintaining a functioning family.

Living in a house of cards

The goal for the families in this study with a child member who is technology dependent was to achieve some degree of stability so that optimum child and family development can be attained. The dimensions of managing daily life with technology, maintaining a functioning family, and making sense of life were essential components in the lives of these families, and a change in any one of those areas altered the balance and forced the family to restructure. Unfortunately, a change in balance is a constant element of family life with a child who is technology dependent. Families reported multiple and frequent changes in family life over the course of time, especially in the areas of child health status, schedules and routines, and family roles and responsibilities. One parent described her life in the following way:

And you can never really sit back and say, “OK, now you've done all this work. Now let's just leave it alone and it will work.” It doesn't work that way. It's daily, or there's always something that comes up that you gotta jump on somebody for. It gets very frustrating and very tiring.

The potential for frequent and unexpected change, unpredictability, and limited parental control, inherent in all dimensions of family life with technology, contributed to families' perceptions of the fragility and instability of their lives. Parents stated that no matter how carefully they planned, something unexpected could, and generally did, happen. Consequently, families felt as if they were living in a house of cards. The mother of a 10-year-old girl who has multiple technologic needs provided this perspective:

All in all, I think we have done well. Our daughter has certainly done well. We have survived. I would like to think that we are more settled now, and in some regards I believe that to be true. But I am not so unrealistic as to not know that everything hangs together by a thread. And as we try to build stability into our future, we still have, we always have, that component of everything hanging together by a thread. And it's like living in a house of cards. It does not take much and it all crumbles.

Another parent described this feeling as she spoke of her efforts to arrange for the care of her child while she worked full-time:

You have these convoluted setups, and one person doesn't show up, or one person's late, and then the person who's at the house is calling me at the office and saying, "I gotta go," and you're like, well, what can I do? That really impressed me, you know, with how fragile the whole system is. We've got our lives going, and one little piece falls out, and then splat!

Families attempted to increase the stability of their lives through three main strategies: vigilance, advocacy, and reframing. Families used these strategies with a fair amount of success, although they realized that even these strategies could not totally mitigate the cyclic and changeable nature of family life with long-term childhood technology dependence.

Vigilance

Vigilance was a universal strategy used by the families in this study to promote family equilibrium. Examples of vigilant behaviors included constant monitoring of the health status of the child who is technology dependent, close attention to the proper and timely performance of physical care and prescribed medications and treatments, and careful selection and oversight of all who interacted with the child. Parents regarded this vigilance as a positive element in family life, for it enabled them to foster child and family well-being, ascertain potential problems, and intervene in situations before they became serious or out of control. However, this constant vigilance was difficult and fatiguing for both the parents and the siblings. As one father commented, "You can try to set things on the back burner, and you can try to kind of place them out of your mind, and you can displace them with other things, but the reality is, it's still there. And it's always there."

Advocacy

Another strategy used by families was advocacy. Families functioned as advocates for the child who was technology dependent and for the family as a whole. Many parents also engaged in activities that were directed towards advocacy for other children with special needs and their families. As with many other aspects of managing life with technology, advocacy was a continuous process.

Reframing

Finally, a third strategy for promoting stability in families was that of reframing. Reframing was the most prevalent and most dynamic strategy used by the families in this study. Family members adjusted to a new and different way of living, reexamined their beliefs and values, and changed some of their priorities in life. Many families used humor to help them manage difficult situations. Other frequently mentioned coping strategies included focusing energy on achievable outcomes, looking for the positive qualities in people or situations, and maintaining hope for the future. In one mother's opinion, "When you get past the anger and the frustration and all of that stuff, and if you just have some time to count the blessings, there are so many blessings really involved."

Without a doubt, experiences with long-term childhood technology dependence had a major influence on the philosophies and worldviews of the families in this study. Parents reported that their perspectives had changed over the years and could conceivably change again in the future. The parent of a twelve-year-old boy who is technology dependent described this process:

It kind of depends where you catch me in the cycle. Right now my life is not hindered by having my son at home. To me, I view it that it's enriched, it's better for having him here. But if you'd asked me that first 5 years, I could have listed innumerable hindrances to having a handicapped child, and wondering seriously whether I would survive it.

Dimensions of family life with a child who is technology dependent

When participants were asked to describe their family life at home with a child member who was technology dependent, their responses could be categorized into four dimensions: (1) making sense of life, (2) managing daily life with technology, (3) maintaining a functioning family, and (4) negotiating with outside entities. The dimensions of making sense of life, managing daily life with technology, and maintaining a functioning family (Table 1) are presented in this article.

Table 1. Dimensions of Family Experiences With Long-Term Childhood Technology Dependence

Making sense of life
Reconciling the past and present
Changing priorities
Imagining the future
Managing daily life with technology
Child's care needs
Time management
Home environment
Maintaining a functioning family
Meeting the needs of family members
Finding time for the family
Financial considerations
Involvement of extended family and friends

According to the social ecology theory, these dimensions belong to the microsystem of the family, whereas the category of negotiating with outside entities relates primarily to the ecosystem.

Making sense of life

The first dimension of family experience with long-term childhood technology dependence involves making sense of life. Aspects of this theme include reconciling the past and present, changing priorities, and imagining the future. Participants struggled to find a reason for their child's disabilities and to incorporate the changes in their lives into their overall belief systems and perspectives on life. In general, families that included a child member who is dependent on technology attempted to accept the circumstances of their lives that could not be changed and make the best of those circumstances that could be altered.

Reconciling the past and present

One of the ways parents tried to make sense of life was to review the past and place it in perspective. Most parents eventually came to believe that having a child with special needs could have happened to any family and that they had not been singled out to be the parents of a child who was technology dependent. In fact, several parents resented other people telling them that they had a child with health problems because they were special or extraordinary people. As one mother stated, "People would come up to me and say, 'Oh, you must be such a good person to have a child like this.' And I'd say, 'If I were a little more rotten, she'd be OK?' " Finding a purpose for the events that had occurred over the years was instrumental in parents' attempts to put the past in perspective, as was being able to make positive comparisons between the child's past condition and present health or developmental status. Seeing family growth and adaptation over time was also helpful for parents in their efforts to view life as making meaningful sense.

Changing priorities

Parental expectations and priorities for the child who was technology dependent were modified and reanalyzed over the years. Parents put a high priority on their child's happiness, lack of suffering, and achievement of optimal quality of life. In addition, parents reported that having a child who is technology dependent had changed their lives to a greater degree than they had ever imagined possible. The experience caused them to re-examine what they considered important and enabled them to develop their own talents and strengths. In the words of one father, "It's brought us closer in a lot of ways, too, because it gives you a different set of values, your career's not as important, and things like that. It's more emphasis on your family, and it changes your outlook on life a little bit, I think."

Imagining the future

Parents had multiple questions and concerns about the future, both for their child and for their family as a whole. Only one mother said she deliberately tried not to think about the future because it was too uncertain. Concerns frequently mentioned by participants included the length and quality of life for the child who was technology dependent, who would care for the child in the future and whether the child would have needed financial resources, the effects of growing up with a sibling who is technology dependent on their other children, and concerns about the parent's own future health and well-being.

The primary uncertainty expressed by parents when trying to imagine the future was the quality of life of their child who was technology dependent. One mother expressed her conflicting views about her son's future as follows:

In my fantasies, I see him having independent living skills with just an administrative type person to come in and take care of ordering supplies and handling the finances...I see him holding down some type of repetitive, routine job at McDonald's or an assembly type place. But the realities are, he may very well always need to live in some kind of a sheltered care with a resident houseperson to help with personal care. And of course, on our worst days, I can't even see him as a grownup, you know. I don't see him living that long. And in

my real fantasy world, he becomes a lawyer and he sues a lot of the doctors that did things to him during the early part of his life.

In summary, families were influenced in their ability to make sense of life by multiple factors, including resolving discrepancies between predictions about their child's survival and quality of life and the actual outcomes, as well as being able to accept and grow from past experiences. Parents were uncertain in many respects about the future but tried to plan for it as best they could. The view expressed by one mother recurred throughout many of the stories told by parents: "This is reality, this is the way things are. You know, you just build around it, you do what you can do, and give it your best."

Managing daily life with technology

The second dimension, managing daily life with technology, encompassed factors such as the child's care needs, time management, and home environment. Although managing daily life with technology required skill, organization, and creativity, the families in the study were generally very expert in this area. Families became more knowledgeable about technology and more comfortable with their child's care over time.

Child's care needs

Overall, parents identified that taking care of a child who is technology dependent was not easy, but of all the things they needed to do for their child, the physical care was one of the most manageable aspects. Major areas related to the physical care needs of children dependent on technology included nutrition, respiratory status, medications, mobility, and changes in health status. Parents expressed in-depth knowledge about the various devices and treatments needed by their children and were comfortable and competent with care. Child development issues such as communication skills, self-care activities, behavioral issues, and achievement of developmental milestones were also of concern to parents. Many parents found that they did not have the time to concentrate on these areas as much as they wished because of the physical care demands of the child or because of the needs of other family members.

Time management

All of the families in this study felt that they had been forced to become more organized and use their time more effectively as a result of having a child with special health needs. However, activities that involved the child who was technology dependent were described by parents as requiring careful planning and always taking longer than anticipated. Having a set routine and time schedule for daily activities helped families use time effectively, although the inflexibility and lack of spontaneity engendered by the schedules was sometimes frustrating. Other difficulties associated with time management included frequent disruptions in child/family routines, having to make choices about prioritization of cares, and balancing the care demands of the child with the needs of other family members.

Home environment

The home environment also influenced families' abilities to successfully manage the care of a child member who was technology dependent. Parents identified both positive aspects of their home environments as well as areas that needed improvement. In general, families organized the home environment to meet the needs of the child and the child's caregivers. Evidence of technology was often apparent not only in the child's bedroom but also in common areas of the home such as the kitchen, family room, or bathroom. For example, family rooms frequently contained additional equipment such as suction machines, backup ventilators, oxygen tanks, and feeding pumps. Although this equipment was essential for the care of the child, families sometimes felt that the supplies and equipment were "taking over" the home. As one father jokingly stated, "Sometimes I think we'll have to build our own barn for her equipment storage."

In general, families adapted well to managing everyday life with technology. Parents acknowledged that the first few months at home with each new technology were difficult, but care grew easier over time. For the most part, families could see and appreciate the difference that technological devices such as tracheostomies, gastrostomy tubes, and even ventilators made in the lives of their children and in the families' abilities to care for them.

Maintaining a functioning family

The third theme, maintaining a functioning family, involved meeting the needs of family members, finding time for the family, financial considerations, and issues related to extended family and friends. Families expressed the need to structure family life in such a way that it incorporated the demands placed on it by technology but was not subsumed by them. Efforts to maintain a functioning family required family members to pay close attention to multiple, complex issues, to prioritize family needs, and to be willing and able to compromise.

Meeting the needs of family members

The presence of technology in the home influenced each and every member of the family. Families generally made the physical care and health needs of the child who was technology dependent their first priority but attempted to meet as many needs of other family members as possible. These attempts often required flexibility, creativity, prioritization, and delayed gratification, especially on the part of the primary caregivers. The mother of 4 children, 3 of whom had chronic health problems, had this perspective on the relative importance of her own needs:

N (child who is technology dependent) comes first, because he's got the most life-threatening needs. And then I'm probably outside with the wastebasket, you know, as far as my needs being met. I mean, my needs are rarely ever met...it doesn't mean you don't love your children, and you wouldn't trade them for anything, but I sure would like to be able to be like my friends, get up, go out shopping with them, have lunch, not have to worry if the nurses are going to show up for a shift....

For the majority of parents, maintaining the quality of their relationship with their spouse was very important. However, all couples felt that their relationship with their spouse had been affected by having a child with special needs. One mother described her marital relationship in this way: "So far, we've been married

almost 8 years, and it's been touch and go. I mean, our marriage has been strong, but it's been stressed, no doubt. No doubt at all." Another mother stated, "It's taken a toll on, to be honest, with Dad and I in our relationship. We basically have very little relationship anymore because I don't have the energy to have a relationship. I don't have the time anymore. And it's terrible. I mean, we've both lost out." Two of the participants in the study were divorced from the biological fathers of the child who was technology dependent, and another couple was in the process of divorcing. All three of these women identified that their marriages had dissolved in large part because of issues related to having a child with special health care needs.

Finding time for the family

Maintaining a functioning family also included trying to find time for the family to enjoy activities together as a group. Again, this was a difficult and often frustrating task to achieve. The presence of a child who was technology dependent also influenced parental decision-making related to other children, such as whether or not to have other children or when the best time to have another child would be. Some parents made a conscious decision to limit their family size after having a child with special needs, whereas other parents made an equally conscious choice to have additional children. In general, parents reported that the first pregnancy after having a child who was technology dependent was very stressful because of the fear that the next child could have health problems as well.

Financial considerations

Expenses related to having a family member who was technology dependent had a considerable influence on family life, despite the fact that medical expenses were covered by Medicaid and, in some cases, by private health insurance as well. Families paid out-of-pocket costs for items that were not covered by insurance. As one parent commented, "It is more expensive to run a household. I mean, you have lights on all the time, you have equipment on all the time, your heat is always up, and there's no such thing as turning the heat down at night."

A single parent made a powerful statement about the financial consequences of having a child with special needs:

I just did my taxes. And his direct care, receipts in hand, expenses were \$20,000 last year. And Medicaid paid his medical stuff. We're just talking about the rest, you know, and that doesn't even count the intangibles like the fact that all my vacation time went to doctors' appointments. I've borrowed against my pension and have exhausted all my resources. And now we're pretty much living day to day, and who knows what the future is going to bring.

In many parents' opinions, some of the financial expenditures they made were justified by the amount of time or trouble they saved. In the words of one father, "We just pay to get more things done. And we're left with a little more time to spend on the stuff that really matters to us as a family." Cleaning services, in-home therapies, customized vans, and the location and amenities of the family home were examples cited by parents as being worth the expense. However, not all families could afford these "extras."

Maintaining connections with extended family and friends

Extended family and, less frequently, friends served as sources of both emotional and instrumental support for families. According to one mother, “We have families that are very supportive. That helps a lot, a lot. My parents and my husband's parents both live like within 4 miles each. We wouldn't have been able to do it without them.” Several parents, however, worried about their extended families' abilities to continue to provide care for their child who was technology dependent. One father felt guilty having his parents watch his son for any length of time because his mother worried so much, did not sleep well while caring for him, and had increasing difficulty lifting him. Other parents were concerned about the health concerns of their own aging parents and how they would manage to care for them in addition to caring for their child who was technology dependent.

Some extended families and friends were not as supportive as families hoped they would be. The mother of a 12-year-old girl related her husband's family's reaction to their daughter who had become technology dependent as the result of a near-drowning incident:

And then his family is saying, “Put her away. Put her away. She's a gork. She's a vegetable. Put her away. What are you doing with her? What about your family?” It was like, all of a sudden, this child who was so wonderful to her grandfather was dead. He still talks about her like she's dead. He won't go in to see her. He just treats her like she's a nonentity.

Often, parental friendships and relationships with extended family changed over time as families devoted more time and energy to intrafamily needs and responsibilities. Decreased social relationships and decreased opportunities for socialization with friends led to feelings of isolation. Many parents dealt with these feelings by receiving support from other parents who had children with special needs. Some parents first met while in the hospital or clinic setting, whereas others interacted via formal support groups. Parents were not always able to actively participate in support groups, however, because of several factors: (1) the time of day meetings were held, (2) the child's health status, (3) the ability to find child care for the child who was technology dependent and for other siblings, and (4) the difficulties associated with bringing the child and his or her assorted equipment to the meetings. However, interactions with other parents, whether formal or informal, enabled exchange of information about the latest treatments, the reputations of health care providers, and strategies for coping with family life and technology.

Although maintaining a functioning family was challenging and often difficult, parents were able to identify positive outcomes. For example, organizational skills improved, family members developed additional positive coping strategies, and intrafamily communication increased.

Discussion and implications for nursing

The experience of family life with long-term childhood technology dependence is complex and multifaceted. The findings of this study reflect an interpretation of the participants' unique experiences with childhood technology dependence, and generalizability is limited due to the qualitative nature of the study and the characteristics of the participants. However, certain commonalities related to the major thematic areas of concern may be found.

Overall, the families in this study managed remarkably well with issues and concerns that had accumulated over the years. Having a child member who was technology dependent in one's family significantly changed individual family members as well as the family as a whole. According to Denzin (1989), this was a major epiphany, an experience that was transformational and makes one's life never the same again. Family strategies for managing life with a child member who was dependent on technology involved being flexible, making adjustments as necessary, and doing one's best. Parents felt they had choices about how to deal with life and the situations they encountered despite the constraints associated with technology.

Family life was also affected because the children who were technology dependent had all survived longer than had been predicted by health care providers. Parents attributed their child's survival to the home environment; the involvement of family and other caregivers; and their meticulous attention to the child's physical needs, technology needs, and medical treatments. This remains an area that is relatively unexplored in the literature, although there is some evidence that technology-dependent children who have greater family involvement, increased access to normal developmental experiences, and are in a home environment have improved psychological outcomes (Hamlett et al., 1994). Families need to be respected and valued for the contributions they make to the quality and length of life achieved by their children who are technology dependent.

This study supports the contention that families of children who are technology dependent share many feelings and experiences that are similar to those expressed by families who have children with other types of chronic health problems. For example, vigilance was a dominant strategy used by parents in their attempts to manage life with a child member who was technology dependent. Similarly, vigilance was found to be an important component in studies that examined other populations of children with chronic conditions (Cohen, 1995; Miles, D'Auria, Hart, Sedlack, & Watral, 1993; Ray & Ritchie, 1993). Balancing the care needs of the child with the needs of the family, parental advocacy, and reconceptualizing family values and priorities are other common elements of family life with childhood chronic illness, regardless of the particular diagnosis (Austin, 1991; Knafl, Gallo, Breitmayer, Zoeller, & Ayres, 1993).

Parents in this study viewed the lives of their children and of their families as different in many respects from those who were not affected by technology dependence, however. They did not view themselves as normal families but instead tried to establish environments and routines for themselves that incorporated and accommodated the complex aspects of life with a child member who was technology dependent. The cyclic nature of caring for a child who is dependent on technology must also be realized. It is important for families and care providers to recognize that their needs and priorities will change as the family changes, as the child grows older, or as the child's health status changes. The components of caregiving and the situational factors influencing family activities may change over time (Kazak & Christakis, 1994; Kirk, 1998; Ray & Ritchie, 1993). Thus, families may have increased needs for support, care management, or respite at particular points in the trajectory of family life with long-term childhood technology dependence.

Conclusion

In recent years, more and more children are surviving with a great need for and dependence on technological devices. Families can and do provide competent, safe care for their child members who are technology dependent, but the psychosocial impact on families remains considerable (Boland & Sims, 1996; Capen & Dedlow, 1998; Fleming et al., 1994; Kirk, 1998).

Additional research using larger and more diverse samples would be helpful to further explore family experiences with long-term childhood technology dependence. In particular, research with families of adolescents who are technology dependent is essential. Parents of several of the older children in this study mentioned the need to begin thinking about developmental issues of adolescence such as sexuality, peer relationships, independence, and vocational preparation.

Parents in this study identified managing the technological aspects of their child's care as generally the easiest aspect of family life with a child who is technology dependent. Longitudinal studies to ascertain factors involved in the process of becoming comfortable with technology, which generally occurs over the first 6 to 12 months of having the technology-dependent child at home (Murphy, 1997), should be undertaken. Continued exploration of the cyclic nature of family experiences with long-term childhood technology dependence, as well as the factors that increase or decrease the stability of family life, would also be warranted. The perceptions of families who have chosen not to provide home care for their children who are technology dependent should be examined as well to gain insight into possible differences between those families and families who have cared for their children at home.

Finally, there were multiple similarities among families with child members who were technology dependent and families with child members with other types of chronic conditions. Continued research to explicate the similarities and differences among families affected by various childhood chronic health problems is recommended.

Increased knowledge, understanding, and appreciation of the experiences of families who are living with childhood technology dependence on a daily basis can have a powerful effect on nursing practice. The nurse can make important contributions when working with this population by helping families in adjusting to long-term childhood technology dependence (Diehl, Moffitt, & Wade, 1991; Kirk, 1998); providing quality, family-centered nursing care so that parents are better able to keep their children at home (Coffman, 1995; Patterson et al., 1994); and assisting families to find the additional resources and support they may need (Capen & Dedlow, 1998; Fleming et al., 1994; Smith, Layne, & Garell, 1994). It is hoped that increased knowledge of the phenomenon of childhood technology dependence will enable families and the health care providers who interact with them to better understand the short-term and long-term effects of technology on family life; will assist nurses in empowering families in the areas of family coping, overall functioning, and quality of life; and will serve as an impetus for additional research with families with a child member who is technology dependent.

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