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Rearing The Child Who Is Technology Dependent: Perceptions of Parents and Home Care Nurses

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Abstract

ISSUES AND PURPOSE: Most children who are dependent on technology for survival live with their families at home. This study explores the perceptions of parents and home care nurses regarding rearing the technology-dependent child. **DESIGN AND METHODS:** In this qualitative study, interviews were conducted with 16 parents whose child is technology dependent and 15 registered nurses who provided home care. **RESULTS:** Rearing the child who is technology dependent is similar to but different from raising other children. Parental communication and negotiation of child-rearing expectations with home care nurses is essential. **PRACTICE IMPLICATIONS:** Improved collaboration and communication between parents and nurses may reduce parental stress and enhance development for children who are dependent on technology.

Search terms

Child rearing, home care, parent-- nurse relationships, technology dependence

A growing number of American children are dependent for their well-being and survival on sophisticated technologies and expert care, which traditionally was provided only by registered nurses and physicians in institutional settings. The number of children who are technology dependent and living at home, including children dependent on home ventilation and/or tracheostomy, has increased substantially since the early 1980s (Okun, 1995). With the assistance and support of home care nurses, parents can competently and safely care for the child who has a tracheostomy and/or requires a ventilator. In fact, the benefits of home care over institutional care in terms of the physical, emotional, and cognitive growth and development of the technology-dependent child have been supported by various studies (Kirk, 1998). Living at home normalizes the life of the child, with child rearing-an essential component of normal family life-taking place in an appropriate setting.

U.S. society expects parents to care for their children and to socialize them for adult roles and responsibilities. Elements of child rearing include providing discipline and emotional support, fostering growth and development, encouraging achievement of developmental milestones, providing safety, promoting self-care/independence, and assisting the child to develop social relationships with peers, siblings, adults, and the community (Friedman, 1998). Chronic illness in the child can affect the parental perception of child rearing and can contribute to inconsistency of child-rearing practices (Hillman, 1997; O'Brien, 2001). In addition, inconsistency in child-rearing practices between parents and home care nurses can lead to confusion in children as to what is expected of them by adult caregivers. Children who are dependent on tracheostomies and/or home ventilation are unique because they require =>4 hours of daily one-to-one skilled nursing care. Because nurses are in the home consistently for long periods of time, they participate not only in providing medical care to the child, but also in child rearing. The purpose of this study was to explore perceptions of parents and home care nurses regarding rearing the technology-dependent child.

Background

Childhood chronic illness affects all aspects of family life, leading to increased parental stress that can affect child rearing. However, there are few studies comparing the child-rearing practices of parents with chronically ill children to those of parents of healthy children. In one study (Ievers, Drotar, Dahms, Doershuk, & Stem, 1994), the parenting behaviors of mothers of children with cystic fibrosis or diabetes mellitus differed significantly from those of mothers of healthy children only in the area of limit setting. This may be due to the mother's need to focus on adherence to the medical regimen and/or to the lack of time available for limit setting.

Parents of children receiving treatment for cancer differed significantly from a normative sample in the domains of parental expectations, discipline, expression of emotion, parental concern/worry, and overprotectiveness (Hillman, 1997). The author concluded that overprotectiveness and discipline could be related to the paradox of treating a child with cancer as normal, while being simultaneously aware of the life-threatening nature of the illness. In another study (Davies, Noll, DeStefano, Bukowski, & Kulkarni, 1991), child-rearing practices of parents of children with cancer who were in long-term remission were compared to those of parents of healthy children. Mothers of children with cancer responded significantly differently from the mothers of healthy children in that mothers of children with cancer worried more about the health of their child and often were overinvolved in the child's daily activities.

As the above research studies demonstrate, chronic illness has an impact on child rearing, especially in the areas of limit setting and overprotectiveness. There is a gap in the research, however, on the impact of technology dependence on parental child-rearing practices. In addition, the influence of home care nursing on child rearing has not been studied.

Parents of children who are technology dependent identify stressors such as loss of privacy, disruption of usual family routines, and changes in family interactions related to the presence of nurses in the home (Coffman, 1995; Kirk, 1998). Nurses provide support to both the family and the child, but their very presence is disruptive to family processes (Coffman, 1997; O'Brien, 2001). Studies of families whose child requires home care nursing have focused mainly on issues of privacy and crossing boundaries.

Murphy (1997) interviewed families of technology-- dependent children who required home nursing. The primary stress factors the parents experienced due to nursing care were conflicts over authority and control, loss of privacy, judgments made by nurses to family members about the family's lifestyle, and issues surrounding control of child-rearing activities. The loss of privacy and other stressors affected the parents' interactions with other family members and with the home care nurses.

Discipline was a theme in Agazio's (1997) interviews with families whose home care nursing was terminated when the child was no longer technology dependent. The majority of parents described readjustments in discipline of the child after home care nursing ended. A few families found that maintaining discipline when nurses were no longer present was easier than they had expected.

Coffman (1995) interviewed families of technology-- dependent children receiving home nursing care, and found themes related to child rearing such as "struggling to be normal" and "sharing the child." Sharing the child was described by parents as feeling as if they were in second place as they observed the nurse express affection for the child. Coffman (1995, 1997) also found that parents wanted qualified nurse providers who showed genuine caring for their child. Family members are not likely to consult healthcare professionals, however, for child care issues such as discipline, toilet training, or nutrition (Youngblut, Brennan, & Swegart, 1994). Thus, the research cited illustrates the ambivalence parents feel about nurses assuming child-rearing activities, which is traditionally a parental role.

Few studies have addressed the specific issue of healthcare professionals' perceptions of child-rearing practices of parents of chronically ill children. Davies et al. (1991) examined professional and parental perceptions of child-rearing practices in parents of children with cancer. The results showed disparities in perceptions of child-rearing practices between the parents and the healthcare professionals, suggesting that healthcare professionals may not have the same perceptions of child rearing as parents of chronically ill children. Coffman (1997) interviewed nurses who provided home care for technology-dependent children. These nurses identified boundary issues such as needing to know when to distance oneself or join in on family activities. They also identified conflicts between nurses and parents over the child's medical needs. Child-rearing issues included the need to empower the family by facilitating the parents' efforts to be with their child, honoring family preferences for the child's involvement in family activities, and providing child-rearing information to parents.

In conclusion, the home environment is a private place for family nurturance. The presence of professional nurses in the home is not the norm; as such, it creates stress and potential role conflict for both parents and nurses (Coffman, 1995, 1997; Kirk, 1998; Murphy, 1997). Childhood technology dependence and home nursing care may change usual child-rearing patterns and the typical strategies used by parents. The specific childrearing activities in which home care nurses engage and how these activities are negotiated with parents remain largely unknown.

Methods

A descriptive, qualitative, naturalistic design was used to answer the research questions of this study. Onetime, semistructured interviews with parents (n = 16) and home care nurses (n = 15) were conducted to provide insight into the phenomenon of rearing the technology-dependent child. Specific research questions were:

1. What are parents' and home care nurses' perceptions of rearing the technology-dependent child?
2. In what ways do these perceptions vary?
3. What is the effect of technology on the ways parents and home care nurses engage in child-rearing activities?
4. How do parents negotiate aspects of child rearing with home care nurses?

Sample

Participants in this study were a convenience sample of parents of technology-dependent children and home care nurses who care for technology-dependent children. Sixteen parents, representing 14 families, and 15 nurses were interviewed, for a total sample of 31 participants. Data collection continued until saturation was reached (i.e., no new information was being obtained). Parents and the nurses who worked in their homes were not matched, although the majority of nurses interviewed had cared for the children of one or more of the parents who participated in the study.

Criteria for parental participation included (a) have a technology-dependent child between 2 and 7 years of age who has been living at home for at least 6 months prior to the study; (b) have current experience with home care nurses; and (c) be able to read and understand English. Criteria for participation for the home care nurses were (a) currently working in the home with a technology-dependent child aged 2 to 7; (b) have at least 6 months of home care experience; and (c) be able to read and understand English. In this study, technology--assisted Category I (children on mechanical ventilators) and Category III (children with tracheostomies) were used as prototypes of childhood technology dependence (Office of Technology Assessment, 1987).

Parent participants ($n = 16$) included 14 mothers and 2 fathers (age range: 24-54 years; $M = 35.9$, $SD = 8.46$). Fourteen were married and 2 were single parents. Fourteen parents were white, 1 mother was Hispanic, and 1 mother was African American. Parental education ranged from 10th grade to graduate degrees, with most parents having a college degree. The majority of mothers were not employed outside the home. Four of the 16 parents (25%) had taken a formal parenting or child-development class. Eleven of the 14 families were the biological families of a child who was technology dependent; 3 were foster or adoptive families. Only 2 of the families had no other children.

The technology-dependent children ($n = 14$) of the parents in this study ranged in age from 3 to 7 years ($M = 4.25$, $SD = 1.44$), and had been technology dependent from 1.5 to 6 years. Twelve were male and 2 were female; 9 children were white, 3 were African American, and 2 were Hispanic. All had tracheostomies, 11 of the 14 (78.6%) had gastrostomy tubes, and 2 were ventilator dependent. Diagnoses included cerebral palsy, vocal cord paralysis, chromosomal abnormalities, congenital infection, and various syndromes, with 80% (12 of 14) having some degree of cognitive and/or physical developmental delay.

Nursing care used by families in this study ranged from 20 to 120 hours per week ($M = 62.75$, $SD = 28.7$). Nine families (64%) used agency nurses, 4 families received nursing services from independent providers, and 1 family used a combination of both types. The number of nurses working with any particular family ranged from 1 to 13.

Nurse participants ($n = 15$) were female and ranged in age from 29 to 58 years ($M = 43.7$, $SD = 8.52$). Fourteen were white; one nurse declined to state her racial/ethnic background. All except one had children of her own, and one was the parent of a special needs child. The nurses had a mean of 19.6 years of nursing experience (range: 4-38 years) and a mean of 10.9 years of pediatric nursing experience (range: 2-35 years). Home care experience ranged from several months to 10 years. All were RNs, and 53.3% were BSN prepared.

Data Collection

Parents and nurses who potentially met the eligibility requirements for the study received an informational letter distributed by a regional tertiary pediatric healthcare facility, home health agency, or independent nurse provider organization in a midwestern state. Participation in the study was strictly voluntary. Individuals who indicated interest were contacted by phone to discuss the study and set up an appointment for an audiotaped interview. All participants signed an IRB-approved consent form prior to the interview.

Interviews took place in participants' homes or at another location of their choice, and lasted 45 to 90 minutes. Interviews were initiated with the following question related to child rearing in general: "As a parent/home care nurse, you know that raising a child is a very complex task. What sorts of issues come to mind when you think about child rearing in general? In relation to [technology-dependent child's name]?" Additional questions were used as probes to elicit further descriptions, such as "How is raising/parenting [technology-dependent child's name] different from parenting your other children? How is it the same?" or "Could you give me an example of a time when you had a conflict with a parent/home care nurse about some aspect of child rearing?" As the interviews progressed, questions became more structured and focused, as the ongoing processes of data collection and analysis informed the parameters of the inquiry. The interviews were audiotaped and transcribed verbatim. Sociodemographic data from parents and home care nurses were obtained.

The privacy and confidentiality of all participants in the study was ensured at each stage of the research process. Tapes were transcribed in a manner that removed identifying data. Code numbers were assigned to each participant, and only the code numbers were used in recording, transcribing, and analyzing data.

Data Analysis

The criteria of credibility, transferability, dependability, and confirmability were used to evaluate the trustworthiness, or rigor, of this qualitative study (Streubert & Carpenter, 1999). Strategies used to assure rigor included (a) engagement with parents and home care nurses who had current experience with the phenomenon of childhood technology dependence; (b) accurate transcription of data; (c) thick descriptions of the sample and data; (d) validation of interpretations with additional informants during the analysis phase of the study; and (e) separate and joint analysis and interpretation of data by the investigators (Thorne, Kirkham, & MacDonald-Emes, 1997).

All interviews were transcribed verbatim and checked for accuracy as soon after data collection as possible. Descriptive statistics were used to summarize the demographic characteristics of the sample. Transcribed data were analyzed by engaging in repeated immersions in the data prior to beginning coding, with an emphasis on synthesizing and reconceptualizing the data (Thorne et al., 1997). All interviews were read several times by each of the investigators. The researchers coded independently at first to identify and name major categories, properties, and dimensions of the data. An initial coding schema was agreed on, and the interviews were recoded as necessary. Techniques proposed by Miles and Huberman (1994) were used for data reduction, display, conclusions, and verification. During data analysis, the researchers met with a group of six mothers of technology-dependent children to validate our interpretations of the data. Two additional home care nurses were asked for their input. Connections among categories were made, and joint consensus was reached regarding major themes, patterns, and linkages.

Findings

Analysis of the data revealed two major themes: (a) rearing the child who is technology dependent is similar to but different from raising other children, with differences primarily caused by the presence of technology; and (b) parental communication and negotiation of child-rearing expectations with home care nurses are an essential, yet often challenging, component of the childrearing experience.

The Same But Different

In defining and describing child-rearing issues, almost all the parents described the overall experience of raising the child with technology needs as the same as raising any other child. As one mother stated, "He's no different than the rest of the kids, he just has a trach." However, parents also identified multiple differences in raising the child with technology. Parents described differences in the time required for provision of the child's medical care as well as differences in raising the child due to the equipment associated with the illness. In one mother's words, "You don't realize how much you take for granted when you have a healthy child as opposed to having a child who has these special needs and needs all this equipment." Several parents felt that equipment factors limited the ability of the child to participate in family activities. Child-rearing challenges such as how to respond to the child's attention-seeking behaviors of self-decannulation were reported by several mothers. A difference in the child's socialization with peers was mentioned frequently. One mother said the difficulty was in "helping him to have friendships. And it isn't naturally going to happen. He looks different. He acts different. He's not as interactive."

Parents also described differences in the emotional aspects of parenting a child with technology dependence. Participants spoke of changing their vision of the parenting role in ways such as: "His medical needs are way beyond what I ever imagined doing as a mother." Mothers described feelings of worry and concern about the child's safety and health. The mother of a 3-year-old stated: "I get scared. I'm just thinking of his safety ... his trach pops out or they're [other children] playing too rough ... or he'll stop breathing." Parental fatigue associated with provision of medical care was identified and contributed to heightened emotional responses.

Unlike the parents, few of the nurses described the experience of raising/parenting the child with technology needs as the same as raising other children. Several nurses felt that parents treated the technology-dependent child differently from the other children in their family.

One nurse stated: "They [parents] just don't use normal behavior expectations for the technology-dependent kids as you might with healthy kids." According to the nurses, differences in the treatment of the child were due to differences in parental expectations/actions because of the child's health problems, parental denial of the child's problems, or discipline that was affected because the child "had respiratory distress when disciplined."

Nurses and parents agreed that the equipment, additional time commitments, and need for trained caregivers affected the child's ability to participate in normal childhood and family experiences. The child's technological needs also affected socialization with peers. In addition, parents and nurses felt that family dynamics and privacy were affected by the presence of nurses in the home. According to one mother, "Nursing care has been my greatest difficulty. I was always a really private person. It was quite a shocker to have somebody in my house all day long that I didn't know."

Both parents and nurses identified issues related to the specific child rearing area of discipline. The majority of parents felt they disciplined their technology-dependent child in the same way as they disciplined their other children. Examples of disciplinary activities used included time-outs, taking away toys or TV privileges, and physical punishment such as hand slapping. However, all parents noted differences in the discipline used with their technology-dependent child: "With the other kids, you know, if they were getting into trouble sometimes, you could just say, 'OK, you need to sit on the couch for a minute,' and you can't do that with him. So I think that we have to kind of reinvent the wheel in a lot of ways." Half the parents felt that RNs should participate in disciplining their technology-dependent child, and the majority of these parents agreed with the type of discipline used by the RN. Only one parent specifically stated that the RN did not have any role in discipline; in two other families, parents did not approve of the type of discipline used by the nurse.

Nurse participants mentioned discipline much less frequently than parents, although similar types of disciplinary activities such as time-outs were mentioned. Interestingly, one third of the nurses felt discipline was not a pertinent child-rearing concern because the technology-dependent child was not capable of having behavioral problems that would require disciplinary action.

The mothers in the study generally felt nurses should participate in child-rearing activities. In the words of one mother, "Everything I'm doing as a parent, they're supposed to do." However, the majority of parents described specific situations in which the nurse should not participate; for example, the nurse should not call the physician. Regarding moral development, one mother stated, "Teaching him right from wrong, that's a responsibility I won't relinquish to anyone." Other parents did not feel that a nurse should be engaging in child-rearing activities if that nurse was not in the home on a regular basis. Most parents were able to describe child-rearing activities in which the nurse engaged, and some acknowledged differences between the way the mother and nurse interacted with the child. For example, one parent felt that "the nurses overprotect and treat him like a baby."

In general, the nurses believed they should participate in child-rearing activities, and described activities they performed with the children. They also described situations where they felt the nurse should not participate in child rearing. For example, the nurse's participation in child rearing should be dependent on how much the parent is in the home when the nurse is there, and the number of hours the nurse was in the home. Several of the nurses described situations in which they felt the parent had abdicated the parental role and child-rearing decisions to the nurses.

Communicating and Negotiating About Child Rearing

The communication of child-rearing expectations was seen as important by the parents. The majority of parents verbally informed the nurses of their child-rearing expectations. As one parent described the challenge in explaining her expectations to the 10 nurses involved in her child's care: "You're training them ... not on medical skills, but it's your parenting skill and I don't think that's always easy to do with another adult." Some parents had care conferences with the nurses and wrote childrearing expectations in a communication book. Several of the nurses described the parents as asking their input on child rearing; however, parents indicated it was rare for them to elicit the RN's opinion.

Parents employed a variety of methods for resolution of their conflicts with home care nurses. The most frequently cited means of resolving conflict was to speak with the RN to resolve the situation. However, one third of the mothers reported that they did not communicate directly with the RN to resolve conflicts. As one mother reasoned: "I feel kind of, well, I'm not a nurse and I don't feel like I should have to be telling them their job, but I know I should open up my mouth more. I feel intimidated but I really should do that." Other common strategies for conflict resolution included speaking to the case manager or nursing supervisor, requesting that a particular nurse no longer be scheduled to provide care, switching home care agencies or changing to independent nursing for provision of care, and communicating expectations to all nurses. One mother simply stayed at home while a particular nurse was there, because she felt obligated to closely monitor the care that was being given.

Establishing house rules and ongoing efforts to maintain a good working relationship with nurses were additional strategies parents used to avoid conflict. Also, parents felt conflict could be avoided by employing nurses who had specific qualities such as being religious, trustworthy, sensitive, and competent in the provision of medical and nursing care. Parents felt nurses should make the child a priority and be accepting and loving with the child. These qualities, according to parents, were consistent with the family's own values and promoted family-centered care in the home.

The most common way for the nurses to obtain information about parental child-rearing expectations was through verbal or written communications from parents. In general, nurses felt the parents needed to be in control of making child-rearing decisions and direct the RN. More than half said they would follow the parent's child-rearing decisions as long as the child "remained safe." However, conflicts related to child rearing were mentioned frequently by the nurses, with the most common conflicts described as the RN not agreeing with the parent as to the acceptability or appropriateness of the technology-dependent child's behaviors or the RN disagreeing with specific child-rearing strategies employed by the parent.

Strategies identified by nurses for conflict resolution were varied. Most frequently, the nurse attempted to resolve the conflict by speaking with the parent. However, approximately one third did not communicate with the parent directly. Some of these nurses simply did what they thought was correct in the situation and stated they did not feel responsible for what happened in the home when they were not present. Many nurses reported calling their case manager or supervisor to report conflicts. In some cases, the nurse decreased her involvement with the family by working fewer hours, changing to night shift, or quitting the case altogether.

Discussion

In this study, parents' and nurses' perceptions of child rearing varied in several areas. The parents' perception that rearing the child with technology needs was the same as other children and the need to normalize the care their child received was evident. The normalization of the child with a chronic health problem is consistent with the findings of many previous researchers (Deatrick, Knafl, & Murphy-Moore, 1999). Parents further described how their child's reliance on technology affected normal daily activities because of the time and planning required for care of the child. Parents described difficulty obtaining child-rearing information specific to children who are technology dependent, yet the finding that families were not likely to consult healthcare professionals for child-rearing information (Youngblut et al., 1994) was supported.

Most nurses did not share the parents' perception that rearing the child with technology needs was the same as with other children. They felt the parents treated the child with technology differently from other children. This difference in perception is similar to perceptions of professionals regarding parents of children with cancer (Davies et al., 1991).

Nurses and parents felt the presence of equipment hindered the ability of the technology-dependent child to participate in normal childhood and family activities. Therefore, it would be helpful for the inpatient discharge teaching program to include opportunities for the family to role-play, preparing the child with equipment for outings and interactions with friends. The initial home care plan and subsequent updates should include strategies for integrating the child into normal activities. The impact on the family of having a child with technology needs in the home and the effects of home nursing on the family need to be part of the orientation for all nurses working in the home setting (Coffman, 1995; Murphy, 1997).

Limitations

The results of this study are not generalizable to all parents of children who are technology dependent. The study's limitations include one-time interviews and a fairly homogeneous group of participants. In-depth, longitudinal studies with more culturally diverse samples are needed to identify coping strategies that help families deal with the disruption of family life, lack of privacy, and other aspects of having a child with technological needs. Finally, research is essential related to the impact of multiple care providers on the technology-- dependent child's development.

Conclusion

Parents are responsible for identifying essential aspects of child rearing and determining how child rearing should occur. However, the presence of home care nurses who provide direct care for a technology-dependent child alters the usual functions of the family, including the child-rearing function; therefore, it is expected that the nurse may directly influence child rearing. It is essential that nurses acquire increased knowledge of parental views of child rearing for the technology-dependent child in order to facilitate the provision of quality family-centered care.

Although child rearing was identified as a role for the nurse in this study, not all parents verbalized their expectations to the nurse, and it was unclear how child rearing is included as part of the care provided by home care nurses. A more systematic approach to assessing child-rearing issues and the development of ongoing dialogue between parents and nurses about child rearing would provide an opportunity for all parents to verbalize their goals, foster collaboration between nurses and parents, and provide consistency in the provision of child-rearing activities with the child who is technology dependent.

How Do I Apply These Findings to Nursing Practice?

The number of technology-dependent children in the United States is a relatively small portion of the overall population of children with chronic conditions. However, this is a growing population with many needs, and further research and intervention are indicated. Continued collaboration between care providers and families is essential to further knowledge generation and dissemination. By learning more about aspects of child rearing in families with technology-dependent children and the role of home care nurses in child rearing, parents and nurses may be able to more successfully negotiate childrearing expectations and activities.

Home care nurses describe conflicts between nurses and parents around multiple issues, including child rearing. Caring for a child who is technology dependent in the home is not the same as caring for a technology--dependent child in the hospital. Resources must be identified and orientation to pediatric home care nursing must contain increased information and opportunities for discussion about the unique nature of home care. Development of standards for home care of the technology-- dependent child, closer supervision of nurses in the home, and inclusion of child-rearing strategies on the plan of care would be additional strategies toward improving pediatric home care.

The presence of nurses in the home affects family relationships and dynamics. Parents and nurses need to establish trusting partnerships to provide optimal care for both the technology-dependent child and his or her family. Improved collaboration may result in reduced parental stress and increased job satisfaction for home care nurses, and can maximize opportunities for additional growth and development in the technology--dependent child.

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