Daily Struggles:
Living With Long-Term Childhood
Technology Dependence

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Les enfants atteints de maladie chronique survivent maintenant plus longtemps grâce aux avancées de la technologie. Cette amélioration du taux de survie s'accompagne d'une augmentation du nombre de familles dispensant des soins à domicile à un enfant présentant des besoins complexes. Dans cette étude fondée sur une théorie à base empirique, nous avons exploré quel effet avait sur les proches le fait de prendre soin à la maison d'un enfant qui a besoin d'un respirateur. Ces familles vivent une expérience de *lutte quotidienne*. Ce combat perpétuel comporte trois dimensions distinctes : *surmonter l'épreuve, se mettre à respirer* et devoir affronter *un événement subséquent*. L'article analyse les implications de ces résultats sur le plan de la pratique et des orientations futures de la recherche en sciences infirmières.

Mots-clés : soins à domicile, respirateur, familles, enfants, étude fondée sur une théorie à base empirique

With advances in technology, children with chronic illnesses are surviving longer. This improved survival rate has resulted in a growing population of families caring for their children with complex needs at home. This grounded theory study explored how caring for a child who requires home ventilation affects family members. Families moved through a process of *struggling daily* as they cared for their child with complex needs. This ongoing struggle was characterized by three distinct dimensions: *getting over the hump, starting to breathe,* and having to deal with a *subsequent event.* Implications for practice and future directions for nursing research are discussed.

Keywords: technology dependence, home ventilation, family functioning, children, grounded theory

With advances in medical technology, children with chronic illnesses are surviving longer. This improved survival rate has resulted in a

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growing population of families caring for their children with complex needs at home (Patterson, Leonard, & Titus, 1992). A large number of these children are dependent on ventilators. The experience of families caring for their ventilator-dependent children at home was the focus of this study.

Literature Review

Few studies have focused specifically on the experiences of families with ventilator-dependent children at home. However, the literature does suggest that caring for a child with complex needs has important financial, psychological, physical, and social consequences. Indeed, all facets of family life may be affected. The demands of caregiving can isolate families from sources of support. Caregivers of technology-dependent children report less interaction with family and friends because of their child's illness (O'Brien, 2001).

The constant demands associated with caregiving can adversely affect the physical and mental health of caregivers (Patterson et al., 1992). Financial issues are also a common concern for these families and a further source of strain (Thyen, Kuhlthau, & Perrin, 1999). Alteration of normal family functioning can have a negative impact on the family's quality of life (Baumgardner & Burtea, 1998).

The few studies that have been conducted raise numerous concerns about this population and point to important gaps in the literature. The majority of available studies did not focus solely on the concerns of families caring for ventilator-dependent children. Many were cross-sectional surveys assessing the needs of this population. Further exploration using a qualitative approach would enrich the level of knowledge in this area.

Purpose

The purpose of this study was to enhance our understanding of how caring for a child who requires home ventilation affects family members. The specific aims were to explore the perceptions of family members caring for these children and to describe the impact on the family.

Method

Grounded theory was chosen as the methodology for the study. Grounded theory produces a theoretical model of the subjective expe-

rience of a particular phenomenon and the process of managing the phenomenon in a specific context (Kearney, 1998).

Key Informants

Families were recruited through the home-ventilation program of a metropolitan pediatric hospital. Theoretical sampling consistent with the chosen methodology continued until further data collection yielded no new theoretical material (Kearney, 1998). The five families selected for the study had children who required a ventilator or a positive airway pressure device at home. The children's ages ranged from 8 to 16 years. The children fell into two diagnostic groups: those with respiratory illnesses such as central hypoventilation syndrome, a rare disorder affecting the central control of breathing, and those with neuromuscular disorders requiring ventilation support due to respiratory muscle weakness. Both of these groups have a long-term need for this type of technology.

Families were eligible for inclusion if they had been managing the care of their child at home for more than 1 year, if their child was medically stable at the time of the study, and if family members were able to speak English or French.

The primary physician approached families who met these criteria and asked them if they would like to learn more about the study. If families wished to learn more, they were contacted by the researcher, who was clearly differentiated from the care providers to reassure families that their decision whether to participate would not affect the care they received. The purpose of the study was explained, as were the measures taken to ensure anonymity. Once the families had agreed to participate, an interview was arranged in their home. Families who lived more than 50 kilometres from the referral centre were interviewed when their child was hospitalized for a check up. The interviews with family members were audiotaped after written consent to do so was obtained.

Data Collection and Analysis

Preliminary data such as the child's recent hospitalizations and previous surgical procedures were obtained from the hospital's computer database. Participant observation of family interaction and the home environment were an integral part of data collection. Family experiences were explored using a semi-structured interview technique. The data obtained related to the impact of caring for a technologically

dependent child, the concerns of family members, coping strategies employed to manage daily life, the type of care provided, the use of external resources, and an account of their experiences. Interviews varied in duration from 1 to 3 hours.

The criteria of credibility, confirmability, meaning in context, saturation, transferability, and recurrent patterning were used to evaluate the rigour of this study (Leninger, 1994). Verbatim transcription of data and thick descriptions of data, sample, and setting enhanced the rigour of the study. Emerging themes were validated in subsequent interviews and theoretical sampling continued until saturation was achieved.

Data analysis was conducted concurrently with data collection. Audiotapes were transcribed verbatim as soon as possible after data collection. Family genograms and observations were recorded in the form of field notes. Initially the transcripts were examined line by line and concepts identified. The identified concepts were continually compared with prior data and similar concepts were grouped into larger categories. Theoretical hunches and preliminary diagrams were developed. Commonalities and differences across families were examined. A process that reflected the cyclical experience of these families was identified.

Findings

A central theme of *struggling daily* characterized the experience of the families. Parents described their experience as a "battle" or a "fight" and emphasized that this struggle was a part of daily life. One mother stated: "It is a fight every day. You solve a problem, then there is always something else." Struggling daily was a continuous cyclical process that began when the child was taken home from the hospital. Three distinct dimensions of the struggle were identified: *getting over the hump, starting to breathe,* and *dealing with a subsequent event.* Additional findings related to the challenges faced by the families, the resulting sentiments, and coping strategies employed to manage these challenges are described elsewhere (Alexander, 2002).

The families described *getting over the hump* as an overwhelming and difficult process. One mother told of collapsing in a heap on the bathroom floor and crying because she felt so overwhelmed by it all. One father stated:

> So you have to change diapers, refill the milk, monitor the parameters in case he desaturates — you may need to suction. We had him at home for a year without a nurse. It was impossible. You can't work. Doing the night [and] working during the day. It can't be done.

The families moved through this difficult time by learning how to care for their child and how to manage their situation successfully. One mother said: "Everything looks like a huge mountain when you are first told, and after that you have to take it in stride and keep going." The families then moved into a period of relative stability. This was a time when they could start to breathe. The struggle was described as less intense and more manageable. One mother stated: "We are *starting to breathe*. Before this, things were going a little less well. When you think that you are buying diapers at [age] 13…the point when you don't bring the diaper bag with you, you are happy." Another mother stated: "The first few years were hard. Then, after that, you get to the point where it just plateaus a little bit."

The families remained in this period of relative stability until a new problem arose and they were faced with having to manage the situation with renewed intensity. The precipitating event could be an illness, a change in family structure, or a developmental milestone. A mother described her feelings when her child caught a cold:

> *Our stomach would be in knots because he has plugs — his lungs would collapse. This is the first time since September we can actually relax a bit. If he starts to get something our stomachs are in knots. We are feeling like we are literally going to get sick.*

Another mother spoke of her concerns as her child approached adolescence:

> *Maybe at some point she'll be interested in a boy and because she is the way she is the boy won't be interested. My son…there are girls around and some of them he finds attractive; if they don't want anything to do with him, he doesn't have to wonder if it's because he's different from the others. She will have that. Growing older, adolescence, it's going to be a little more difficult.*

The findings of this study reflect the complex nature of the families' experiences. All the families interviewed described the same process, although there was variation in terms of length of time spent in each phase of the cycle. Additionally, their experiences appeared to be profoundly influenced by three intervening conditions: the accessibility and availability of formal resources, the involvement of family and friends, and the family's socio-economic status.

Discussion

The findings of this study support the notion that the concerns of families living with long-term technology dependence are similar to those

of families managing other chronic illnesses requiring complex home care. The findings also reveal important differences in how the process of struggling daily unfolds for such families.

The families moved into a period of relative stability by learning how to manage the struggles inherent in caring for their child. Although this period was characterized by the absence of change, the daily struggle clearly continued. The notion of a period of stability is not new. In Steele's (2000) exploration of the experiences of families caring for children with life-threatening neurodegenerative illnesses, the primary goal identified by the families was to maintain the periods of stability. O'Brien (2001) reports similar findings: the identified goal of families caring for children with various types of technology dependence was to achieve stability in the face of constant change and unpredictability. In Gravelle's (1997) study with families of children with progressive life-threatening illnesses during the complex chronic phase, the families moved through a series of successive hardships by defining adversity and then managing it. Thus, in spite of differences in study population and illness trajectories, the sense of ongoing struggle inherent in the daily lives of these families is congruent with the findings of the current study.

The findings of this study have implications for nursing practice. The continuous, cyclical nature of the daily struggles inherent in caring for a child with complex needs suggests the need for ongoing assessment of the family. Even when families are *over the hump*, they may require help in addressing ongoing issues, as well as guidance and support when changes can be anticipated such as the transition to adolescence. An understanding of the process these families go through would also assist nurses in preparing families who are just beginning this journey. An awareness of intervening conditions that may influence their experiences would enable nurses to target particularly vulnerable families.

Family, learning, collaboration, and health are central features of the McGill Model of Nursing (Gottlieb & Rowat, 1987). In the present study, families shared their experiences of learning to meet the challenges of caring for their child with complex needs. The process of learning moved the families *over the hump* to a period of relative stability. They then had to learn anew in order to adjust to subsequent changes. In the McGill Model, the family is the unit of concern and learning takes place within the context of the family. The findings of the present study support this conceptualization. Changes in the health of one family member affected all family members.

Limitations

The design precluded analysis of differences within families since family members were interviewed together. In addition, in two cases only one parent was available. These aspects of the study limit the scope and transferability of the results.

Future Directions

This study provides new insight into the experiences of families caring for their ventilator-dependent children at home. Further study of the cyclical nature of the experiences of such families is indicated. A longitudinal approach would provide further information about how the process of struggling daily changes over time. In addition, an examination of how this process applies to families caring for children with other types of technology dependence is warranted. Lastly, a design that incorporates both individual and family interviews may reveal differences not explored here.

It is likely that the number of families caring for technology-dependent children at home will continue to rise as a result of medical advances and a continued emphasis on transferring care to the community. Increased knowledge and understanding of the ongoing struggles of these families is vital if we are to meet the challenges that lie ahead.

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