Mothers' Perspectives of an In-Home Nursing Respite Service: Coping and Control

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Quelles sont les expériences des mères relativement aux services de relève à domicile qu'elles reçoivent pour les aider à soigner un enfant à la santé fragile ou qui souffre d'un problème médical complexe? Le présent article met en lumière les conclusions d'une étude exhaustive de deux ans qui visait à évaluer les retombées d'un programme canadien de soins infirmiers de relève. Des données ont été recueillies à trois reprises aux domiciles des 27 familles participantes, au moyen de méthodes quantitatives et qualitatives. Les auteurs présentent un concept élaboré à partir des entretiens non structurés et de leurs observations, à savoir apprivoiser le système. Un sous-ensemble de 10 mères a été choisi pour effectuer une analyse comparative constante de leurs points de vue, laquelle a permis de déceler un processus en 4 étapes : *intégration, perte de la maîtrise, prise en charge* et *gestion efficace en fonction des contraintes imposées par des règles rigides*. Ces résultats devraient permettre d'approfondir les connaissances en matière de soins de relève, dans le but de répondre adéquatement aux besoins des mères qui soignent un enfant aux prises avec un problème médical complexe.

What are mothers' experiences of receiving in-home nursing respite care for their children with medically fragile or complex conditions? This paper highlights selected findings from a comprehensive 2-year study designed to evaluate the impact of a Canadian nursing respite program. Data were collected at 3 time points in the homes of 27 families, using both quantitative and qualitative methods. This paper reports on 1 construct arising from unstructured interview and observational data: *learning to manage the system*. A specific subset of 10 mothers was chosen for constant comparative analysis of their perspectives of receiving in-home nursing respite, revealing a 4-phase process: *taking in, losing control, taking charge*, and *managing effectively within the constraints of inflexible rules*. These findings contribute to nursing knowledge about meeting the in-home respite needs of mothers of children with complex medical conditions. Implications for nursing include how to better support maternal coping, decrease uncertainty, and foster more effective relationships with mothers of children with complex conditions.

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Children with medically fragile conditions, including those who are dependent on life-sustaining technological equipment, are increasingly being cared for in their communities, usually in the family home (Kirk, 1998; Kohrman & Kaufman, 1997; Perrin, Shayne, & Bloom, 1993). It is believed that home-based care is better for children's social, emotional, and psychological development than long-term institutional care (Thompson & Gustafson, 1996), but possibly at a cost to community-based caregivers, usually their parents. Although care for children with chronic conditions, disabilities, or special needs is demanding for each family member and for the family as a whole (Hayes, 1992; Knafl, Breitmayer, Gallo, & Zoeller, 1996), in most cultures the primary responsibility for home care falls to the mother. Due to the complex nature of care demands, parents of such children frequently experience high levels of stress, burnout, and mental and physical exhaustion (Eiser, 1993; Kirk, 1998; Perrin et al.; Wade, Taylor, Drotar, Stancin, & Yeates, 1998). In addition, mothers are uncomfortable leaving their child with friends or relatives due to the complexity of the care required and the need for high-level skills and knowledge (Diehl, Moffitt, & Wade, 1991; Kirk, 1998).

The Canadian Association for Community Care (1996) defines respite care as "a service whose main function is to relieve the parent/ family/primary caregiver for a specific period of time while facilitating a positive and rewarding experience for the child with a chronic illness" (p. 5). There is evidence that technology-dependent children usually require the services of registered or licensed practical nurses because of the specialized knowledge needed to manage the complex equipment (Olsen & Maslin-Prothero, 2001; Sherman, 1995). The literature suggests that while attempts have been made to put appropriate and comprehensive services in place for families to safely care for their children at home, there are some oversights and service gaps that significantly contribute to family members' stress and inability to cope with the child's care demands. Notable among the service gaps is the lack of *nursing* respite care (Bamford, Griffiths, Long, & Kernohan, 1997; Robinson, Jackson, & Townsley, 2001; Spalding, Hayes, Williams, & McKeever, 2002; Wegener & Aday, 1989; While, Cornish, & Citrone, 1996).

To date, there has been little published research that has looked specifically at the benefits of nursing respite programs for caregivers of children with complex care needs (Breckbill & Carmen, 1999; Hazlett, 1989; Olsen & Maslin-Prothero, 2001).

This article reports on one component of a comprehensive evaluation of nursing respite services. The findings reported here address, in a subsample of mothers in the overall study, the question: *How do mothers who are primary caregivers of children who are dependent on technology at home view the role of nursing respite in managing their stress and increasing their coping ability?*

Literature Review

Children Who Are Technology-Dependent

Since the early 1980s there has been a rising trend towards parental in-home care of children who are dependent on ventilators, oxygen therapy, and parenteral nutrition. Common sources of stress identified by the families of such children are: persistent gravity of the situation, fears about their own medical/nursing incompetence, inadequate respite care, financial burdens, constant fatigue, social isolation (Stevens, 1990, 1994), and continual adherence to the child's care regime (Wegener & Aday, 1989; Youngblut, Brennan, & Swegard, 1994). Obtaining, keeping, and maximizing respite care continues to be a major challenge for many North American families of children with demanding home-care needs (Capen & Dedlow, 1998; Cernoch & Newhouse, 1997; Spalding et al., 2002).

Mothers as Caregivers

For most families in North America, it is the mother who assumes the primary child-care responsibilities at home (Bridges & Lynam, 1993; Eiser, 1993; Robinson, 1997). Mothers' personal sacrifices include giving up their careers and the attendant personal and financial losses. Some authors report that caring for children with special needs at home is worrisome and a constant struggle for mothers (Miles, Holditch-Davis, Burchinal, & Nelson, 1999; Monsen, 1999), requiring heightened vigilance (O'Brien, 2001). Furthermore, living with uncertainty (Cohen, 1995; O'Brien; Sparacino et al., 1997) contributes to mothers' stress and lack of flexibility in their lives. The stress of caregiving can strain a woman's personal resources and lead to mental and physical exhaustion.

Parental Stress and Coping in Children's Chronic Illnesses

Due to high stress levels, mothers of chronically ill children commonly suffer from chronic sorrow, depression, loneliness, and a lack of support

(Florian & Krulik, 1991; Gravelle, 1997; Miles et al., 1999; Monsen, 1999; Phillips, 1991) and often complain of feeling trapped (Brinchmann, 1999; Hendricks, De Moor, Oud, & Franken, 2000), chronic fatigue, guilt, anger, anxiety about the future (Gravelle; Murphy, 1991), social isolation (Brinchmann; Murphy; Stevens, 1990), and a lack of leisure time (Geary, 1990; Hayes & McElheran, 2002). The above studies, and an excellent review by Kirk (1998), reveal that the primary caregivers of chronically ill children experience significant physical, emotional, and social strain.

Knowledge about the child's condition and treatment and the skills to safely care for the child in a non-medical environment are essential means of parental coping (Gravelle, 1997; Hall, 1996; Sterling, Jones, Johnson, & Bowen, 1996). Heinzer (1998) found that parents directed their energies towards the special needs of the child rather than their own health and that of other members of their family. In the chronic-illness literature, social support is identified as one of the key resources for increasing individual family members' ability to cope (Dunst, Trivette, & Deal, 1988; Ray & Ritchie, 1993; Sterling et al.). Primary care-givers have identified the support of spouses, members of the immediate family, and friends as more valuable than that of health-care professionals (Florian & Krulik, 1991; Geary, 1990; Stevens, 1990).

Professional support is, however, critically important for families who have children with complex home-care needs. Mothers report that even when several family members have been trained to care for the child, it is difficult to provide care at home without some form of outside assistance (Dunst et al., 1988; Hayes & McElheran, 2002; Kirk, 2001; Ray & Ritchie, 1993). Parents in Olsen and Maslin-Prothero's (2001) study valued nursing respite support because it allowed them time to catch up on their sleep, recover emotional strength, and attend to their own personal hygiene. While the mothers in these studies did believe that respite was important, the majority felt it was inadequate. Despite receiving respite services, mothers still experienced significant levels of stress from caregiving.

Nursing Respite for Technology-Dependent Children

Children with medically complex conditions require specialized care and, when the caregivers need a break, respite care by a registered nurse (Aday & Wegener, 1988; Sherman, 1995; Stevens, 1990, 1994). Respite caregivers must be able to assess and respond to the changing

needs of medically fragile children and be competent in the use of such technologies as tracheostomies, respirators, and suction equipment.

Parents find it difficult to deal with home-care nursing (Diehl et al., 1991; Murphy, 1991). They complain about poorly trained nurses and poor care, staffing inconsistencies (Hayes & McElheran, 2002; Murphy, 1991), and insufficient numbers of nursing respite hours (Gravelle, 1997; Petr, Murdock, & Chapin, 1995; Sherman, 1995; Stevens, 1990). All the parents in Sherman's study reported that nursing respite decreased mothers' somatic complaints (anxiety and depression). Parental care-givers experience less stress if they receive respite services. However, many mothers report that while nursing respite has many benefits, it can be a mixed blessing (Hayes & McElheran; Olsen & Maslin-Prothero, 2001; Ray & Ritchie, 1993).

Our practice experience and literature review identified a signifi-cant gap in knowledge on the effectiveness of current nursing respite programs in meeting the needs of families, particularly the needs of mothers of technology-dependent children. Program evaluation research is essential if policy-makers and service providers are to be informed about how best to meet the needs of this population (Tan, Hayes, & Hollander, 2000). Clearly, policy does not target families with high service needs in ways that adequately support them in caring for children with complex health conditions. While the shift to community-based health-care delivery may be saving governments and funding agencies a significant amount of money, it appears to be at significant cost to the well-being of primary caregivers and families. This study was a first step in exploring parental coping, particularly mothers' expe-riences with nursing respite services in the home setting.

Sensitizing Concepts

This component of the study was based upon two sensitizing concepts: stress and coping. These sensitizing concepts provided global bound-aries for the exploration of the phenomenon of interest — mothers' responses to an in-home nursing respite program. Psychological stress was defined as "a particular relationship between the person and the environment that is appraised by the individual as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19). Coping was defined as "constantly changing cog-nitive and behavioural efforts to manage specific external and or inter-nal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, p. 19).

Method

The original study was a single-sample, descriptive evaluation carried out at three points: before starting the Nursing Respite Program (NRP), and 6 and 12 months after starting the NRP. The study included both quantitative and qualitative components. The quantitative analysis examined outcome measures relating to an number of variables: overall annual costs of the child's care, nature of nursing care, changes in the child's activities of daily living, and changes in caregiving demands for parents. The qualitative component was intended to draw a picture of parents' perceptions of how respite services affected their lives. This paper reports on the qualitative component for a subset of 10 mothers who were caring for technology-dependent children at home. A secondary constant comparison analysis was used to examine the transcribed interviews of the 10 mothers in discussing their experiences with an in-home nursing respite program (Hinds & Vogel, 1997; Strauss & Corbin, 1998; Thorne, 1994).

Sampling

The sample for the main project included all families (sequentially) newly admitted to the British Columbia NRP over a period of 15 months commencing in April 1994. A total of 27 families took part. There were incomplete data sets for nine of the 27 families (two families withdrew, four children died during the research, and three families were discharged from the program). The selection criteria were that all family members consent to participate and be able to speak and read English well enough to speak with a researcher and complete the pen-and-paper instruments (used for the quantitative evaluation), and that the child not be palliative. The criteria for inclusion in the current subset were that families participate in all three data collections and that the parents and observations speak to the issues of respite and parental stress and coping.

True theoretical sampling, as is customary in grounded theory, was not employed due to the inflexibility of the quantitative data collected. Nonetheless, parents and families were all excellent informants for the phenomenon of interest. The report presented here is based on a subset of the qualitative data, which was examined for theory related to the process of mothers' adapting to respite — from their own perspectives. The sample will be described below.

Data Collection

Ethical clearance was obtained from the University of British Columbia human ethics review committee. Data were collected using unstructured interviews (conversations) and participant observation. Typically, a home visit began with a general observation about the family situation, the complexity of care, and the progress of (or desire for) nursing respite services. The unstructured format encouraged participants to share their thoughts on home caregiving and respite. Family conversations were audiotaped and transcribed verbatim along with the researchers' dictated, detailed field notes.

Analysis

Transcripts, field notes, and coding memos were read to get a general sense of the themes in the data. Careful attention was paid to Strauss and Corbin's (1998) recommended analytical steps, a constant comparative method of collecting and analyzing data. Open coding began simultaneously with the reading of the first transcription and naturally progressed through the other analytic phases of axial and selective coding. As the analysis progressed, questions were asked of the data — for example: Why do some mothers seem to be content with the number of nursing respite hours they have qualified for, while others feel the need to advocate for their children and their situation? In the process of axial coding, relevant concepts emerged that were later condensed into categories and their properties and dimensions. Finally, the relationships between the relevant categories were determined, and the constant comparative method of data collection and analysis continued until there was saturation of all the relevant categories. During selective coding, a core variable was conceptualized that encompassed everything in the mothers' stories about the role of nursing respite in decreasing their stress and increasing their ability to cope: *learning to manage the system.*

Description of Sample

In all 10 families selected for this analysis, the mother was the primary caregiver. Seven of the mothers were married to the child's father. One had never been married to the child's father. Another had become separated from her husband since the birth of the child. One couple was an Associate Family who had been caring for the child for 8 years. (This British Columbia program remunerated families for caring for children

in their homes, similar to foster families, with the biological parents remaining involved in the child's life.)

At the time of enrolment in the respite program, the technology-dependent children, consisting of five boys and five girls, ranged in age from 5 months to 16 years; there were seven infants (< 1 year of age), two toddlers, and one adolescent (see Table 1). The children's diagnoses varied considerably. They included: bronchopulmonary dysplasia, seizures, short gut syndrome, Nager syndrome, chronic renal failure, and tracheal malasia. The primary reasons why the children qualified for nursing respite were tracheostomy ($n = 2$), gastrostomy tube feedings ($n = 7$), home oxygen ($n = 6$), jejunostomy tube feedings ($n = 1$), and TPN ($n = 2$). Eight of the children were dependent on more than one of these life-saving measures.

Amount of respite. There was a wide range in the number of nursing respite hours the families were receiving at the time of the study (see Figure 1). The number of hours the family had been allocated at the time of the initial interview ranged from 4 to 70. In all but one instance the hours allocated per week were not flexible, meaning that unused hours from one week could not be saved for later. In the one family that had been assigned "flex" hours, the caregiver could accumulate unused time in order to have a larger block of continuous nursing respite hours.

Table 1 *Description of the Children*		
Age	**Diagnosis**	**Nursing Care**
5 months	Bronchopulmonary dysplasia	O_2, C-pap respirator
5 months	Short gut syndrome	TPN, ostomy
8 months	Seizures	O_2, suction
8 months	Bronchopulmonary dysplasia	Tracheostomy care, G-tube
9 months	Short gut syndrome	TPN, G-tube
10 months	Bronchopulmonary dysplasia	O_2 therapy
10 months	Nager syndrome	Tracheostomy care, G-tube
21 months	Tracheal malasia	O_2, J-tube
2 years	Cerebral palsy, seizures	O_2 therapy
16 years	Chronic renal failure	Gastrostomy

Figure 1 *Allocated Hours of Respite*
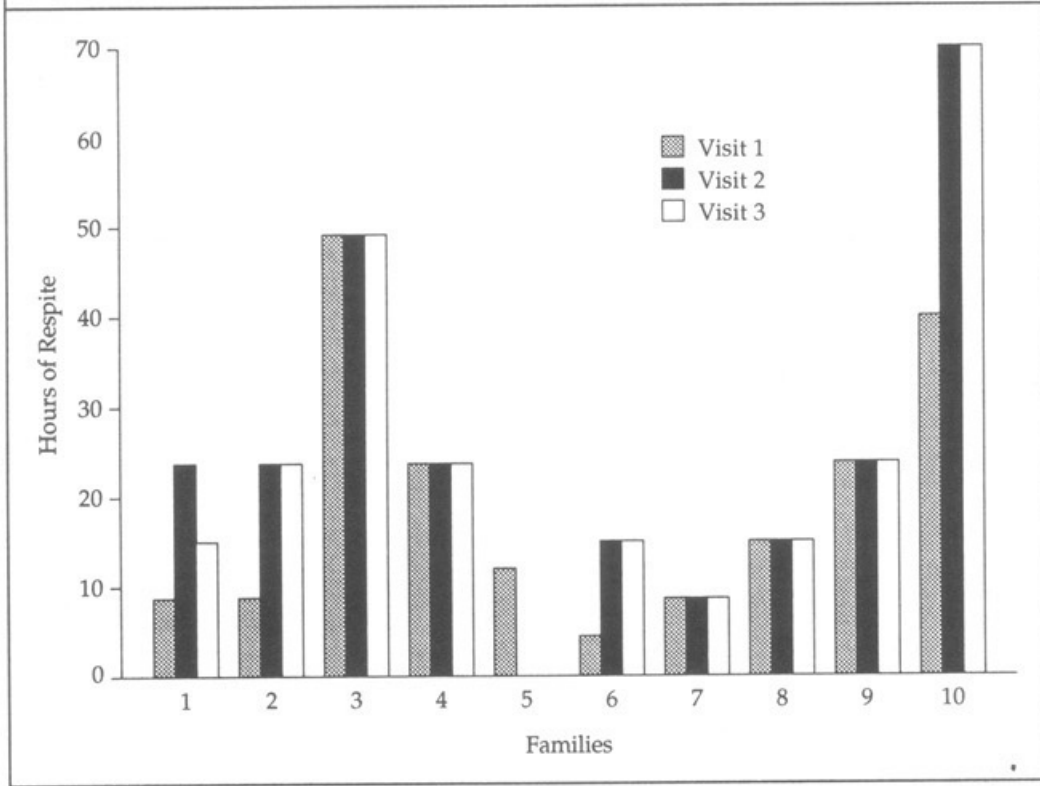
Findings

The mothers in this grounded theory analysis told similar stories of *learning to manage the system* in order to maximize the benefits of nursing respite, specifically to decrease their own stress and increase their ability to cope. The core concept is seen to have four phases: *taking in, losing control, taking charge,* and *managing effectively within the constraints of inflexible rules*. In describing how they learned to manage the system, the mothers simultaneously illustrated a process of changing relationships with the health-care professionals in control of their child's care. These four phases have been named *blindly trusting, becoming enlightened, seeking effective collegial relationships,* and *establishing working relationships* (see Table 2).

The focus of this article is limited to a description of one of the findings: *learning to manage the system*.

The process of *learning to manage the system* started immediately when it became apparent to the mother that her child's condition was serious and needed tertiary-level medical intervention in order to sustain life. While the child was in hospital, the mother learned a great deal about her child's illness and care, how to deal with setbacks and

Table 2 *Learning to Manage the System*

Taking in	Losing control	Taking charge	Managing effectively within the constraints of inflexible rules
Learning the skills required for care	Transition from hospital to home	Learning the rules of the program	Mothers' recommendations for improving the program
Inflexible respite assessment criteria	Role of uncertainty	Taking it one day at a time	
Assessment criteria do not tell the true picture	System or program uncertainty	Taking control	
	Professional uncertainty	Keeping a positive outlook	
	Illness uncertainty	Just getting on with it	
	Living with daily uncertainty	Seeking social support	
Blindly trusting	Becoming enlightened	Seeking effective collegial relationships	Establishing working relationships

disappointments in her child's illness trajectory, and how to live with uncertainty. The period prior to the initiation of respite has been conceptualized as the *taking in* phase.

Taking In

During the *taking in* phase of *learning to manage the system*, the mothers spent a great deal of time and energy gathering information in order to assume the responsibilities of caregiving. The mothers' experiences with hospitalization were generally positive, and their stories reflect a trusting relationship with the health professionals involved in their child's care. Their stories revealed three variables that significantly affected their ability to *take in* information: *learning the skills required for care, inflexible respite assessment criteria,* and *assessment criteria do not tell the true picture.* These mothers felt that the NRP rules were too rigid, had the wrong focus, and did not consider families' "true situations." One mother described her feelings with the assessment phase as follows:

> *A nurse should go into the home for a week and assess the child and the whole thing, and get to see what the parent looks like every day, the main caregiver...because when you just come in for a 45-minute visit, or an hour and a half, you may see nothing. When they first came he slept through the whole visit so they thought he was okay; meanwhile they really didn't realize how bad it was.*

This mother's son had a severe seizure disorder, regularly experiencing eight seizures in a 24-hour period. She described her son's seizures as life-threatening because he would stop breathing and turn blue.

Prior to their initial contact with NRP personnel, the mothers carried their trust of the system over from their acute-care experiences and assumed that the child's transition from hospital to home would progress smoothly. They assumed that the NRP consultants would ensure that they received sufficient nursing respite to allow them to carry on a fairly normal life when their child was discharged home — meaning having time to do their chores both inside and outside the home and time for themselves (e.g., to exercise, read, visit their own physician).

As the time grew closer for nursing respite to begin, the mothers became disillusioned with the program. Most believed it would not live up to their expectations. Families whose respite commenced at or close to the time of discharge experienced less disenchantment with professionals than those who were left totally responsible for their child's care

at home for some time. Simultaneously, this first phase of mothers' evolving relationships with the system's health-care personnel has been conceptualized as *blindly trusting*.

Blindly Trusting

Nine of the 10 mothers had developed good therapeutic relationships with the doctors and nurses during their child's initial hospitalization. They had learned to trust and depend on the professionals who cared for their critically ill child. Mothers believed that their future relationships with community-based providers would be the same. As it became clear that NRP and other community supports would be insufficient, their trust waned. The mothers assessed the adequacy of the number of respite hours on the basis of whether they were able to get enough sleep. Those who were able to get enough sleep generally viewed the program and their number of respite hours much more positively. One mother expressed her feelings in this way:

> *If you can get sleep all night, then you can handle the day. But it's when…you only get 2 hours of sleep in between each time…when you're up that much at night you can't function as well.*

When rest was inadequate and respite support seen as too little, the mothers felt their situations were not understood and their trust in community-based service providers was undermined. The next phase of *learning to manage the system* we have called *losing control*. The mothers experienced loss of control when care demands were excessive and they felt they were not coping.

Losing Control

The majority of mothers, at some point during the initial months of caring for their child, experienced a sense of *losing control*. They described this feeling as living with disorganization and various degrees of uncertainty. Their lives were unpredictable. They were unable to plan ahead or gain a sense of control over their child's and their own daily routines. One mother was extremely frustrated by the setbacks in her daughter's condition that delayed her projected initial discharge from hospital by 8 months. This rocky transition from hospital to home had a significant impact on her ability to cope:

> *They were going to send her home in May…. Then they discovered that her breathing wasn't very good…it set her back…and then…her feeding as well. They [the physicians] kind of jumped the gun, I think…. They were preparing us for discharge and they hadn't sorted her feeding out…*

That was May…end of May…and it's been, like, June, July, August, September — thinking she's coming home and then one thing after another. So it's frustrating.

At the time of this conversation (before respite began), the mother was predicting that her daughter would be discharged about a month later. At the time of the next interview (6 months later), her daughter had been home for only 3 weeks. Even after an 8-month delay in her daughter's homecoming, the necessary supplies were not available right away: "She came home on Saturday and we never got our supplies until that Wednesday." This was the beginning of this mother's lack of trust in the system.

Living with uncertainty also significantly contributed to these mothers experiencing a loss of control. The mothers' accounts reveal four types of uncertainty: *program uncertainty, professional uncertainty, illness uncertainty,* and *daily uncertainty.* One mother expressed her feelings about *illness uncertainty* in this way:

In the back of your mind, over time he gets sick: "Is he going to make it through this?" And if you fretted about it all the time you'd drive yourself crazy. And the reality is, he may not make it through it, and that doesn't mean we love him any less — but it's painful, painful.

Living with *daily uncertainty* markedly affected the physical and emotional well-being of these primary caregivers. For example, one mother described the toll that uncertainty took on her emotional health:

The time isn't there [to take care of anyone or anything else]… You're too tired…your brain is just in a frazzle and your nerves are jumping…you get to the point where you start snapping at one another and it's not because you want to…it's just like — boom, you explode — and then 5 minutes…you're sitting there and you're feeling sorry because you knew that it never should have happened. So then you apologize… I've broken down so many times from it, you know, from being tired.

This young mother was expressing a lack of control over her emotions and her actions caused by exhaustion. The above quotation illustrates how *losing control* has interfered with her ability to cope effectively. During the *losing control* phase of *learning to manage the system* the mothers were also entering the second phase of their relationship with health-care professionals, named *becoming enlightened.*

Becoming Enlightened

Becoming enlightened meant that these mothers were coming to the realization that the NRP health-care personnel were not able to truly under-

stand or empathize with their care responsibilities. Many mothers had expected to receive nursing respite services on demand and to have more choice in how and when they used their respite hours. The mothers did not remain in this second phase for long, because feelings of *losing control* were uncomfortable. As these mothers fought to gain a sense of control, they were naturally progressing to the next phase of *learning to manage the system*, named *taking charge.*

Taking Charge

In order to gain some control over their situations, the mothers used a number of coping strategies. *Taking charge* enabled them to focus on the positive aspects of their lives. Some examples of strategies they used are: (a) learning the rules of the program, (b) taking it one day at a time, (c) taking control, (d) keeping a positive outlook, (e) just getting on with it, and (f) seeking social support. Taking it one day at a time was a theme running throughout many of the mothers' stories. This is how one mother described the strategy:

> *No one knows what it's like until they experience it themselves, and everybody has a different way of dealing with things. The only thing is...you have to take it one day at a time and not get frustrated, because sometimes it's very frustrating, and you find yourself feeling very emotional about things, and you've just got to deal with it.*

Taking control for certain mothers meant fighting health-care personnel for what they believed they needed in order to cope. Three mothers had to fight "the system" to qualify for any respite hours, and another two mothers fought to receive more hours. The mothers found these battles exhausting and stressful:

> *A nerve-racking experience...I'm just so tired of the system and so tired of dealing with people and just always seeming to hit a brick wall constantly and just getting the run around, and we're just sick of it.*

Thus, during this phase, the mothers were beginning to take charge of the problems they were having with the NRP professionals and were entering the parallel relationship phase we have called *seeking effective collegial relationships.*

Seeking Effective Collegial Relationships

Despite the difficulties they were facing with various aspects of the NRP and the consultants who were its primary gatekeepers, the mothers started to accept the fact that they needed the support of these professionals in order to continue receiving NRP benefits. They began

to compromise their expectations in order to receive maximum benefit from the nurses and the program. One mother who was initially denied services — and at the time of the third interview still felt she needed more respite hours — found positive things to comment on:

> *It's a really good program due to the fact it does help parents.... I really like the way they try to match the nurses to the medical needs of the child.... I'm sure lucky to have it, because if I didn't I don't know what I would do.*

The means that mothers used to cope in this phase were: *keeping a positive outlook, just getting on with it*, and *seeking social support*. When mothers were able to take control of their lives and were satisfied that their children were well taken care of by the nurses, they were progressing into the fourth and final phase of *learning to manage the system*. We have called this final stage *managing effectively within the constraints of inflexible rules*.

Managing Effectively Within the Constraints of Inflexible Rules

Managing effectively meant that mothers were able to exert maximum control over their lives. They were comfortable in their situations because they were able to predict certain outcomes in their own life and that of their child. This control was achieved mainly by using the coping strategies described in the *taking charge* phase of *learning to manage the system*. For example, mothers who focused on the positive were able to mobilize more strategies for dealing with their situations. One mother who adopted this attitude began to organize other forms of child care when she knew that respite services were going to be cut. Unlike many of the mothers in our study, she felt comfortable having family members care for her daughter. In the weeks prior to respite services being cut, this young, single, working mother trained her sister and her daughter's maternal grandmother to take over child-care responsibilities.

Establishing Working Relationships

Establishing working relationships meant that mothers were able to reconstruct a relationship of trust with health-care professionals. This trust was based on their ability to accept the limitations as well as the strengths of the professional. All 10 mothers spoke of the many positive aspects of the NRP and described having established trusting therapeutic relationships with the consultants and the nurses providing care. At this time, as at any other time in the transition to establishing

(good/functional) relationships with community-based health-care professionals, the relationship could regress. We noted that the "roller-coaster ride" was influenced by threats to the stability of mothers' lives, such as frequent turnovers in nurses, cuts in the number of respite hours, or deterioration in their child's condition.

Discussion

The findings from this research show that mothers receiving a nursing respite program progress through a four-stage process of *learning to manage the system*. This is not an easy road. The participants indicated that they faced an uncertain future with their children and the process of building a relationship with health-care providers required more work and energy than they could sometimes give, as they struggled to care for their child within the demands of family and community life.

Among those who care for the chronically ill at home, living with uncertainty is now a familiar concept (Cohen, 1995; Stewart & Mishel, 2000). In their recent synthesis of the pertinent literature, Stewart and Mishel articulate the antecedents of parental uncertainty, all of which the mothers in our study described as challenges and adaptations in their care of their child: those that arise from individuals (that is, their children or themselves), those that are due to their child's condition and its changes, and those that arise from the environment, such as members of their support circle or specific health-care professionals. It is these antecedents and their consequences that constantly challenged the mothers in our study to journey (unevenly) forward in *learning to manage the system*, working all the while to "just manage," or "just get on with it," or simply just keep their heads at water level.

Learning to negotiate for all the resources they need and negotiating or "fencing" with the gatekeepers and service providers constitute additional strain for mothers (Thorne & Robinson, 1989; Wuest, 2000; Wuest & Stern, 1990) and require significant energy and time in already over-full, stressful lives. Consistent with the findings of Thorne and Robinson, the mothers in our study were guarded about their re-establishment of trust once they had mastered *learning to manage the system;* "walking carefully" was just one more challenge in the care of their child — a constant theme.

Lazarus and Folkman (1984) discuss professional assistance as a material resource for individuals in stressful situations. However, what has not been discussed in coping theory is the fact that material resources can in themselves be a source of stress. The mothers in our

study used a process of *learning to manage the system* to manage a material resource, a nursing respite service. While this service did in fact enable mothers to care for their technology-dependent child at home, it also proved to be an additional source of stress. For example, mothers reported higher stress levels when there was a lag between time of discharge and time of initiation of respite services. These mothers demonstrated the same exceptional abilities, resourcefulness, and resiliency in coping with the rigidity of the NRP. Consistent with the findings of Lazarus and Folkman, the mothers in this study used both emotion-focused and problem-focused coping strategies to deal with their stressors.

The findings from this study illuminate significant gaps between the hospital and community arenas of nursing practice (Kaufman & Hardy-Ribakow, 1987; Perrin & Ireys, 1984; Spalding et al., 2002). In this study, mothers often criticized "the system" for its lack of organization and coordination in care delivery during the period when their child with special needs was ready for transfer from hospital to home. Like Olsen and Maslin-Prothero (2001), we found that the immediate discharge-planning phase and transition to home requires sensitive, coordinated support and good communication. This first separation from the security of the hospital environment and the expertise and support of acute-care professionals is a particularly vulnerable time, one in which nursing expertise could be better used to assist parents, partly as a basis for future home-care and health-care relationships (Thorne & Robinson, 1989).

Further advancing our knowledge about how government and policy-makers can meet the needs of this unique population of caregivers, our findings suggest that primary caregivers of technology-dependent children at home should be in communication with government and policy-makers. Only caregivers who have actually experienced day-to-day life first-hand can understand and speak about what services are needed. This does not mean that nurses do not play a role in advocating for these families. Nurse practitioners possess the knowledge and skills to ensure that adequate assessments are conducted of the child's technological needs and the family's strengths and ways of coping.

In our study, as in others (Murphy, 1991; Olsen & Maslin-Prothero, 2001; Sherman, 1995; Stevens, 1990, 1994), mothers were found to experience less stress with the day-to-day demands of caring as the result of receiving home-based nursing respite services. Similar to those in other studies, our participants valued nursing respite support because it

allowed them to catch up on their sleep, recover emotional strength, run to the bank, or simply have a bath (Olsen & Maslin-Prothero). While the mothers agreed that respite is an important form of support, the majority felt it was inadequate (Gravelle, 1997; Spalding et al., 2002). Respite services enhance mothers' sense of control over their situation; nurses are in a critical position, as front-line care providers and consultants, to promote this sense of control. All health-care providers and government personnel must work with parents to develop more efficient and creative respite-care options, as part of an integrated system of care specifically aimed at individual children and their families (Spalding et al.).

As economic pressures result in cutbacks, it is important that nurses not only provide the best possible care for children and families in their homes, but also advocate for mothers and their children, individually and at the policy level (McKeever, 1996; Tan et al., 2000).

Implications for Nursing Research

As the current shift towards home care continues, it is likely that the complexity of the issues facing parents caring for the technology-dependent population of children will also increase. The implication of this trend is that more research is needed into the nature of caregiving for technology-dependent children. What kinds of services do families require to ensure that the needs of caregivers and children are being met? What resources do mothers perceive as most likely to ensure their physical and emotional well-being? What types of assistance do mothers perceive as most likely to allow them to cope during the initial transition from hospital to home? Intervention studies are sorely needed. Further research should include a larger sample with broader socio-economic and educational representation.

This theory needs further density, refinement, testing, and validation. This study lends eloquent support to the idea that nursing respite care is crucial to mothers' coping with almost intolerable situations. More research is needed to determine the characteristics these programs need in order to help families achieve optimal functioning. In short, more evaluation and policy research is essential to keep respite-care options for families, who extend the formal health-care system and save it money, on the policy-making and government agenda.

These mothers' accounts provide a graphic, detailed, and rich picture of the demands of caring for medically complex children at home and the impact of in-home nursing respite services. The findings

highlight the assertion that "support of all families must be paramount, and private and public resources must be redirected to allow families the choice and control over their own lives" (Cernoch & Newhouse, 1997, p. 409).

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