

Trajectory of Certain Death at an Unknown Time: Children with Neurodegenerative Life-Threatening Illnesses

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Les enfants atteints de maladies neurodégénératives graves constituent une proportion importante des enfants nécessitant des soins palliatifs. Bien que la plus grande part de leurs soins soient prodigués à la maison par leur famille, et ce pendant de nombreuses années, il existe peu de recherches qui se penchent sur le vécu des familles ayant un enfant qui se meurt d'une telle maladie au sein de leur foyer. Pour cette étude théorique concrète, des données ont été cueillies auprès de huit familles au moyen d'observations et d'entrevues sur cassettes audio. En vivant avec leur enfant en voie de mourir, les familles ont évolué dans un processus qui les a conduit à *naviguer en territoire inconnu*. La trajectoire de la maladie menant à une mort certaine et temporellement indéterminée ne se traduisait pas par un déclin continu. Au contraire, pour la plupart du temps, ces familles atteignaient des plateaux relativement stables et se sentaient souvent seules et loins des professionnels de la santé. Inévitablement, des périodes d'instabilité se sont manifestées au cours des événements déclencheurs subséquents qui s'inscrivaient dans le processus menant les familles à *quitter le plateau* en raison de la mort inévitable de l'enfant. Les implications quant à la recherche et à la pratique font l'objet de discussions.

Children with neurodegenerative life-threatening illnesses (NLTIs) account for a significant proportion of children requiring palliative care. Most of their care is provided at home by their families over many years, yet there is a paucity of research examining families' experiences when a child with an NLTI is dying at home. In this grounded theory study, data were collected from 8 families through observations and audiotaped interviews. Families moved through a process of *navigating uncharted territory* as they lived with their dying child. The illness trajectory of certain death at an unknown time was not a steady decline. Instead, families lived much of their lives on plateaus of relative stability where they often felt alone and isolated from health-care professionals. Inevitably, periods of instability originated in subsequent precipitating events in the process that led to families *dropping off the plateau* on the way to the child's inevitable death. Implications for research and practice are discussed.

The numbers of children with a prolonged terminal illness are low when compared with adults. At any one time, there are over 200 children in the province of British Columbia living with progressive life-threatening illnesses (PLTIs) (Davies, 1992). One estimate from the

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United Kingdom is that 1:1000 children may be affected by PLTIs (Goldman, 1996). Although the numbers are relatively small, these children pose substantial management problems (Caring Institute of the Foundation for Hospice and Home Care, 1987). Additionally, the numbers are projected to increase as the incidence of life-threatening diseases rises and as advances in technology and medicine reduce mortality rates (Broome, 1998; Davies & Howell, 1998). Care for these children is typically provided at home by their families over an extended period of time, often years (Burne, Dominica, & Baum, 1984; Goldman, 1998; Stevens, 1998), yet there is little available research to guide professionals in assisting such families.

Children in pediatric palliative care suffer from a wide variety of diseases and syndromes. About 20% of these children have cancer. Many have progressive neuromuscular or neurodegenerative conditions (NLTIs) that will eventually cause their death (Ashby, Kosky, Laver, & Sims, 1991; Davies & Howell, 1998; Goldman, 1996). There is a lack of knowledge about the experiences of their families. Health professionals have barely begun to document the effects on families of caring for a child with an NLTi, and little is known about the most appropriate interventions.

Literature Review

Some researchers (Davies, 1996; Martinson, 1993; Parker, 1996; Stein, Forrest, Woolley, & Baum, 1989; Stein & Woolley, 1990) have begun to investigate the impact on families of caring for a child with a PLTI at home. However, research in pediatric palliative care has been minimal. Only two studies were found that focused specifically on families of children with neurodegenerative disorders (Davies, 1996; Parker), and there is no published pediatric research documenting the illness trajectory of certain death at an unknown time — that is, a death that is inevitable but the timing of which cannot be predicted by anyone, including health-care professionals. The majority of available research has been published only within the past few years. It tentatively suggests, however, that a child's illness has a profound impact on every dimension of family life. The impact falls into five broad categories: emotional, physical, financial, and spiritual disruptions, and changes in family structure and patterns of interaction.

The emotional impact on families of caring for a child with a PLTI, including cancer, cystic fibrosis, HIV/AIDS, and NLTIs, is beginning to be documented (Bluebond-Langner, 1996; Clarke-Steffen, 1997; Davies, 1996; Gravelle, 1997; Parker, 1996; Stein et al., 1989; Stein & Woolley,

1990; Wiener, Theut, Steinberg, Riekert, & Pizzo, 1994). Most parents are anxious and worried (Parker; Stein et al.; Whyte, 1992). Many are depressed (Wiener et al.) or experience varying levels of anxiety, insomnia, and social dysfunction as they struggle to balance the demands of their ill child with the management of everyday living (Stein & Woolley). Because some NLTIs are genetic, parents may feel responsible for causing the child's illness (Davies, 1996; Hunt & Burne, 1995; Parker).

A few authors have noted that parents of children with PLTIs are exhausted (Gravelle, 1997; Martinson, 1993; Stein & Woolley, 1990). In addition, exhaustion has been observed in mothers of chronically ill children (Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994) and has been recognized as having a significant impact on their lives (Gravelle), although this effect has not been well described. Only one study provides some insight into the possible physical impacts of caring for a child with an NLTI (Leonard, Johnson, & Brust, 1993), reporting declining health in mothers of children with disabilities.

Families face many financial costs that are invisible to others yet drain family resources. High cumulative monetary costs are related to buying medications, special diets, and equipment, or frequent attendance at health-care facilities with the associated costs of travel, food, and telephone calls (Birenbaum & Clarke-Steffen, 1992; Stein et al., 1989; Stein & Woolley, 1990). There are also indirect costs, such as reductions in a mother's work hours resulting in decreased family income just as financial costs are increasing (Parker, 1996).

There is some evidence that parents seek spiritual guidance and support (Davies, 1996). Spirituality and faith provide both emotional and network support for many parents. Faith has been shown to be a key factor in a family's ability to keep an ill child at home (Davies, 1996).

A child's life-threatening illness may disrupt family patterns of interaction, require family reorganization, and impose shared adaptational changes. Management of the child's illness may necessitate changes in family roles (Clarke-Steffen, 1997; Gravelle, 1997; Stein et al., 1989; Stein & Woolley, 1990). In addition, routines imposed by the child's needs may cause disruptions in the daily routines of family life (Parker, 1996; Stein & Woolley). Little is known about how family structure and interactions change over time. It is not unrealistic to expect that families will undergo many changes when a child has a terminal illness. However, little is known about when and how these changes occur, and the literature offers little guidance for professionals in providing care to such families.

Purpose

This paper presents selected findings from a dissertation study (Steele, 1999). The purpose of the study was to enhance understanding among health-care professionals of the experiences of families with a child who has an NLTI. The specific aims were: (1) to describe families' perceptions and experiences of living with a child who has an NLTI, and how those experiences change over time; (2) to describe the impact on the family of living with a child who has an NLTI; and (3) to describe families' perceptions of the factors that influence their ability to care for their child with an NLTI. The purposes of the paper are to provide a brief overview of the grounded theory that emerged from the study and to describe the illness trajectory when families face a child's certain death at an unknown time.

Method

Procedure

Data were collected through a pediatric hospice-care program and a children's hospital after ethical approval had been obtained from each facility and from the researcher's university. Families were excluded if the child had been diagnosed within the previous month, because it was anticipated that they would lack the depth of experience required to act as key informants. Families were also excluded if the child was expected to die in less than 1 month, because of the potential stress of this period and because it was anticipated that they would have unique needs and experiences. This decision was made after careful deliberation with colleagues in pediatric palliative care and on the strong recommendation of four parents whose children had died. Further eligibility criteria were: that the ill child be no more than 17 years of age and be diagnosed with an NLTI; that at least one adult who lived with the child and provided care agree to participate; that participating adult family members understand English well enough to give informed consent and to be interviewed; that participating siblings be able to communicate in English; that in addition to parental consent, minor children aged 7 and older give their assent; and that the family be emotionally and physically capable of participating in the study. Families who were considered at risk were not approached.

Hospice and hospital staff made initial contact with families to explain that a study was in progress and that agreeing to talk with the researcher did not commit them to participating in the study. The researcher was clearly differentiated from the care provider, and verbal consent was obtained to allow the nurse to forward the family mem-

ber's name and telephone number to the researcher. The researcher then contacted parents by telephone, described the study to them, invited them to participate, and followed up by obtaining written consent in the family's home.

Participants

A total of eight families comprising 29 family members participated in the study. A total of 10 sick children (six boys, four girls) were observed, as two families had two children with an NLTi. The children's ages ranged from 3 to 13 years. At the time of the study, the children had been diagnosed for 2.5 to 6 years. While all of the children had an NLTi, the actual diagnoses will not be named to ensure anonymity. Most of these individual illnesses affect very few children throughout the world. Indeed, some of the study children represented the only known case of the particular illness in their geographic area. Identifying the diagnoses would effectively identify the children and their families. While the different illnesses are manifested in many ways, common attributes such as changes in verbal ability, changes in motor skills, and a proliferation of feeding disorders meant that these families experienced many of the same opportunities and challenges during the course of the illness.

There were siblings in only three of the families. Because the NLTIs are often genetic, most of the parents chose to have no more children once they learned of their child's diagnosis. Thus the small number of siblings was a result of a significant parental decision rather than serendipity. Out of four siblings, three — all female — had been born before the child was diagnosed. The other sibling was male. The siblings ranged in age from 2 to 9 years.

In the majority of families the parents were married and lived together, although there were difficulties in most of the marriages. The length of the marriages ranged from 8 to 15 years. The parents ranged in age from 28 to 48 years. Most had completed high school, although educational levels varied from Grade 6 to university degree. Occupations included both professional and non-professional. Some of the parents were currently unemployed, often because they were caring for the ill child.

Socio-economic diversity was apparent, with annual family incomes ranging from \$11,000 to \$112,000. Four families subsisted on incomes of less than \$15,000 per year, while the others earned \$50,000 or more. However, all families reported a substantial drop in actual or anticipated income due to the child's illness. All but one family identified

with the dominant Caucasian Canadian culture; the other family came from an East Indian background.

Data Collection and Analysis

The primary analytical method used was grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990), a qualitative research method in which theoretical explanations of participants' subjective experiences and situational meanings are generated. Because of its focus on social processes, grounded theory is particularly suited to family research. The main method of data collection was in-depth interviews with families supplemented by participant observations in the home. First each family member was interviewed individually; then the family was interviewed as a group. None of the ill children were interviewed because of their limited ability to communicate. Interviews were audiotaped and transcribed verbatim by the researcher. Data collection ceased when theoretical saturation was reached. Initial data collection occurred over a period of 1 year. During the following year, the evolving analysis was shared with the families. After the first interview and observations were completed with all eight families, each family was sent the preliminary analysis by mail. Second interviews took place by telephone, except for one in-home interview. Two families requested major iterations of the evolving theory so they could make comments; the data were sent by mail and these families were interviewed by telephone on a few occasions. The other families simply requested a copy of the completed research report.

Data analysis was carried out concurrently with data collection. Memos and diagrams were used to document the process and to capture relationships between categories and subcategories. Commonalities and differences both within and across data sources were checked through constant comparative analysis of each transcript and field note. The process involved in families' experiences was identified by linking action/interactional sequences. During "open coding," data were examined line by line to identify codes or words that captured the meaning of events. Similar phenomena were given the same conceptual name and these concepts were then grouped into preliminary categories. Connections between a category and its subcategories were made during "axial coding," when the researcher asked questions of the data and compared concepts. A coding paradigm was used to specify a category in terms of the conditions that gave rise to it: context, intervening conditions, action/interactional strategies, and resultant consequences. Finally, the core category was selected through a process of "selective

coding.” The researcher systematically related this central category to other categories, validated those relationships, and filled in the categories that needed further refinement and development. The core category was named with a high level of abstraction, and the chosen conceptual label fit the story it represented.

Findings

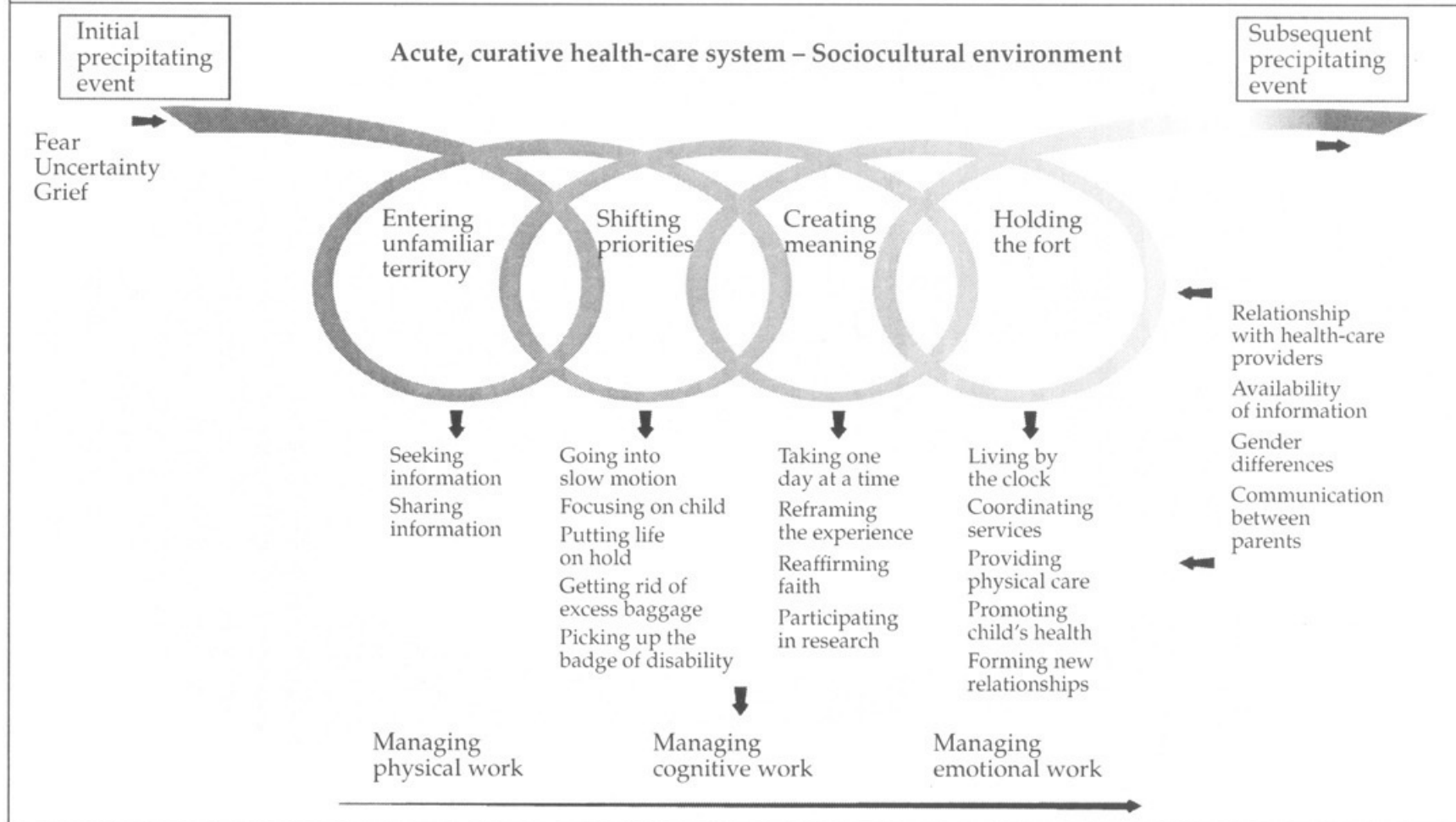
Overview

The basic social process of *navigating uncharted territory* characterized the experience of the families. Strong emotions of fear, uncertainty, and grief gave the process momentum. While these emotions were always present, they changed in intensity over time. *Navigating uncharted territory* comprised four dimensions: *entering unfamiliar territory*, *shifting priorities*, *creating meaning*, and *holding the fort*. Each dimension, in turn, involved strategies that the families used to manage the experience. The context of the illness experience included *acute, curative health-care system* and *sociocultural environment*. In addition, the families’ experiences were moderated by four intervening conditions: *relationships with health-care providers*, *availability of information*, *gender differences*, and *communication between parents* (see Figure 1).

Families sought ways of dealing with the unfamiliarity, uncertainty, and unpredictability in their lives. Parents tried to describe an experience they perceived as unique, filled with poignancy, and indescribable. Their grief encompassed many losses, such as their lost dreams for their child and their loss of relationships with extended family and friends. Some parents underwent a transformation that resulted in personal growth. Those parents who made peace with their emotions, accepted the situation, and formed positive meanings from the experience felt more in control of their lives, were not overwhelmed by their emotions, and believed that they had gained from the experience.

The illness placed heavy demands on families, taxing them cognitively, emotionally, and physically and requiring them to undertake extensive work to manage the experience. Many parents suffered from exhaustion, injuries, migraine headaches, anemia, or hives. Parents also experienced extreme emotional distress. This often lessened as they became more familiar with the illness, its treatment, and the prognosis. However, a change in the child’s health, such as an acute chest infection, inevitably produced increased distress as well as a heavier workload.

Figure 1 *Navigating Uncharted Territory*



Siblings were sad that the child was dying and that they were losing a playmate and sibling. They were also angry because the child was dying, and angry or upset that their parents and others focused most of their attention on the child. One sibling feared that her parents would separate. On the positive side, a couple of siblings were self-sufficient, confident, empathetic, and adaptable to changing circumstances. The siblings were generally viewed as less demanding than other children of their age. In addition, some siblings had reasoning abilities that would be expected of an older child.

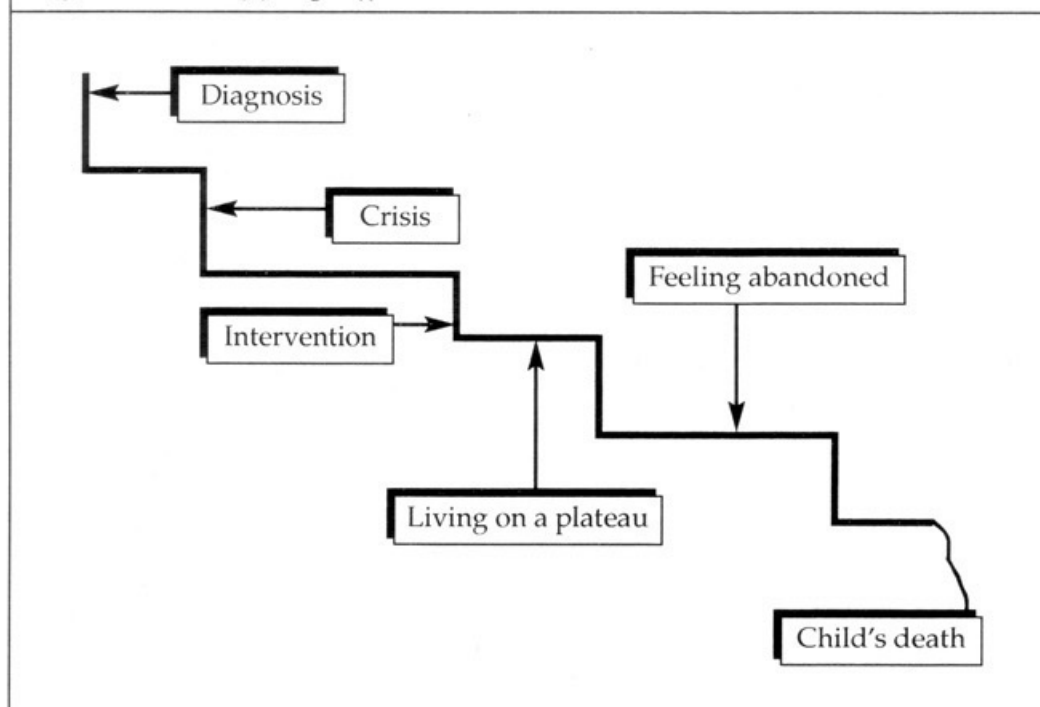
Parents reported a range of onset patterns for the child's illness. For many, the beginning had come when a parent, usually the mother, noticed the child exhibiting some unusual behaviour or symptom. The process of diagnosis was often long and drawn out and was usually accompanied by severe emotional distress. A major component of the distress was uncertainty and fear about the diagnosis, yet most parents were relieved once the diagnosis had been made. Although the children were diagnosed with NLTIs that would lead to their eventual death, the families remained uncertain about how the child would respond to medical treatments, how long the child could be expected to live, and how their ability to manage would be altered as the child's disease progressed. The uncertain course of the illness caused enormous stress for families and contributed to increased intrusiveness in their lives. They were taken on a roller-coaster ride over which they had little control.

Illness Trajectory

Navigating uncharted territory was a continuous process set in motion by the initial precipitating event. Over time, families shifted their priorities, found meaning in the situation, and settled into a period of relative stability. Although families explored their new territory and found ways of managing their new world, that world did not stay the same for long. Subsequent precipitating events, such as a decline in the child's physical health or a need for new medical equipment, sent families into unfamiliar territory once again and impacted on the other dimensions of the process. Families described these times as *dropping off the plateau* (see Figure 2).

Families adjusted their lives every time their child's condition changed. In most families, changes occurred most rapidly at the beginning of the illness, eventually slowing down. However, there was no predictable pattern. Occasionally a child's condition improved slightly for a period, yet parents knew that the child was on a downward trajectory towards inevitable death.

Figure 2 *Dropping Off the Plateau*



The trajectory, however, was not a steady decline. Instead, families lived their lives on plateaus of relative stability, waiting for the next crisis or a sudden decline in their child's condition. While on a plateau, parents tended to keep their thoughts about the illness and prognosis in the background. When the child became really sick, their thoughts about the illness and prognosis moved to the forefront. During each crisis, families dropped off the current plateau and fell until they reached the next plateau:

She will go along on a plateau of doing things. Well, say for instance, like right now she is going along seeing things and then all of a sudden she will drop off not seeing anything.

The extent of the drop depended on both the severity of the precipitating event and the corrective options available. In the beginning, families were often faced with short plateaus accompanied by sharp drops as the child lost abilities. Then, as the child's condition worsened and there was little more to lose, the drops would become less severe. Treatments could shorten the drop, but treatment options became more limited as the illness progressed.

Families worked hard to extend the length of the plateaus. They expended much time and energy promoting the child's health in order

to prevent the deterioration that would push them off the plateau. The primary goal for many families was to keep the child as healthy as possible, for two reasons: to make the child live longer, and to lessen disruptions to family life. Parents worked hard to keep the child safe, prevent the child from becoming ill, and provide the child with good nutrition. They continually monitored the child to identify potential health threats. Families lived in fear of the child developing pneumonia or another illness that might hasten death. They developed strategies to limit contact with those who might be infectious. If the child attended school and other students were ill, the child was kept home until the perceived danger was over. In one case nurses and other workers in the home had "strict instructions that if they have, if they think they are even coming down with anything, don't bother setting foot in the door." A parent with even a minor illness such as a cold did not, wherever possible, provide care to the child. Either the other parent assumed full responsibility for care or, as in one case, "You wear rubber gloves. You don't breathe anywhere near her trying to keep your face away. You wash your hands 500 million times in a day."

Families spent most of their lives on plateaus. Living on a plateau was easier than dealing with crises:

Right now we are at a stage where he's reached a plateau. Although he is still deteriorating, we can cope because he is moving at a really slow pace.

Yet many families also felt frightened and alone on the plateaus, abandoned by the health-care system. Although parents emphasized the importance of an ongoing relationship with a few key individuals in the health-care system, they often interacted with and received help from the system only when they were in crisis. In many cases, consequently, professionals failed to see the whole picture. Some professionals made decisions based on intermittent, crisis-induced interactions, decisions that were irrelevant to the families' everyday lives. For example, a dietitian insisted that a child needed a gastrostomy tube because of his low weight, even though the weight loss had been caused by an episode of pneumonia. The child's father said:

They're looking at this situation right now, right here, right now. But...right here, right now is diddly on the overall perspective. [The nutritionist] only sees him when he's sick, so she wants a [feeding] tube in him. She's never seen him when he's in good health. Or on a good day.

Professionals seldom recognized a family's need for ongoing support when the child's condition was relatively stable, thus families often struggled in isolation. One mother urged passionately:

When people like us end up in your world, don't leave us alone. Just don't shove us out of the door and leave us alone...once we left [the hospital], that was it. That was IT. It was like they were throwing us to the wolves.

Dropping off the plateau affected all other dimensions of the process. There was an increase in either fear, uncertainty, or grief, depending on the particular precipitating event. Each time families fell to the next plateau, they found themselves once again in new territory. Consequently, they needed to once again learn about the new area and find ways to manage their world. Families continued moving through the process of *navigating uncharted territory* as they encountered further precipitating events. The process would eventually end with the child's death.

Discussion

Life with a child who has an NLTi cannot be reduced to simply identifying the coping strategies used by individual family members, or even the family as a whole, when faced with acute or chronic stressors. The family's full biography and illness trajectory must be taken into account. The families in this study experienced an incredible workload because of the child's illness. They had to manage the physical, cognitive, and emotional work generated by the situation, while also continuing with daily life. Managing the work required a great deal of effort and extensive maintenance. Professionals, extended family, and friends seldom recognized the effort involved as families navigated this uncharted territory.

The work of chronic illness has been well documented by Corbin and Strauss (1988, 1991). While their framework was developed with adults only, many of its areas are relevant for exploring the experiences of families with a child who has an NLTi. This current study extends Corbin and Strauss's theoretical formulations to include such families. Corbin and Strauss describe the management of a chronic illness as a complex process, and this was found to be true in the present study, as families managed the long-term illness of their child.

A significant finding of this study is the importance of understanding that the work faced by families caring for a child with NLTis does not consist simply of a list of tasks. Often with little outside support for extended periods of time, the families carried out this work while grieving the losses associated with the child's diagnosis, prognosis, and deterioration. Moreover, the demands of each task were not static. Family

members could not relax once they had learned one task: over time, the demand for a particular task changed or other tasks became necessary as families moved through the illness trajectory.

Corbin and Strauss (1988, 1991) use the term *trajectory* to encompass not only the course of the illness, but also the organizational work involved and the impact on those who carry it out. These authors view the illness trajectory as a way of recognizing the active role that people take in changing the course of an illness, and as a way of capturing experiences involving time, work, non-medical features, and the interplay of patients, spouses, and health-care providers. In the present study, families were a critical component in all aspects of the child's illness trajectory. They played a vital role in changing the course of the illness, did most of the organizational work, and suffered the impact of that labour. These findings provide evidence that the work of Corbin and Strauss could be extended to include families.

For the families of children with NLTIs, the experiences of navigating uncharted territory were found to be unrelated to steady decline in the child's health. Families lived their lives on plateaus of relative stability, waiting for the next crisis or sudden decline in the child's condition. With each crisis, the family dropped off the current plateau and fell until they reached the next one. Ground that was lost could seldom be regained. Families therefore faced frequent losses and held out little hope for rehabilitation. They concentrated on making the best of the abilities their child still had and worked hard to prevent further losses. While initially some decline could be slowed down medically if an appropriate treatment was available, most of the credit for preventing deterioration belonged with families. Their management skills in health promotion and illness prevention were key in extending the length of the plateaus. Health-care professionals may not always recognize the expertise of families, yet it was this expertise that kept the child as healthy as possible. The skills and knowledge developed by families may be an invaluable resource for professionals.

The uneven and stair-like trajectory of certain death at an unknown time has not been previously documented in pediatric research. However, Rolland (1994) notes that progressive illnesses are often characterized by a stepwise or progressive deterioration, either rapid or slow. He suggests that patients and caregivers receive minimal relief from symptoms during progressive illness, as they have to constantly adapt and adjust to role changes. The idea of plateaus and drop-offs is also partially supported by research with parents of chronically ill

children that identified critical times in a child's illness when the family faces increased needs or changes in the support structure (Clements, Copeland, & Loftus, 1990; Whyte, 1992). Family researchers also support the concept of plateaus during illness experiences, though indirectly (Clements et al.; Whyte). They describe families as living in a state of equilibrium when emotional and physical support is available to meet their needs.

The present study found that relationships with health-care professionals were very important, both in the home and in tertiary settings. Although the families spent most of their lives at home, the inevitable crises in the child's life brought them into intermittent contact with the system of acute health care. Relationships with key individuals in tertiary care were important to families as these individuals could function as entry points to the system (e.g., physicians) or as ongoing resources (e.g., nurses, social workers). In addition, families wanted to have someone in the system who knew the family history and could facilitate access to relevant information, resources, and professional and non-professional assistance. The potential for these relationships to make a family's journey smoother and less stressful should not be underestimated.

Researchers have identified feelings of isolation and loneliness among those living on plateaus (Davies, 1996; Diehl, Moffitt, & Wade, 1991; Walker, Epstein, Taylor, Crocker, & Tuttle, 1989; Woolley, 1991; Woolley, Stein, Forrest, & Baum, 1991). When families have little contact with health-care providers in hospital, they often feel lost and alone. Many families have advocated for an ongoing relationship with one person who will coordinate care, provide guidance, and develop a close and trusting relationship with them (Chambers, Oakhill, Cornish, & Curnick, 1989; Davies, 1996; Diehl et al.; James & Johnson, 1997; Stein & Woolley, 1990; Woolley; Woolley et al.). Research on the effectiveness of such contact, however, is limited. One group of researchers (Burke, Handley-Derry, Costello, Kauffmann, & Dillon, 1997) used a two-group, pretest-posttest design to determine the efficacy of a community-based, stress-point nursing intervention with families of chronically ill children. A research nurse worked with parents in the experimental group to identify their stresses and to develop coping strategies. She maintained contact with families by telephone, mail, and face-to-face meetings. Results showed improved coping and family functioning when the families received the intervention. It appears that contact with the tertiary system, even if minimal, may provide a sense of comfort or a safety net for families who are largely managing on their own.

Research and Practice Implications

A variety of both qualitative and quantitative research methods and data-analysis techniques need to be developed and tested for their usefulness at the family level. Neither qualitative nor quantitative research alone seems sufficient to capture the complexity of family life. There is a need to examine the links between qualitative and quantitative research. Practitioners need to know both the processes by which families manage the experience and the outcomes associated with different subjective perceptions and management approaches.

There is little available research that examines the link or interface between families and the health-care system. Yet the present study found that relationships within the system played an important role. Further research, using both qualitative and quantitative methods, might examine family interactions with the health-care system so that practitioners can gain a better understanding of the types of intervention that are most appropriate for families.

The families in the present study clearly valued ongoing contact with one person in the health-care system. An intervention study could be designed to evaluate interactions between a coordinator and a family. Outcomes could include families' satisfaction with care and their perception of the degree of fragmentation in the system before and after the intervention.

There is little research examining the trajectory of certain death at an unknown time. Copp (1996, cited in Copp, 1998) appears to be the only researcher to have explored this trajectory. Apart from her study, the nature of the form, shape, and duration of this death trajectory has not been articulated in any depth. This current study adds to the available knowledge about the trajectory of certain death at an unknown time, but further research, to determine similarities and differences across varying populations, is warranted. While it may be possible to extend Corbin and Strauss's (1988, 1991) conceptualization of chronic illness to include families of children with NLTIs, further research is required to validate this suggestion.

Clinicians may believe they lack the knowledge to help the families of a child with an NLTi. However, if they resolve to move beyond the medical diagnosis and think in terms of illness trajectory and its implications, clinicians may find that the knowledge they have accumulated in practice can be applied in many ways. Clinicians should also be honest about areas in which they lack knowledge and make an effort to educate themselves. A willingness to learn from families and collabo-

rate with them may result in positive relationships and the sharing of valuable knowledge.

Two specific suggestions arise from this study: recognizing the work that families undertake; and identifying and sharing strategies that families can use to mitigate their work. Clinicians can then work with families to identify interventions that might lessen their workload. Telling a family that they are doing a great job in caring for their child is an intervention that takes little time and costs no money, yet is very important in helping them feel appreciated.

Ongoing contact with a professional who provides information and coordinates care may alleviate a family's anxiety and sense of isolation. Having one person who knows the family and can provide continuity of care may prevent problems and, when necessary, facilitate movement through the health-care system. Advocacy and support are extremely helpful as families learn how to provide the best care for their child. Information may help reduce fear and uncertainty. Written rather than verbal information is often the most useful, as families can read it repeatedly as needed. Anticipatory guidance on an ongoing basis and raising possibilities for the future as changes occur may help families manage plateau drop-offs.

Finally, providing care to the whole family is extremely important. It requires that professionals develop skills in family-level care, yet education of health professionals has primarily focused on the ill individual as the unit of care. Learning about a family's biography and providing family-level care require time and specialized skills. These are not abundant in the current system. However, professionals can learn ways of providing family-level care in basic and continuing-education courses. Collaboration with colleagues and professional support groups can also be used to improve one's expertise.

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