Parenting and Childhood Chronicity: Making Visible the Invisible Work

Lynne D. Ray, RN, PhD

The work required to raise a child with a chronic illness or disability is above and beyond that of raising a typical child. This article presents a model, Parenting and Childhood Chronicity (PACC), that was developed during an interpretive study with 43 parents of 34 children (aged 15 months to 16 years) with various chronic conditions, is presented. "Special needs parenting" describes the additional care that a child needs and includes medical care, parenting plus, and working the systems. "Minimizing consequences" reflects the struggle to balance the rest of family life and includes parenting siblings, maintaining relationships, and keeping yourself going.

SOCIETY DEPENDS ON families to provide complex care at home to those with chronic illness and disability. Acquiring the requisite knowledge, skills, and organization necessary to raise a child with a chronic health condition creates many challenges and claims a significant portion of family resources. The nature and process of parenting must be restructured to meet these challenges, and this has significant consequences for the entire family.

Research describing parents' experiences with raising a child with a chronic condition began over 35 years ago (Davis, 1963). Since then, many descriptive and correlational studies have been performed. For reviews, see Beresford (1994), Burke, Kauffmann, Costello, Wiskin, & Harrison (1998), Drotar (1997), Hayes (1997), and Holditch-Davis & Miles (1997), Only recently have intervention studies begun to appear in the literature (Burke, Handley-Derry, Costello, Kauffmann, & Dillon, 1997; Pelchat, Bisson, Ricard, Perreault, & Bouchard, 1999; Pless, Feeley, Gottlieb, Rowat, Dougherty, & Willard, 1994; Ritchie, Stewart, Ellerton, Thompson, Meade, & Viscount, 2000). Two methodological building blocks need to be in place to support intervention studies. The first is empirically based, family-centered models of caregiving. The second is conceptually and methodologically sound measurement instruments. This article addresses the first criterion.

To date, models of the content parental caregiving responsibilities have focused on adaptive tasks (Canam, 1993), stressors and tasks (Burke, Kauffmann, Costello, Wiskin, & Harrison, 1998; Burke, Kauffmann, Harrison, & Wiskin, 1999), and concerns (Feeley & Gottlieb, 1998). These models are an excellent beginning for enumerating the sources of stress and tasks that parents face, but they do not capture the full range of parental responsibilities that result from caregiving. In particular, these models do not distinguish between the work that is publicly visible versus that which is invisible. When aspects of caregiving are invisible, professionals, policy stakeholders, and the general public cannot fully understand or appreciate caregiving and its consequences. A representation that makes visible the invisible is critical for understanding, assessing, and supporting the caregiving parents.

The purpose of this study was to validate a model describing the work required to raise a child with a chronic health condition with a sample of parents providing theoretically diverse care. The model, Parenting and Childhood Chronicity (PACC), was developed through 3 iterative cycles of interpretation with different parent samples. The first version was developed as part of a study that examined stress and coping among caregiving parents (Ray, 1988). That version was revised with use of data from a hospital-based evaluation of

---

From the Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada.

Address correspondence and reprint requests to Lynne D. Ray, RN, PhD, Faculty of Nursing, 3rd Floor CSB, University of Alberta, Edmonton, Alberta, Canada T6G 2G3. E-mail: Lynne.Ray@ualberta.ca.

0882-5963/02/1706-0007$35.00/0
doi:10.1053/jpdn.2002.127172

discharge planning (unpublished data) and a review of other detailed interpretive reports (Hagedorn, 1993; Hayes, 1992; McKeever, 1991). In the current study, feedback on the second draft was sought from caregiving parents who could speak from diverse caregiving contexts.

PARTICIPANTS

In the current cross-sectional study a heterogeneous sample was purposively recruited to maximize variation in the ill or disabled children's age, diagnosis, home medical care, and condition severity. All children required at least one form of care for a medical condition. Children who had behavioral or developmental disabilities alone were excluded. Once ethical and administrative approval was obtained, participants were recruited through clinicians at a developmental center, pediatric rehabilitation hospital, respite program, and two support associations. Each agency served children of all ages and a variety of diagnoses and was therefore able to support the purposive sampling. The complexity of the children's care ranged from mobility aids to 24-hour ventilator support. The age of the children with chronic health problems ranged from 15 months to 16 years.

Thirty families with 34 children who had chronic health conditions participated. Thirty mothers and thirteen fathers were interviewed. Family composition reflected the variety of families in society: 24 heterosexual couples either married, remarried, or living together; 1 lesbian couple; 2 engaged mothers; 2 single mothers; and 1 single father. Of the 30 mothers, 20 were wage-earners in some capacity. This included part- and full-time employment as well as in-home and out-of-home employment.

PHILOSOPHIC PERSPECTIVE AND METHOD

The interpretive perspective that informed this study was philosophic hermeneutics (Bernstein, 1991; Gadamer, 1975; Thompson, 1990). Within this hermeneutic tradition, a person's understanding of his or her situation stems from social and historical roots and cannot be separated from his or her interests, culture, language, history, or ethical standpoints. The prior meanings in families' everyday lives provide both the conditions and the limits of their understanding. Context is primary (Rabinow & Sullivan, 1987); there can be no single authoritative interpretation of the caregiving experience (Linge, 1976). A parent's interpretation of the different states of his or her child and the family's development, health, and well being is determined by his or her history and social and practical context. A parent's understanding of his or her situation is reinterpreted as his or her context evolves over time. Understanding families' interpretations is critical to understanding the health of families raising children with chronic conditions, as well as the range of situated options their interpretations allow. Just as families' interpretations evolve with contextual changes, research interpretations evolve as new data are acquired. From a hermeneutic perspective, "validation" of the caregiving model is an ongoing process of reinterpretation and revision based on increasingly shared meanings.

Data Collection

Families chose the most convenient interview location for their interview; 28 chose the family home and 2 mothers preferred to be interviewed at work. I began interviews by giving each parent a pie-chart diagram representing the major sections of PACC. The pie chart contained 7 equal-sized sections labeled as follows: doing special care, parenting plus, working the systems, changing relationships, keeping yourself going, keeping the household going, and changing family priorities. After I provided a brief explanation of what I meant by each section in the pie chart, parents explained what each section meant in the context of their lives. This prompt was sufficient to launch parents into 1- to 3-hour descriptions of their caregiving experiences. Some sections generated much more discussion than others, depending on how much parents struggled with that particular issue.

Data Management and Interpretation

Thirteen hundred pages of text were transcribed verbatim in Microsoft Word (Microsoft Corp, Redmond, Wash) and imported into a hypertext database (FolioVIEWS (Folio Corporation, Provo, Utah) for data management. Analytic notes were created in a separate database, and hypertext links were made to related text. Advanced search techniques allowed data searching, viewing, and printing of coded data in a variety of ways. Ray (1997) previously described these techniques in detail.

The first interpretive step was to code the transcribed data according to the themes and organization of the preliminary model. As new or different interpretations occurred, they were added to the coding scheme. Thematically similar codes were combined to produce the 6 major sections of the revised model. These sections represented substantive issues only; within each section, parents offered multiple interpretations of the issues. In step two, new, repetitive, convergent, and divergent interpretations in parents' accounts were identified. In the final step, the similarities; differences, antecedents, and consequences of various interpretations were analyzed and compared with data in the previously published literature. The revised version of PACC is shown in Figure 1. The top half represents the work of "special needs parenting," and the bottom half represents the work of "minimizing the consequences" of caregiving for the rest of the family.

SPECIAL NEEDS PARENTING

Doing the Medical Care

Technical care

As other investigators have found (Jerrett & Costello, 1996; McKeever, 1991; Ray & Ritchie, 1993; Thorne, Radford, & Armstrong, 1997), the task of learning to carry out the medical aspects of a child's care was initially frightening, but parents quickly became accustomed to doing the technical aspects of their child's care and then did the tasks automatically. One parent explained:

> Oooohh! We would be scared. Even with his trach. Decanulation. I remember I used to shake after. I would pop it back in and then I would shake. Now it's just a daily thing—we just pop it in.

Parents estimated that it took 6 months before the technical aspects of care became the most taken-for-granted part of their child's care. This time frame seemed to apply regardless of the complexity of the care. Parents noted that care necessitating a daily lengthy struggle between parent and child or that was believed to cause suffering for the child was especially difficult. Meeting nutritional needs of children with oral feeding problems was a prominent example in this and other studies (Adams, Gordon, & Spangler, 1999; Humphry, 1991; Spalding & McKeever, 1998; Thorne, Radford, & Armstrong, 1997).

For the population of children who require medical equipment, the technical care is the most visible and the aspect of care that gains more recognition both by professionals and by the lay public. Parents noted that it is the technology that frightens extended family, school personnel, and the public. The level of technology has also been emphasized in policy decisions regarding the allocation of services. In contrast, many parents believed that technology such as a gastrostomy tube (G tube) was a minor issue in their child's care. One mother said,

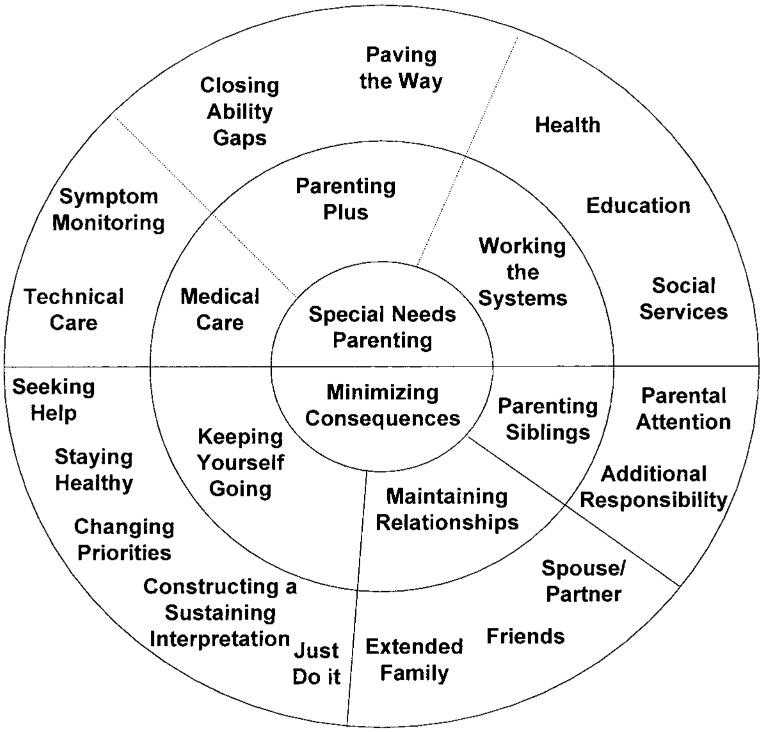

Figure 1. PACC Model: The work of raising a child with a chronic health condition.

"Okay, you have to pour her formula into the bag. And get her plugged in. But it's not that DIFFICULT. The fact that she has a G tube makes her a level two [and eligible for services]. But that's the simple part." As this mother noted, other aspects of care require more sophisticated clinical judgment and management skills.

Not only did parents become experts in caring for their child's medical needs, they also became experts at observing and supervising the technical and interactional competency of professionals—both in the hospital and in the home (Nicholas, 1999). One parent said the following:

> We completely know her care from head to toe. And this helps us in knowing who are good nurses and who are not good nurses. What is not acceptable to us. If you have a certain way of holding a catheter that's not a problem. But we KNOW whether you are doing things correctly, or not. Whether you are harming our children or not. Whether you are confident in you skills, or not. We KNOW that.

Symptom monitoring

Caregiving parents have first responsibility for accurately diagnosing and managing worrisome symptoms, complications, or emergencies (Anderson, 1990; McKeever, 1991). Through this monitoring, they became very attuned to their child. One parent said, "I've become so aware of him, that even though I'm sleeping, I can tell whether his breathing has changed or not. Whether he's just playing in the crib or whether he's having a seizure."

As shown in other studies (Fedewa & Oberst, 1996; Hinds et al., 1996; MacDonald, 1996), the need for vigilant monitoring of symptoms or problems with equipment meant that parents were constantly on guard. This constant level of uncertainty (Cohen, 1993; Horner, 1997; Mishel, 1990) combined with the tension of always being on guard is what has led parents in many studies to note that caregiving is a "24-hour job" (Anderson, 1990; Knafl, Breitmayer, Gallo, & Zoeller, 1996; Turnbull, Patterson, Behr, Murphy, Marquis, & Blue-Banning, 1993).

Parents were responsible for clinical decisions regarding symptom management. Their decisions were guided by what they felt was the priority for the child and for the family (Gallo & Knafl, 1998; Gibson, 1995). Although this purposeful clinical judgment has often been labeled as "noncompliant" or "nonadherent" behavior, a growing number of writers are critiquing and reframing the compliance issue (Atkin & Ahmad, 2000; Gallo & Knafl, 1998; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000; Thorne, 1990; Wuest, 1993b).

Parenting Plus

This section addresses more typical aspects of parenting, but because of the child's condition, these developmentally defined parenting roles are greater in intensity and duration—sometimes lifelong. This is largely invisible work, yet it is probably the most time-consuming because daily activities, milestone achievements, and anticipating future options all take longer when a child has a chronic health condition. Parenting plus is similar to the notion of compensatory parenting of Miles & Holditch-Davis (1995).

Closing or filling the gap

Often, children's physical, sensory, physiological, or communicative abilities are such that parents must compensate for skills that are delayed, that the child will never acquire, or that the child is losing (Gagliardi, 1991). When there was hope for the child to achieve delayed abilities, parents in this study put great effort into helping their child close the gap. Parents taught themselves and their children sign language, assumed responsibility for occupational therapy and physiotherapy, and learned how to operate talking computers. They sought out creative opportunities to promote their child's development, such as mounting a stroller on skis or an oxygen tank on a bike.

When the children were unlikely to be able to achieve certain abilities, parents filled that gap. Some parents felt that their personal development was arrested along with their child's. One father explained, "I'm 50 years old. I know people who are 46 years old and their kids are all gone. I still have to go up there and wipe his butt." The consequences of this prolonged or indefinite parenting are compounded by society's lack of recognition for this invisible "low-tech" work (Wuest, 1993a).

Although vigilant monitoring is required for children with unpredictable illness trajectories, it is also an important aspect of parenting a child who has a cognitive or developmental dimension to their condition. Other parents were concerned with issues of safety or social disruption; one mother stayed during preschool to curb her son's potentially disruptive behavior. Some parents with teenagers had reached the conclusion that this watchful parenting would be necessary for the remainder of their child's life.

Paving the way

Societal expectations and reactions necessitate another aspect of special needs parenting. Many parents found that they needed to create social opportunities for their child and bolster his or her self-confidence in preparation for the public's reaction to disability. In one mother's words, "It's a CRUEL world and the instinct is to SHELTER her from it. But she's got to be out in it sometime." As prior authors have noted, many experiences such as staring (Goffman, 1963; Hayes, 1992) and teasing (Hagedorn, 1993) contribute to this interpretation of the world. One father related the following experience: "I've found out in the public people have not been comfortable with him. At all. You can see adults are staring at him. Then you hear them get down and say 'Oh that POOR child!'"

Because of these reactions, parents created a variety of opportunities to prepare their child and/or to "desensitize" the people who would be meeting their child. One mother brought her daughter into work believing that the more her colleagues were exposed to her daughter, the easier it might be for the next child they met. Another mother wrote a children's storybook about her child's condition and shared it with friends and future classmates. This opened up the lines of communication and reestablished friendships that were starting to drift apart.

Gaining a level of acceptance or tolerance was one thing, but achieving true friendship was a major challenge (Crocker, 1998; Heiman, 2000). One parent provided this example:

> She had one little friend here. She was coming over every two weeks just to visit. She stayed the night a couple of nights and her mother called me and asked about [my daughter's] disease and was it terminal? And she said "I don't want Samantha being her friend anymore cause if she dies Samantha will be upset."

Other children had broken off friendships saying, "We can't come over anymore, my Mom and Dad think you're too much trouble." Faced with this, some parents acknowledged that their child was going to be living in a world of adults, and they turned their energies to finding as many ways as possible to entertain their child. Other parents, who had the financial resources, created ways of enticing healthy children to come and play at their house.

Overall, parents invested tremendous energy in anticipating how their child could best fit into the social world. Everything needed to be thought through from a novel perspective, as social structures designed for typical children needed some form of adaptation. Special needs parenting involved a level of anticipation well beyond that of typical parenting and was accompanied by much uncertainty about the best course of action; yet it remained invisible.

Working the Systems

Health and social services

Parents required no explanation of the concept "working the systems." They spoke at length about the frustrations of working with the health, social service, and education systems. Parents generally had greater difficulty with the system structure than with individual professionals. There were a mix of helpful and unhelpful professionals, but the system problems were constant. Several parents indicated "working the systems" was the worst part of having a child with a chronic condition, consuming up to 50% of their caregiving time.

Almost all parents spoke of being overwhelmed when their child was first diagnosed. They grappled with what this was going to mean for their family, and they did not know what questions to ask or what help they might need. As one parent stated, "You don't KNOW what you need. And you don't know what people have to offer." Over time and with experience, parents were able to clearly articulate what they hoped for from the system. Some of these hopes included "Just knowing that people understand and are there for you. That as a parent you are not totally alone with the responsibility." They wanted a system that treated their child as a whole person rather than each discipline or service claiming a piece. They explained that it was "the practical stuff" that they wanted professionals' expertise and advice on. They wished for a system that would be flexible enough so that a program of care could be planned around the child, rather than trying to fit the child into preexisting structures and eligibility categories. They needed information that was freely available, complete, and correct. In addition, they wished there had been one consistent person to whom they could turn who would have helped them sort through the maze of people and programs that fell under the Ministries of Health, Social Services, and Education.

Despite extensive literature promoting principles of family-centered care (Ireys & Perry, 1999; King, Rosenbaum, & King, 1997; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000; Shelton & Stepanek, 1994; Van Riper, 1999), these were exactly the attributes that parents found lacking in the systems. In their experience both parents and professionals struggled with institutional structures and policies that did not support families. Faced with these system limitations, parents tested a host of investigative, management, advocacy, negotiation, and lobbying skills. Although parents arrived at varying interpretations regarding what the most effective strategies were, they all developed greater "participatory competence" (Gibson, 1995).

Collectively, parents spent an extraordinary amount of time searching for information, people, and services. This was done in a trial-and-error or word-of-mouth fashion. The process involved a lot of phone inquiries and meetings and "learning the hard way." Once parents found people who they could rely on for information, the searching became easier. Setting up an integrated program of services for their child often took up to 2 years. Rarely did parents identify one person who had played a key coordinating role with their child's care. Among the 30 families, only two professionals were mentioned who stayed with the family in a committed long-term supportive role. Other families wished they had this kind of person. One parent offered the following recommendation:

> I guess the one thing that's been lacking is a center or a leader. I've had to act in that capacity and it has been very difficult because I DON'T know what's out there. I don't KNOW who to ask. I DON'T have the authority in many cases to let's say, make a referral. So a person to look at the whole picture. And coordinate efforts. That would be the most helpful thing in our lives. ONE person to do that.

As in previous studies (Gibson, 1995; Heaman, 1995; Thyen, Kuhlthau, & Perrin, 1999), parents, almost exclusively mothers, became their child's manager. Often, this meant restructuring employment hours to accommodate the care-management role (Cuskelly, Pulman, & Hayes, 1998). Parents organized and "chaired" team meetings, wrote letters to government officials, sat on advisory councils, and attended conferences to keep abreast of the latest developments in the medical management of their child's condition.

Some strategies used to coordinate professionals were ingenious but a poignant reflection on the lack of coordination within the health care system. One mother invited the professionals involved in her son's care to a luncheon at her home. The professionals were able to meet each other, and her son had one assessment in his home environment.

All parents found that they had no choice but to become an advocate for their child. They tested a variety of strategies for working with professionals and ultimately adopted a wide array of approaches. Some believed in the "power of humility," whereas others claimed that "you don't ask permission, you beg forgiveness." Parents generally preferred to step back and let professionals do their job, but when faced with care that threatened their child, they stepped in and took over. One parent spoke of her experience in a regional hospital:

> I went to the nursing station, phoned the Children's [hospital]. And I said, "These guy's are driving me insane. This child is septic. He's massively perforated his intestine. He has no counts. His temperature's 42. I need an air evac." He said, "It's on it's way."

Some parents also learned that their child's care was affected by the politics between physicians and between hospital departments. When advocating for a particular plan of care for their child, they were acutely aware of the need to avoid political ramifications. Despite the extensive and sophisticated management and advocacy skills that parents developed, this still remained largely invisible to a significant proportion of the health professionals.

Respite

For families who found out about respite and successfully sought it out, it provided critical relief. For several parents in this study, nighttime respite allowed them to sleep so that they could continue through the day. Other parents spoke of the personal support they received through respite. For example, some nurses fulfilled roles as "part of the family," "a best friend," a home-school teacher, and a legal guardian in the parents' will. However, other parents spoke of nurses who would work to rule and had minimal interaction with the child or siblings. The degree of commitment and flexibility among nurses shaped the efficacy of the respite experience.

What remains invisible to most people is the work that stems from having respite personnel in the home. Some, but not all, families had been responsible for finding and training or orienting their own nurses, associate families, or homemakers. This work was sometimes an obstacle for those most in need of help. One mother explained:

> Now I just need somebody in the family to figure out respite for us. Nobody's taken that ball. How to make the calls. To interview the people. There's just NO time. It's hard to FIND people. . . . All I want to do is go to bed.

Parents of children with the most complex needs tended to have the responsibility of keeping time sheets, coordinating schedules, and essentially maintaining a pool of staff. Parents decided what care was assigned to staff and what they, as parents, would be solely responsible for. For all parents receiving respite, the most important part of their management role was ensuring that the person caring for their child was competent and that their child was safe. One parent said the following:

> The bottom line is that you get confident with this person, and then you can actually RELAX. For a while we had other respite help. And it was not respite. You have to stay up and watch them. Teaching, you have to teach them. It's not only important to get respite, but to get respite with someone you can trust.

Three parents were amazed when their respite staff complained of being burned out and took a leave to recover from the strain of the care—the same care that parents had been expected to do on their own. Others found professional staff to be less confident around their child than they were as lay parents. "I have a nurse, she has 28 years of experience with seizure kids. And she still gets petrified when [my son] has a seizure." Overall, parents who located committed, clinically skilled, pragmatic, and flexible respite personnel benefited the most.

Education

There is some evidence that the school system can also prove challenging for families, but this is less well documented in the literature. The school-related literature has focused on the effects of chronic conditions on academic performance (Bender, 1995; Celano & Geller, 1992; Ireys, Salkever, Kolodner, & Bijur, 1996), providing medical information for teachers (Armstrong & Horn, 1995; Bender, 1995), rates of absenteeism (Ireys, Salkever, Kolodner, & Bijur, 1996), school reentry (Sexson & Madan-Swain, 1993), and cognitive sequelae of conditions or treatments (Armstrong & Horn, 1995; Black & Hynd, 1995; Holmes, O'Brien, & Greer, 1995). Less attention has been paid to barriers and attitudes within school systems (Sexson & Madan-Swain, 1995). Parents in this study emphasized issues of access, availability of aides, the public debate regarding integration, and ideological differences regarding responsibility and cutbacks within the school districts.

A major decision that many parents faced was whether their child should be in a fully integrated, partially integrated, or segregated educational setting. Integration was a contentious issue. In an integrated setting both the child and parents faced resentment from teachers and other parents who believed special needs children consumed a disproportionate share of resources. In a segregated school it was difficult to find an optimal match that would support group affiliation and normalcy. Parents were reluctant for their child to be segregated with children who had more severe disabilities.

> Most of the time she spends in the resource room with other kids who are mostly quite severely mentally handicapped. And that has ALWAYS bothered me, because she isn't mentally handicapped. There's never been any real spot for her to fit into.

Parents of children with special needs wanted their child to appear maximally able. Parents of healthy children were concerned about unfair appropriation of the teacher's attention. Despite different motivations, the consequences were the same: no one wanted their child in class with the most severely affected children.

Parents used a host of strategies to facilitate a positive academic experience for their child. All attended school meetings. Other strategies included being on the parent advisory council, volunteering at the school regularly, speaking with the teacher daily, and even donating equipment and funds to the school. Mothers were primarily responsible for these interactions, either because of work schedules or because they were believed to have the patience and people skills required for the task. Parents who were less involved with the school tended to describe a more conflicted relationship with school personnel and more doubts about the adequacy of their child's school experience.

Overall, parents found working with systems "a CONSTANT struggle. You're always constantly having to be on top of things, and making sure things are set up." So, in addition to maintaining vigilance with respect to their child's health status, parents felt compelled to monitor the actions of professionals and institutions with a similar vigilance.

MINIMIZING CONSEQUENCES FOR THE FAMILY

Parenting Siblings

Parental attention

Across studies, parents have demonstrated consistent concerns that siblings are "lost in the shuffle" (Cuskelly & Dadds, 1992; Faux, 1993; Hagedorn, 1993; Williams et al., 1997). Parents in this study had similar worries and found that a special effort was required to set aside time for siblings. To compensate, they tried to set up activities that were dedicated to the healthy siblings. Parents were acutely aware that the child with the chronic condition became a focal point. Some parents were searching for ways to try to shift that focus but were having varied success. One parent said, "What we are trying to do in terms of changing our OWN family priorities is stop the focus being around her. Because it is so unfair to everyone else." Often the family tended to be split up; one parent would do things with the healthy children while the other parent cared for the child who was unable to participate.

> You never have this sense that your whole family is doing something. Very seldom do we do things with our whole family. Very seldom. It just is too complicated. So we don't even pretend that we're going to live a "normal" life. And we're okay with that. Most of the time. Although sometimes it's kind of resented.

Additional responsibility

The literature on siblings also suggests that healthy siblings assume more responsibility, including monitoring their sibling's health status and worrying about their welfare (Davies, 1993; Faulkner, 1996; Howe, 1993; Klein & Schliefer, 1993). Girls are thought to be particularly at risk for greater responsibility, either at parental request or of their own choosing (Hallum, 1995; Stoneman & Berman, 1993). In this study parents claimed that they made specific efforts not to give undue responsibility to healthy siblings. One mother described how her daughter would take on caregiving responsibility as a way to be with her parents. Some parents noted that healthy children worried about their ill brother or sister. For example, one young girl insisted on accompanying her sister on respite weekends so that she could ensure that the respite family was caring for her sister properly. A teenage brother worried about the teasing and hurtful pranks his sister might face in high school.

Maintaining Relationships

Previous studies have shown that when a family has a child with a chronic condition, parents' relationships with their partner, friends, and extended family are tested and usually change in some way. One of the truisms that is often heard is that "some people draw closer, some drift away, but all relationships change." This observation applies for the most important relationship—that with one's spouse or partner (Taanila, Kokkonen, & Järvelin, 1996).

Spouse or partner

Investigators have looked at social support and its effect on families of children with chronic health conditions from a range of theoretical and methodological perspectives. The primary conclusion in this body of literature is that spousal support is most important for mothers. The evidence and explanations for why some relationships grow stronger and others drift apart have been more complex and less conclusive.

There is a widespread belief that the presence of a chronically ill child is associated with more frequent divorce rates. In this study 6 of 30 couples had been divorced; 3 of those were in new long-term relationships. In 3 of the 6 divorces the custodial parent believed that the child's condition played a direct role in the marriage breakdown. Of the 24 couples who remained together, one mother offered the following explanation:

> Sometimes we wonder if we stay together because of [our son]. Or because we love each other. I just can't pack up my son and go. I couldn't imagine coping without my husband. And I know he couldn't without me. So we just sort of—we do. It's our son that has really cemented us together.

Seven couples in this study volunteered their understanding that they were statistically at risk for divorce. The ubiquity of this belief has become one more preconception that families struggle against (Hayes, 1992; Poyadue, 1993). More recent studies on divorce rates are finding that marital dissolutions in this population do not exceed rates in the general population. (Eddy & Walker, 1999; Hallum, 1995; Katz & Krulik, 1999; Taanila, Kokkonen, & Järvelin, 1996). A mutual approach to parenting the child with a chronic condition may be a key element (Knafl & Zoeller, 2000). Couples seem divided among those who felt that the experience of raising a chronically ill child brought them closer together and those who felt further apart as a couple.

Friends

Just as there are changes in spousal relationships, there changes in friendships. Despite the substantial amount of evidence indicating the beneficial effects of support (Thyen, Terres, Yazdgerdi, & Perrin, 1998; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999), especially from other parents of chronically ill children (Ritchie, Stewart, Ellerton, Thompson, Meade, & Viscount, 2000; Taanila, Järvelin, & Kokkonen, 1999), parents frequently report a strong sense of isolation

(Boland & Sims, 1996; Florian & Krulik, 1991; Silver, Bauman, & Weiss, 1999). Data from this study support the interpretation that parents have limited access to other families who share and fully understand their experience. Parents spoke more often of friends drifting away than rallying around them, but often couples experienced a mixture of both. Several parents used the phrase “you find out who your friends really are.” A similar pattern of both drifting away and rallying around occurred among members of the extended families.

Extended family

Within the group of families studied, there was a 3-way split between those whose family lived far away, those who had at least one family member highly involved, and those who had limited or conflicted relationships with extended family members. Some grandparents were too old to cope with the child’s care or were in need of family care themselves. Parents offered two interpretations of why their extend family withdrew: they were uncomfortable and fearful, or “they just didn’t get it.” One mother described her family’s discomfort:

> A lot of my family DOESN’T come around. And I think it is because they don’t really know what to do when they see [him] going into a seizure. Or him having his tube feed. And it’s really hard having to see a two-year-old going through all of the stuff he has to go through, and yet still be so happy. And it’s very hard on my family. So a lot of them DON’T come around very much.

Despite the fears and lack of understanding that distanced some parents from their extended family, there were other extended family members who demonstrated a deep commitment. One parent said, “That night when [my daughter] was operated on, I felt my dad in the corridor. I didn’t see him, I felt him. And then he was there by my side, and he never left me. He never left [my daughter]. He was there for the whole two and a half years.”

Explaining variations in support

The people who remained supportive could be described in two ways: they were very committed to the parents and/or the child, and they had a shared understanding of the experience. Not all supportive people started out with a shared understanding. But when their degree of commitment to the parents and/or the child was sufficiently strong, they moved beyond any discomfort and worked to establish a shared understanding of the family’s situation.

For other supportive people, the understanding preceded the commitment. These people included parents who were sharing the experience of raising an ill child and health professionals who became committed to a particular family. Among parents who shared the experience of raising a chronically ill child, communication was no longer effortful. One parent described an evening with her friends:

> Well there’s a different level. You feel that you can come as really YOU. It’s not that we spend a lot of time talking about our kids. But there’s a level of connectedness. And also with the kids. If you had come over to my house on Friday night, everyone except [one child] had a label.

Some parents shied away from these friendships, in part because sharing the experience also meant sharing the painful times in a deeply personal way.

Keeping Yourself Going

There is extensive literature that addresses how caregiving parents keep themselves going and why some seem more successful than others. It is usually a coping or adaptation perspective that has framed these studies (Kazak et al., 1997; Krulik, Turner-Henson, Kanematsu, al-Ma’aitah, Swan, & Holaday, 1999; Lesar & Maldonado, 1996; McDonald, Poertner, & Pierpont, 1999; Pelchat, Richard, et al., 1999; Stephenson, 1999). Most investigators have focused on the psychological or emotional aspects, ignoring the physical health of caregiving parents (McKeever, 1991). Several studies include descriptions of mothers who are exhausted and floundering (Brinchmann, 1999; Knafl, Breitmeyer, Gallo, & Zoeller, 1994; McKeever, 1991; Williams et al., 1999).

Just do it

In this study, parents’ primary explanation of how they kept going was “You just do it,” “You have no choice,” or “You don’t think about it.” As Gibson (1995) found, parents were so busy doing things for their child that they did not have time to think about it. When the workload was demanding but not overwhelming, parents became so accustomed to their way of life that they did not realize how hard they were working until the workload was lightened or they had a healthy child. One parent spoke about her healthy baby:

> One thing that we had noticed with [this baby], in the eight weeks, it’s been so easy, and we can go out. And we can go on walks. And we can do things that we could never do with [our first child]. . . . I keep looking at her, and I think, “I’m not talking to her enough.” And I’m thinking, “I don’t HAVE to!!’ She’ll pick it up.”

Although the notion of taken-for-grantedness is used to explain the interpretive and practical "stumbling" that occurs with onset of illness (Charmaz, 1991; Frank, 1991), it also works in reverse. To have free time is something out of the ordinary; at that point, it becomes the subject of reflection (Mulderij, 1996).

Most parents claimed that there was nothing to be gained by dwelling on their situation because there was not any other option; they just had to "get on with the show." The following passage illustrates that the ease of assuming this interpretation varied.

> It comes down to choice. You can fall apart or you keep going. When you are having a really bad day, you end up getting a good sleep that night. I think God just sort of says to you "YOU are going to sleep well." You get up in the morning and you feel better. And you just DO it. And anybody who says "Oh my God. I don't know how you do it." Well if you love your child, you would do it too. You have no choice [voice cracking]. Okay, I'll just sit here and cry. I don't know, you JUST DO IT. JUST DO IT.

In the final analysis, parents kept going because they had no alternative (Gibson, 1995; Gravelle, 1997; Nicholas, 1999). The condition that made this pragmatic stance possible was their absolute commitment to do everything that they could to help their child.

Constructing Sustaining Interpretations

Numerous authors have offered descriptions of how parents construct a sustaining interpretation of their situation (Brinchmann, 1999; Hinds et al., 1996; Milo, 1997; Turnbull, Patterson, Behr, Murphy, Marquis, & Blue-Banning, 1993). These efforts have been variously labeled as drawing on "positive comparisons" (Affleck & Tennen, 1993; Behr & Murphy, 1993), emphasizing growth (Crocker, 1998; Miles, Holditch-Davis, Burchinal, & Nelson, 1999), gradual resignation (Bruce, Schultz, & Smyrnios, 1996), and normalizing (Deatrick, Knafl, & Murphy-Moore, 1999; Knafl & Deatrick, 1986; Monsen, 1999; O'Halloran, 1993). These representations are based on the interpretation that there are real limits to how much parents can change their situation, reduce caregiving demands, or obtain help. Consequently, parents must change the way that they think about their child, themselves, and their life.

Parents found ways to positively interpret their situation that were not always publicly apparent. They often noted that other children were worse off than their own, as demonstrated in Affleck & Tennen's notion of downward comparisons (1993). Before parents could draw strength from such comparisons, they needed to be aware of other children's circumstances; this usually occurred through hospitalizations. Entering the world of chronic childhood illness is a completely new experience for most parents, and their meanings and understanding of events and good fortune are permanently shifted: "We're pretty LUCKY that way. We don't have to do any feeding tubes or anything like that. That's pretty lucky."

Perhaps the most sustaining interpretations were the rewards of seeing one's child progress, no matter how small the incremental gains. Even when a child was not improving, the parents' ability to interpret their child as strong and in control was infinitely more sustaining in painful situations than seeing their child as a helpless victim. The next two passages illustrate the tone of these contrasting interpretations.

> She's a very DETERMINED STUBBORN little girl. And that's the only reason why she's here. She WANTS to be here. And I think when she's ready to leave she will go. And if it's before me, I have to accept that. And it's just the way it is. Yeah. I can handle that.
>
> It's almost cruel, what they've done. . . . It's like an article that I read in one of the magazines. "This is what Pinocchio is REALLY like: held together with strings and tubes wants to be a real child." My poor little Pinocchio here.

Often the parents who were able to construct a more positive interpretation of their child's situation were also those who were more successful in receiving help.

Changing Priorities: Gearing Down and Letting Go

The presence of a chronic illness in the family sets new limits on the range of situated options that families have available. Similarly, there are a multitude of activities, small and large, that families find are not an option or simply not worth the effort. Illness dimensions play a large role in determining what family options are available. For example, allergens, lack of wheelchair access, cumbersome equipment, special diets, and immunosuppression may all lead to families remaining at home (Hayes, 1992).

Over time, parents came to realize that they were going to have to pace themselves for the long term. They realized that there were limits to what they could do for their child and family and still be able to keep going themselves. Even during hospitalizations, some parents noted that they could always spot the parents of chronic children, because those parents knew that they had to take breaks so that they would have the energy reserves to cope with the intense work that would follow their child's discharge. When a child was clearly not developing or improving as hoped, eventually parents had to begin the process of letting go of expectations and actively reinterpreting what was important in their lives. One parent said the following:

> So we just go along, and HOPEFULLY he will do it. If he doesn't, well that's just [our son]. And we just accept him that way. But learn not to beat our heads. For a long time it was like 'What was I doing wrong.“ And now it's just 'This is [our son]. And if he doesn't talk, he doesn't talk.”

When a child's condition was severe, life became more focused around the simple and more immediate things. One parent said, “We appreciate all the little things that he does. Like growing so well. Like that gives us satisfaction. We've really gone down to the very BASICS. Just appreciate.” It was this focusing and appreciation of fundamentals that accompanied the shift in meaning with chronic illness experience that explained the very different interpretations of what constituted quality of life.

There was also a temporal dimension to gearing down. Perhaps the most ubiquitous expression used by parents was “living one day at a time.” For some, this was because the child's clinical status was very unpredictable and parents simply never knew what would be happening from one day to the next. They had no time or energy to think beyond tomorrow or next week. Other parents realized that the long-term future was so unpredictable that trying to imagine the range of possibilities was both futile and painful. One parent said the following:

> When he was born I was looking very far down the road. And I was putting him in kindergarten. And I was crying because I was imagining him being teased. And all the hardships he was going through. And I was really killing myself. So I really had to go back. And I would honestly say that we do, now, take one day at a time. And that's been a real hard lesson to learn.

As children grew older, parents realized they had no choice but to think further down the road. This was especially important when children would require life-long assistance. One mother described the progression this way:

> At first you plan only a few months ahead. And then it becomes longer planning. And by the time they're 10 you are looking at LONG-term planning. I think that is just a natural growth. Ten or twelve and up you just start thinking of not a 5-year plan, not even a 10-year plan. You are looking at a 40-year plan.

When children were dying, it was rare for parents to think beyond their child's death. Their focus was on the time that they had left with the child.

Staying healthy

All parents spoke of fatigue. The degree of fatigue ranged from manageable to virtually incapacitating. Most parents were ignoring the long-term consequences that this might have for their own health. A few were able to get exercise but most acknowledged that they did not care for their own physical health as they should. Three had been on long-term stress leave from paid employment. There seemed to be a disproportionate number of parents injured from motor vehicle accidents, work injuries, back pain, and hernias from lifting.

As in other studies, parents spoke of reaching or approaching “burn out” (Hoyle, 1992; McKeever, 1991; Stephenson, 1999). One parent said the following:

> I WAS burned out. I wasn't getting enough sleep. He came home one day and I was just a total wreck. And he went to see the doctor and he said, “She's falling apart! You have to help me! She's falling apart!” At that point I said it. I said I didn't want to be a mommy any more. I wanted to give it all up.

What changed this and other mothers' actions was to be told that if they did not look after themselves, then there would not be anyone there to care for their child. This realization was often a prerequisite to gearing down or letting go.

Seeking and accepting help

One of the most fundamental assurances that parents hoped for was to know that they were not totally alone and that they had somewhere to turn if they needed help. Many came to the conclusion that they were alone in the responsibility, and this made the challenge even more difficult.

When help-seeking by parents was analyzed, there were three important elements to successfully engaging family and friends: learning what you need, getting beyond others' discomfort and lack of understanding, and being specific about the help that is needed. Several parents commented that the first obstacle to seeking help was that you might not know, or have the energy to explain, what help you need. One parent gave the following recommendation:

> One of the BIGGEST lessons we learned very early on was that if someone says to you "Can I do something to help?" we make a list. When they say "Can we help?" take them up on that offer. Because if you DON'T take them up on that offer, then they do pull away.

This parent's neighbors would fill up the freezer with meals when her child was hospitalized. Other parents had friends that cleaned or sat with a bedridden child so that the parents could do other chores. The critical issue was that parents learned to direct offers of assistance early, before potentially supportive people started to drift away.

DISCUSSION

Parents raising children with chronic health conditions face a complex array of responsibilities and challenges. The care required for the child with a chronic condition has been described under three sections of the PACC model: medical care, parenting plus, and working the systems. Although dividing caregiving responsibilities into three sections aids the analytic process, it is important to note that parents saw the components as highly interrelated. Any action to care for the child often had implications in all three sections of special needs parenting. For example, a schedule change in the medical care could have implications for whether the child was able to participate in a scheduled play activity with peers or whether special training would be needed for personnel in the school. This overlap is depicted by the dotted line between sections in Figure 1. While parents worked to address all areas of the child's care needs, there was an essential tension between the top and bottom half of the model. Parents constantly struggled to keep the child's needs and the family's needs in balance. It was very difficult to attend to both halves at the same time.

In addition to depicting the need for balance, PACC also makes visible the invisible components of caregiving. These included monitoring the child's physical symptoms, anticipating the need for adaptive strategies, facilitating and monitoring the child's success in social situations, and working with health, education, and social service sectors. Whereas managing the medical care became an automatic part of daily life, interpreting symptoms, the anticipatory work of "parenting plus," and the administrative and political work with various agencies remained labor-intensive and problematic because new situations and challenges were always arising. In particular, parents resented the time, effort, and emotional energy that they needed to expend in administrative, coordinating, and advocacy roles. Unfortunately for parents, these were also the most invisible parts of their caregiving role. Furthermore, the more expertise parents gained in providing these caregiving responsibilities, the more invisible and taken-for-granted their efforts become. This placed parents at risk for acquiring more and more caregiving responsibility, until they faltered in their ability to keep up with the workload. These complex and skilled responsibilities that parents assume need to be made visible.

PACC was developed with the use of data from families of children with medical illnesses sometimes combined with developmental and behavioral challenges. It is possible that by omitting the section on medical care, PACC would be appropriate for families of children with developmental and behavioral challenges alone, but this applicability remains to be tested.

Utility in Research, Policy, and Practice

PACC can be useful in four specific ways: as a basis for identifying foci for intervention studies, as a theoretical basis for instrument development, as a framework for assessing families, and as a tool for parents and clinicians to articulate caregiving issues.

There is an urgent need to move into more intervention research with caregiving families. In designing these studies, investigators need to take invisible caregiving responsibilities into account. In particular, the foci for intervention studies need to be reconsidered. The assumption underlying many studies is that the foci for change need to be within the family. The findings of this study indicate that the area of greatest frustration, working the systems, is the area with the least support and services available. Parents provided many examples of various systems being more frustrating and burdensome than they were helpful. Parents noted that with greater coordination, consistency, family-centeredness, and access to information, they would be able to properly focus time and energy on parenting their ill child and minimizing the consequences for the rest of the family. This indicates a need to rethink our approach to intervention. For example, a key system-level intervention would be to integrate programmatic funding for children with chronic conditions so that home care, medications, equipment, supplies, school aides, and therapies are all funded and coordinated under one program. A second intervention currently being developed is an Internet-accessible resource database that enables both parents and professionals to access information quickly and efficiently.

The findings also identify gaps in our ability to measure caregiving workload for a pediatric population. For example, the Clinician's Overall Burden Index (Stein & Jessop, 1982) was originally developed in 1979 and does not capture the full range of responsibilities that caregiving parents assume today. It was also developed from a medical clinician's perspective, rather than parents' perspective, so it does not capture the invisible work identified in PACC. To address this gap, a new instrument based on PACC, the Scope of Caregiving Scale (SOCS), is currently being tested.

For clinicians to intervene effectively on caregiving parents' behalf, they must first appreciate both the visible and the invisible caregiving responsibilities. PACC provides a comprehensive framework for assessing areas of responsibility and concern for families. Similarly, for parents and clinicians who are seeking ways to articulate needs and concerns to program or policy audiences, PACC can provide a visual aid for conveying the full scope of responsibilities faced by parents of children with chronic conditions.

ACKNOWLEDGEMENTS

I would like to thank Gail Kieckhefer, David G. Allen, Sandra J. Eyres, Karen Schepp, and Mary Richardson, for their thoughtful contributions and support during this study.

The Nursing Respite Program, Family Support Institute, Muscular Dystrophy Association, Sunny Hill Health Centre for Children, and the Variety Child Development Centre helped locate families who wished to participate in the study. Funding was provided by: NHDRP Canada, Electa MacLennan, Gatzert, Hester McLaws Memorial Funds, and the Canadian Nurses Foundation.

REFERENCES

Adams, R., Gordon, C., & Spangler, A.A. (1999). Maternal stress in caring for children with feeding disabilities: Implications for health care providers. *Journal of American Dietetic Association, 99,* 962-966.

Affleck, G., & Tennen, H. (1993). Cognitive adaptation to adversity: Insights from parents of medically fragile infants. In A.P. Turnbull, J.M. Patterson, S.K. Behr, D.L. Murphy, J.G. Marquis, & M.J. Blue-Banning (Eds.). *Cognitive Coping, Families, and Disability* (pp. 135-150). Baltimore: Paul H. Brookes.

Anderson, J. (1990). Home care management in chronic illness and the self-care movement: An analysis of the ideologies and economic processes influencing policy decisions. *Advances in Nursing Science, 12,* 71-84.

Armstrong, F.D., & Horn, M. (1995). Educational issues in childhood cancer. *School Psychology Quarterly, 10,* 292-304.

Atkin, K., & Ahmad, W. (2000). Pumping iron: Compliance with chelation therapy among young people who have thalassaemia major. *Sociology of Health and Illness, 22,* 500-524.

Behr, S.K., & Murphy, D.L. (1993). Research progress and promise: The role of perceptions in cognitive adaptation to disability. In A.P. Turnbull, J.M. Patterson, S.K. Behr, D.L. Murphy, J.G. Marquis, & M.J. Blue-Banning (Eds.). *Cognitive Coping, Families, and Disability* (pp. 151-164). Baltimore: Paul H. Brookes.

Bender, B.G. (1995). Are asthmatic children educationally handicapped? *School Psychology Quarterly, 10,* 274-291.

Beresford, B.A. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry, 35,* 171-209.

Bernstein, R.J. (1991). *Beyond Objectivism and Relativism: Science, Hermeneutics, and Praxis*. Philadelphia: University of Pennsylvania Press.

Black, K.C., & Hynd, G.W. (1995). Epilepsy in the school-aged child: Cognitive-behavioral characteristics and effects on academic performance. *School Psychology Quarterly, 10,* 345-358.

Boland, D.L., & Sims, S.L. (1996). Family care giving at home as a solitary journey. *Image: Journal of Nursing Scholarship, 28,* 55-58.

Brinchmann, B.S. (1999). When the home becomes a prison: Living with a severely disabled child. *Nursing Ethics, 6,* 137-143.

Bruce, E.J., Schultz, C.L., & Smyrnios, K.X. (1996). A longitudinal study of the grief of mothers and fathers of children with intellectual disability. *British Journal of Medical Psychology, 69*(Pt 1), 33-45.

Burke, S.O., Handley-Derry, M.H., Costello, E.A., Kauffmann, E., & Dillon, M.C. (1997). Stress-point intervention for parents of repeatedly hospitalized children with chronic conditions. *Research in Nursing and Health, 20,* 475-485.

Burke, S.O., Kauffmann, E., Costello, E., Wiskin, N., & Harrison, M.B. (1998). Stressors in families with a child with a chronic condition: An analysis of qualitative studies and a framework. *Canadian Journal of Nursing Research, 30,* 71-95.

Burke, S.O., Kauffmann, E., Harrison, M.B., & Wiskin, N. (1999). Assessment of stressors in families with a child who has a chronic condition. *American Journal of Maternal/Child Nursing, 24,* 98-106.

Canam, C. (1993). Common adaptive tasks facing parents of children with chronic conditions. *Journal of Advanced Nursing, 18,* 46-53.

Celano, M.P., & Geller, R.J. (1992). Learning, school performance, and children with asthma: How much at risk? *Journal of Learning Disabilities, 26,* 23-32.

Charmaz, K. (1991). *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick (NJ): Rutgers University Press.

Cohen, M.H. (1993). The unknown and the unknowable: Managing sustained uncertainty. *Western Journal of Nursing Research, 15,* 77-96.

Crocker, A.C. (1998). Exceptionality. *Journal of Developmental and Behavioral Pediatrics, 19,* 300-305.

Cuskelly, M., & Dadds, M. (1992). Behavioral problems in children with Down's syndrome and their siblings. *Journal of Child Psychology and Psychiatry, 33,* 749-761.

Cuskelly, M., Pulman, L., & Hayes, A. (1998). Parenting and employment decisions of parents with a preschool child with a disability. *Journal of Intellectual and Developmental Disability, 23,* 319-333.

Davies, L.K. (1993). Comparison of dependent-care activities for well siblings of children with cystic fibrosis and well siblings in families without children with chronic illness. *Issues in Comprehensive Pediatric Nursing, 16,* 91-98.

Davis, F. (1963). *Passage Through Crisis: Polio Victims and Their Families.* Indianapolis: Bobbs-Merrill.

Deatrick, J.A., Knafl, K.A., & Murphy-Moore, C. (1999).

Clarifying the concept of normalization. *Image: Journal of Nursing Scholarship, 31,* 209-214.

Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *Journal of Pediatric Psychology, 22,* 149-165.

Eddy, L.L., & Walker, A.J. (1999). The impact of children with chronic health problems on marriage. *Journal of Family Nursing, 5,* 10-33.

Faulkner, M.S. (1996). Family responses to children with diabetes and their influence on self-care. *Journal of Pediatric Nursing, 11,* 82-93.

Faux, S.A. (1993). Siblings of children with chronic physical and cognitive disabilities. *Journal of Pediatric Nursing, 8,* 305-317.

Fedewa, M.M., & Oberst, M.T. (1996). Family caregiving in a pediatric renal transplant population. *Pediatric Nursing, 22,* 402-417.

Feeley, N., & Gottlieb, L.N. (1998). Classification systems for health concerns, nursing strategies, and client outcomes: Nursing practice with families who have a child with a chronic illness. *Canadian Journal of Nursing Research, 30,* 45-59.

Florian, V., & Krulik, T. (1991). Loneliness and social support of mothers of chronically ill children. *Social Science and Medicine, 32,* 1291-1296.

Frank, A.W. (1991). *At the Will of the Body: Reflections on Illness*. Boston: Houghton Mifflin.

Gadamer, H.-G. (1975). *Truth and Method*. New York: Seabury Press.

Gagliardi, B.A. (1991). The family's experience of living with a child with Duchene muscular dystrophy. *Applied Nursing Research, 4,* 159-164.

Gallo, A.M., & Knafl, K.A. (1998). Parents' reports of "tricks of the trade" for managing childhood chronic illness. *Journal of the Society for Pediatric Nursing, 3,* 93-102.

Gibson, C.H. (1995). The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing, 21,* 1201-1210.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Engelwood Cliffs (NJ): Prentice-Hall.

Gravelle, A.M. (1997). Caring for a child with a progressive illness during the complex chronic phase: Parents' experience of facing adversity. *Journal of Advanced Nursing, 25,* 738-745.

Hagedorn, M.I.E. (1993). *A Way of Life: A New Beginning Each Day. The Family's Lived Experience of Childhood Chronic Illness* [doctoral dissertation]. Denver (CO): University of Colorado.

Hallum, A. (1995). Disability and the transition to adulthood: Issues for the disabled child, the family, and the pediatrician. *Current Problems in Pediatrics, 25,* 12-50.

Hayes, V.E. (1992). *The Impact of a Child's Chronic Condition on the Family System* [doctoral dissertation]. San Francisco: University of California.

Hayes, V.E. (1997). Families and children's chronic conditions: Knowledge development and methodological considerations. *Scholarly Inquiry for Nursing Practice, 11,* 259-298.

Heaman, D.J. (1995). Perceived stressors and coping strategies of parents who have children with developmental disabilities: A comparison of mothers with fathers. *Journal of Pediatric Nursing, 10,* 311-319.

Heiman, T. (2000). Friendship quality among children in three educational settings. *Journal of Intelectual and Developmental Disability, 25,* 1-12.

Hinds, P.S., Birenbaum, L.K., Clarke-Steffen, L.C., Quargenti, A., Kreissman, S., Kazak, A., Meyer, W., Mulhern, R., Pratt, C., & Wilimas, J. (1996). Coming to terms: Parents' response to a first cancer recurrence in their child. *Nursing Research, 45,* 148-153.

Holditch-Davis, D., & Miles, M.S. (1997). Parenting the prematurely born child. In H. Werley & J. Fitzpatrick (Eds.). *Annual Review of Nursing Research* (pp. 3-34). New York: Springer.

Holmes, C.S., O'Brien, B., & Greer, T. (1995). Cognitive functioning and academic achievement in children with insulin-dependent diabetes mellitus (IDDM). *School Psychology Quarterly, 10,* 329-344.

Horner, S.D. (1997). Uncertainty in mothers' care for their ill children. *Journal of Advanced Nursing, 26,* 658-663.

Howe, G.W. (1993). Siblings of children with physical disabilities and chronic illness: Studies of risk and social ecology. In Z. Stoneman & P. W. Berman (Eds.), *The Effects of Mental Retardation, Disability, and Illness on Sibling Relationships: Research Issues and Challenges* (pp. 185-214). Baltimore: Paul H. Brookes.

Hoyle, J. (1992). Stress in mothers of the disabled. *Canadian Women Studies, 12,* 66-69.

Humphry, R. (1991). Impact of feeding problems on the parent-infant relationship. *Infants and Young Children, 3,* 30-38.

Ireys, H.T., & Perry, J.J. (1999). Development and evaluation of a satisfaction scale for parents of children with special health care needs. *Pediatrics, 104,* 1182-1190.

Ireys, H.T., Salkever, D.S., Kolodner, K.B., & Bijur, P.E. (1996). Schooling, employment, and idleness in young adults with serious physical health conditions: Effects of age, disability status, and parental education. *Journal of Adolescent Health, 19,* 25-33.

Jerrett, M.D., & Costello, E.A. (1996). Gaining control: Parents' experiences of accommodating children's asthma. *Clinical Nursing Research, 5,* 294-308.

Katz, S., & Krulik, T. (1999). Fathers of children with chronic illness: Do they differ from fathers of healthy children? *Journal of Family Nursing, 5,* 292-316.

Kazak, A.E., Barakat, L.P., Meeske, K., Chrisakis, D., Meadows, A.T., Casey, R., Penati, B., & Stuber, M.L. (1997). Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of Consulting and Clinical Psychology, 65,* 120-129.

King, G.A., Rosenbaum, P.L., & King, S.M. (1997). Evaluating family-centered service using a measure of parents' perceptions. *Child: Care, Health and Development, 23,* 47-62.

Klein, S.D., & Schliefer, M.J. (1993). *It isn't fair! Siblings of children with disabilities*. Westport (CT): Bergin & Garvey.

Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1996). Family response to childhood chronic illness: Description of management styles. *Journal of Pediatric Nursing, 112,* 315-326.

Knafl, K., Breitmeyer, B., Gallo, A., & Zoeller, L. (1994). *How Families Define and Manage a Child's Chronic Illness*. (Final Report NR01594). Chicago: University of Illinois at Chicago.

Knafl, K.A., & Deatrick, J.A. (1986). How families manage chronic conditions: An analysis of the concept of normalization. *Research in Nursing and Health, 9,* 215-222.

Knafl, K.A., & Zoeller, L. (2000). Childhood chronic illness: A comparison of mothers' and fathers' experiences. *Journal of Family Nursing, 6,* 287-302.

Krulik, T., Turner-Henson, A., Kanematsu, Y., al-Ma'aitah, R., Swan, J., & Holaday, B. (1999). Parenting stress and mothers of young children with chronic illness: a cross-cultural study. *Journal of Pediatric Nursing, 14,* 130-140.

Lesar, S., & Maldonado, Y.A. (1996). Parental coping strategies in families of HIV-infected children. *Children's Health Care, 25,* 19-35.

Linge, D.E. (Ed.). (1976). *Philosophical Hermeneutics*. Berkeley: University of California Press.

MacDonald, H. (1996). "Mastering uncertainty:" Mothering the child with asthma. *Pediatric Nursing, 22,* 55-59.

McDonald, T.P., Poertner, J., & Pierpont, J. (1999). Predicting caregiver stress: An ecological perspective. *American Journal of Orthopsychiatry, 69,* 100-109.

McKeever, P. (1991). *Mothering Chronically Ill Technology Dependent Children: An Analysis Using Critical Theory* [doctoral dissertation]. Toronto: University of Toronto.

Miles, M.S., & Holditch-Davis, D. (1995). Compensatory parenting: How mothers describe parenting their 3-year-old, prematurely born children. *Journal of Pediatric Nursing, 10,* 243-253.

Miles, M.S., Holditch-Davis, D., Burchinal, P., & Nelson, D. (1999). Distress and growth outcomes in mothers of medically fragile infants. *Nursing Research, 48,* 129-140.

Milo, E.M. (1997). Maternal responses to the life and death of a child with a developmental disability: A story of hope. *Death Studies, 21,* 443-466.

Mishel, M.H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship, 22,* 256-262.

Monsen, R.B. (1999). Mothers' experiences of living worried when parenting children with spina bifida. *Journal of Pediatric Nursing, 14,* 157-163.

Mulderij, K.J. (1996). Research into the lifeworld of physically disabled children. *Child: Health, Care and Development, 22,* 311-322.

Nicholas, D.B. (1999). Meanings of maternal caregiving: Children with end stage renal disease. *Qualitative Health Research, 9,* 468-478.

O'Halloran, J. (1993). Welcome to our family, Casey Patrick. In A.P. Turnbull, J.M. Patterson, S.K. Behr, D.L. Murphy, J.G. Marquis, & M.J. Blue-Banning (Eds.). *Cognitive Coping, Families, and Disability* (pp. 19-30). Baltimore: Paul H. Brookes.

Pelchat, D., Bisson, J., Ricard, N., Perreault, M., & Bouchard, J.M. (1999). Longitudinal effects of an early family intervention programme on the adaptation of parents of children with a disability. *International Journal of Nursing Studies, 36,* 465-477.

Pelchat, D., Richard, N., Bouchard, J.M., Perreault, M., Saucier, J.F., Berthiaume, M., & Bisson, J. (1999). Adaptation of parents in relation to their 6-month-old infant's type of disability. *Child: Care, Health and Development, 25,* 377-397.

Pless, I.B., Feeley, N., Gottlieb, L., Rowat, K., Doughterty, G., & Willard, B. (1994). A randomized trial of a nursing intervention to promote the adjustment of children with chronic physical disorders. *Pediatrics, 94,* 70-75.

Poyadue, F.S. (1993). Cognitive coping at parents helping parents. In A.P. Turnbull, J.M. Patterson, S.K. Behr, D.L. Murphy, J.G. Marquis, & M.J. Blue-Banning (Eds.). *Cognitive Coping, Families, and Disability* (pp. 95-110). Baltimore: Paul H. Brookes.

Rabinow, P., & Sullivan, W.M. (1987). The interpretive turn: A second look. In P. Rabinow & W.M. Sullivan (Eds.). *Interpretive Social Science: A Second Look* (pp. 1-33). Berkeley: University of California Press.

Ray, L. (1988). *Parents' Perceptions of Coping With the Burdensome Home Care of Their Chronically Ill Child* [master's thesis]. Halifax, Nova Scotia, Canada: Dalhousie University.

Ray, L.D., & Ritchie, J.A. (1993). Caring for chronically ill children at home: Factors that influence parents' coping. *Journal of Pediatric Nursing, 8,* 217-225.

Ray, L.D. (1997). Qualitative data management using Folio VIEWS. *Qualitative Health Research, 7,* 301-308.

Ritchie, J.A., Stewart, M., Ellerton, M.-L., Thompson, D., Meade, D., & Viscount, P.W. (2000). Parents' perceptions of the impact of a telephone support group intervention. *Journal of Family Nursing, 6,* 24-45.

Schumacher, K.L., Stewart, B.J., Archbold, P.G., Dodd, M.J., & Dibble, S.L. (2000). Family caregiving skill: Development of the concept. *Research in Nursing and Health, 23,* 191-203.

Sexson, S., & Madan-Swain, A. (1995). The chronically ill child in the school. *School Psychology Quarterly, 10,* 359-368.

Sexson, S.B., & Madan-Swain, A. (1993). School reentry for the child with chronic illness. *Journal of Learning Disabilities, 26,* 115-125.

Shelton, T.L., & Stepanek, J.S. (1994). *Family-centered Care for Children Needing Specialized Health and Developmental Services*. Washington, DC: Association for the Care of Children's Health.

Silver, E.J., Bauman, L.J., & Weiss, E.S. (1999). Perceived role restrictions and depressive symptoms in mothers of children with chronic health conditions. *Developmental and Behavioral Pediatrics, 20,* 362-369.

Spalding, K., & McKeever, P. (1998). Mothers' experiences caring for children with disabilities who require a gastrostomy tube. *Journal of Pediatric Nursing, 13,* 234-243.

Stein, R.E., & Jessop, D.J. (1982). A noncategorical approach to chronic childhood illness. *Public Health Reports, 97,* 354-362.

Stephenson, C. (1999). Well-being of families with healthy and technology-assisted infants in the home: A comparative study. *Journal of Pediatric Nursing, 14,* 164-176.

Stoneman, Z., & Berman, P.W. (1993). *The Effects of Mental Retardation, Disability, and Illness on Sibling Relationships: Research Issues and Challenges*. Baltimore: Paul H. Brookes.

Taanila, A., Järvelin, M.-R., & Kokkonen, J. (1999). Cohesion and parents' social relations in families with a child with disability or chronic illness. *International Journal of Rehabilitation Research, 22,* 101-109.

Taanila, A., Kokkonen, J., & Järvelin, M.-R. (1996). The long-term effects of children's early-onset disability on marital relationships. *Developmental Medicine and Child Neurology, 38,* 567-577.

Thompson, J.L. (1990). Hermeneutic inquiry. In L.E. Moody (Ed.). *Advancing Nursing Science Through Research*. Newbury Park (CA): Sage Publications.

Thorne, S.E. (1990). Constructive noncompliance in chronic illness. *Holistic Nursing Practice, 5,* 62-69.

Thorne, S.E., Radford, M.J., & Armstrong, E.-A. (1997). Long-term gastrostomy in children: Caregiver coping. *Gastroenterology Nursing, 20,* 46-53.

Thyen, U., Kuhlthau, K., & Perrin, J.M. (1999). Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics, 103*(6 Pt 1), 1235-1242.

Thyen, U., Terres, N M., Yazdgerdi, S.R., & Perrin, J.M. (1998). Impact of long-term care of children assisted by technology on maternal health. *Journal of Developmental and Behavioral Pediatrics, 19,* 273-282.

Turnbull, A.P., Patterson, J.M., Behr, S.K., Murphy, DL., Marquis, J.G., & Blue-Banning, M.J. (1993). *Cognitive Coping, Families, and Disability*. Baltimore: Paul H. Brookes.

Van Riper, M. (1999). Maternal perceptions of family-provider relationships and well-being in families of children with Down syndrome. *Research in Nursing and Health, 22,* 357-368.

Warfield, M.E., Krauss, M.W., Hauser-Cram, P., Upshur, C.C., & Shonkoff, J.P. (1999). Adaptation during early childhood among mothers of children with disabilities. *Journal of Developmental and Behavioral Pediatrics, 20,* 9-16.

Williams, P.D., Hanson, S., Karlin, R., Ridder, L., Liebergen, A., Olson, J., Barnard, M., & Tobin-Rommelhart, S. (1997). Outcomes of a nursing intervention for siblings of chronically ill children: A pilot study. *Journal of the Society of Pediatric Nurses, 2,* 127-137.

Williams, P.D., Press, A., Williams, A.R., Piamjariyakul, U., Keeter, L.M., Schultz, J., & Hunter, K. (1999). Fatigue in mothers of infants discharged to the home on apnea monitors. *Applied Nursing Research, 12,* 69-77.

Wuest, J. (1993a). Institutionalizing women's oppression: The inherent risk in health policy that fosters community participation. *Health Care for Women International, 14,* 407-417.

Wuest, J. (1993b). Removing the shackles: A feminist critique of noncompliance. *Nursing Outlook, 41,* 217-224.