Parenting a Child With a Chronic Medical Condition

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PURPOSE. Parents of children with chronic medical conditions and associated disabilities have substantial caregiving responsibilities different from those of typical children. This ethnographic study examined how parents manage these caregiving demands, how they maintain their social lives, and how they form their self identities.

METHOD. Graduate students interviewed eight parents of children with chronic medical conditions and disabilities and participated in 60 hours of activities with them over a 6-month time period. The interview transcripts, students' field notes, and journals were analyzed for themes that related to caregiving, social activities, and self-identity.

RESULTS. Parents felt that they "always needed to be with their child," and most had changed their career plans to devote more time to caregiving. Parents also expressed anxiety about making difficult medical and educational decisions for their children. Activities outside the home required extensive planning and preparation and maintaining a social life was perceived as challenging because friends and relatives did not always understand the families' limitations in activity.

CONCLUSIONS. Although the parents expressed stress related to coping with the caregiving load, they viewed having a child with chronic medical conditions as a positive experience that brought cohesion to their family. The parents explained that their experiences with their children helped them to appreciate life and develop more sensitivity to and tolerance of individual differences. The parents had become strong advocates for their children and other children with similar needs.

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The demands and responsibilities of caring for children who have disabilities appear to be different from those of parents with typical children (Burke, Harrison, Kauffmann, & Wong, 2001; Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996; Innocenti & Huh; King, King, & Rosenbaum, 1996). Although most researchers agree that caregiving for children with disabilities can be stressful (Dyson, 1996; Smith, Oliver, & Innocenti, 2001), the overall effect on families' well-being seems to vary across time and across individual families (Knafl, Breitmayer, Gallo, & Zoeller, 1996; Scorgie, Wilgosh, & McDonald, 1998; Tak & McCubbin, 2002). Early research (e.g., Tizard & Grad, 1961) focused on the psychological effects and the social isolation and adversity associated with raising a child with disabilities (Barnett & Boyce, 1995). More recent studies have demonstrated that families with children with disabilities face complex issues; however, the overall impact on the family is not necessarily negative (Harris & McHale, 1989; Patterson & Blum, 1996; VanLeit & Crowe, 2002). For some families, the impact is positive, strengthening the family as a unit. To implement a model of family-centered care in pediatric practice, professionals need to acknowledge and understand how a child's disability affects the entire family.

Turnbull and Turnbull (1997) use a family systems model to examine how a child's disability affects family functions. The economic function of the family is

affected because parents generally work fewer hours outside the home in order to care for their child and costs for treatment and medication are high. Therefore parents' earning ability decreases at the same time that their costs increase. Additionally, the child care demands on parents' time increases as daily care of the child rises above that required for typical children (Dunlap & Hollinsworth, 1977; Harris & McHale, 1989; Helitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002). For example, parents may regularly implement numerous therapeutic procedures, engage in feeding for long periods of time or frequently throughout the day, administer medications or medical procedures (e.g., suctioning, gastrostomy feedings), and attend therapy and clinic appointments. Because more time is spent in daily care activities, less time is available for other activities, such as recreation and socialization (Helitzer et al., 2002; Turnbull & Turnbull). Barnett and Boyce (1995) found that mothers with children with Down syndrome were unable to maintain employment and spent less time in social activities. Their survey results demonstrated that socialization and work activities were replaced with child-care activities. Fathers also reported more child-care time and less time in social activities.

Turnbull and Turnbull (1997) explain that when parents' socialization is limited, the entire family is affected. Families are the bases from which children learn to interact with others; therefore, children's first experiences with friends and family are vital to their social-skill development. Loss of social activity opportunities early in life can have long-term implications for building friendships and social supports.

Other researchers have investigated the types of accommodation that the family system must make when it includes children with developmental disabilities (Gallimore et al., 1996). These authors define accommodation as the family's functional responses or adjustments to the demands of daily life with a child with special needs (Gallimore et al.; 1996; Gallimore, Weisner, Kaufman, & Bernheimer, 1989). Every accommodation is presumed to have costs as well as benefits to the individuals of the family and to the family as a whole. The types of accommodations that families make change throughout the life cycle. Some investigators report that adjustments are greatest when first learning about the disability (Weisner, 1993); other authors propose that coping becomes more difficult and greater adaptations are needed as children get older and performance discrepancies increase (Bristol & Schopler, 1983; Suelzle & Keenan, 1981). Examples of accommodations made by families are that the mother arranges for flexibility in work or works at home, the family's home is

altered to improve safety or accessibility, and the caregiving responsibilities of both parents increase (Gallimore et al., 1996; Helitzer et al., 2002).

A few studies have examined the impact of children with medical diagnoses who require ongoing intervention and medical technology on parents (see Patterson & Blum [1996] for a review). Caring for a child who requires routine use of medical technology, such as respirators, gastrostomy pumps, suctioning equipment, can be socially isolating for parents. Some parents report that they are virtually housebound (Andrews & Nielson, 1988). For example, parents may not be able to find babysitters, the child's behaviors may create uncomfortable social situations, the logistics of leaving the house for nonessential events may be overwhelming, as when equipment, medical supplies, and medical technology needs to be packed and unpacked. Kirk (1998) and Murphy (1997) reported that most families with children with chronic medical problems must rely on nurses and other health care professions for respite care. In addition, the home environment is not as conducive to social activities when it is filled with medical technology and supplies, taking on the appearance of an intensive care unit (ICU). Although parents seem to accommodate to the presence of medical technology, friends and extended family may feel less comfortable. Concerns about the child's exposure to viruses and bacteria may also limit social opportunities.

Parents have reported that their experiences with a child who requires continual medical care is exhausting and at times overwhelming (Jennings, 1990; Kirk, 1998). The uncertainty of chronic illness and the child's prognosis can produce ongoing anxiety for parents (Andrews & Nielson, 1988; Murphy, 1997). The stress associated with a child's chronic illness can create problems in the mother's relationships with her other children and in the marriage (Kirk, 1998; Murphy, 1997).

Other areas of family function that are often affected when a child has chronic medical problems are parents' self-identity and social–emotional well-being (Turnbull & Turnbull, 1997). When all or most family activities revolve around the exceptionality (e.g., therapies, meetings with professionals, caregiving, hospitalizations), the exceptionality may become the major identifying characteristic to the parents (Patterson & Blum, 1996). For example, the parents may introduce themselves as the parents of a child with a congenital heart condition or a neurological syndrome.

The degree of family stress appears to partially relate to the amount of support available. Families without access to respite and services are more likely to feel overburdened, emotionally exhausted, and socially isolated (Kirk, 1998; Murphy, 1997; Tak & McCubbin, 2002). Support in the

form of friends, extended family, financial security, professional services, and community resources can help families maintain healthy, balanced lives (Gallimore et al., 1993; Humphry & Case-Smith, 2001; Turnbull & Turnbull, 1997; VanLeit & Crowe, 2002).

Understanding how parents' occupations and experiences differ when they include a child with chronic medical problems can help occupational therapy practitioners focus on the issues that matter most to families. Professionals need a deep understanding of the experiences of these families in order to fit their interventions into the family's daily life and to help them make accommodations that are of low cost and high benefit. The purpose of this study was to examine in depth the caregiving, social occupations, and self-identities of parents with children with significant disabilities and chronic medical conditions. We examined these occupational areas because the literature suggests that these family functions are substantially affected by young children with serious medical issues and intense caregiving needs (Barnett & Boyce, 1995; Crowe, 1993; Kirk, 1998; Patterson, Jernell, Leonard, & Titus, 1994).

Method

Design

We implemented an ethnographic approach to examine the caregiving, social occupations, and self-identities of families with preschool-age children with chronic medical conditions and disabilities. The design used multiple sources for data about the families, including in depth interviews with the parents and extended observations of the families. The informants were mothers and fathers, and almost all observations included the entire nuclear family. As part of an interdisciplinary early intervention training project in a Midwest university, the parents consented to allow graduate students to participate with them in 60 hours of family activities and outings. I selected data from 8 of the 22 participating families for analysis because their children had ongoing and complex medical concerns, were dependent on technology, or had significant disabilities that affected all areas of development, or all. Each graduate student conducted an in-depth interview with one set of parents, transcribed the interview, and subsequently participated in 60 hours of activities with the family over a 6-month period. The students described the family outings and activities in depth and detail, generating between 12 and 15 field notes. Following description of the activity and the interactions, each student wrote journal entries that interpreted her experiences based on coursework readings on family occupations and interactions.

Participants

The training project coordinator, who is the mother of a child with cerebral palsy, recruited the families (*n* = 22) with children with disabilities from her school and hospital contacts. Each signed informed consent to participate in the study. The eight families in this study had children with combinations of complex medical issues and significant developmental delays. The children were 4 to 6 years of age. All of the families were married couples and six of the eight had other children. Two of the children with disabilities were adopted at birth. All of the families were Caucasian and middle class. Five of the eight children received 40 or more hours per week of nursing services. The graduate students who interviewed and observed the families were four occupational therapists, one nurse, one special educator, and two speech pathologists. Table 1 lists the diagnoses of the children whose families participated in the study.

Instrumentation/Procedures

The faculty and staff of the training project designed the interview guide, based on family systems concepts defined in Turnbull and Turnbull (1997). Parents were asked to describe a typical day, their family routines, social supports, interventions and their satisfaction with those interventions, and their hopes and dreams for the future. The interviews were transcribed verbatim. Field notes regarding nonverbal responses and the environment during the interviews were recorded. During the 60 hours that the students spent with the families, they accompanied the family to therapy, clinic, and physician visits, Individualized Educational Program meetings, family outings, respite, and typical activities as defined by the family. Examples of family outings and activities were touring the science museum, eating at

Table 1. Medical Diagnoses of the Children With Chronic Medical Conditions

Name*	Participants' Medical Diagnoses and Risk Factors
Annie	Twin, anoxia at birth, cerebral palsy, seizures, cortical blindness
Sean	Congenital heart defect, digestive problems, on transcutaneous peritoneal nutrition (TPN), genetic syndrome
Katie	Premature birth, gastrostomy tube, blind, seizures
Michael	TPN, jejunostomy tube, gastrostomy tube, genetic syndrome: velocardiofacial disorder, heart defects
Carlie	Premature, gastrostomy tube, hypersensitive to sounds and oral stimulation
Jeremy	Near strangling, severe brain injury, cortically blind, seizures, severe cerebral palsy
David	Hypoplastic left heart, cerebral vascular accident following heart surgery
Kevin	Severe spastic quadriparesis cerebral palsy, seizures, mental retardation

*All names are pseudonyms.

restaurants, swimming, and bowling. The students attended baseball games, picnics, birthday parties, and church events with their families. Each student described his or her experiences, focusing on the family's occupations and their interactions with medical and educational professionals.

Data Analysis

Following several readings of the interviews, field notes, and journals, I coded each statement or group of statements with a label that defined its theme. These labeled sections were combined and organized into common and related themes. Data within the thematic categories were analyzed to identify concepts. An iterative process was implemented to reorganize the themes and concepts to obtain the best fit using all of the data. The concepts were interpreted using related literature and reflection based on my experiences with families over 25 years in early intervention programs. Two mothers from the study reviewed the themes and concepts to provide member checks and validate the findings. Two graduate students and three project faculty served as peer reviewers by examining the data and the interpretation. The peer reviewers and member checks resulted in slight modification of the themes and reorganization of the data; this process also served to confirm the truth-value of the themes.

Results

Three themes emerged related to caregiving. "The challenge of always being there" describes mothers' constant efforts to provide for their children's medical, educational, and recreational needs given their total dependency on their parents. "Change in career plans" describes how in each family, one parent gave up his or her career plans to stay home and care for the child with special needs. "Making decisions and tolerating compromises" describes compromises that the parents made in caring for their children. The themes that emerged related to the families' social lives were "Where do we find a sitter?" which describes the lack of resources for respite care and the difficulties the parents experienced when leaving the house, and "anticipating the unanticipated," which describes the elaborate planning required when families did venture from their homes. A third set of themes described issues in the families' self-identify and illustrated how each family's identity was defined by the child with special needs. The parents explained how their experiences with their children helped them to appreciate life and demonstrate more sensitivity to and tolerance of individual differences. They had become strong advocates for their children and other children with similar needs.

Managing Caregiving Responsibilities

Each parent described a typical day, revealing the level of caregiving required of the child with a medical condition. In most of the families, the parents maintained a rigorous, highly scheduled day of medical procedures and caregiving responsibilities. Sean's [all names are pseudonyms] father describes their typical routine:

> We get up at 6:15. We get ready for work. Sean gets up by 7 and gets unhooked from his TPN [transcutaneous peritoneal nutrition]. He gets a bottle and his diaper changed. When the nurse is not there, we draw up his meds. . . . It takes about an hour to get all the medications together for the day and then we lay them out. All of the meds are given over the course of the day. . . . He probably gets some meds every half hour or so. Then he gets a break [at 3:30]. We start the evening meds around 7. He gets insulin at 9 a.m., 3 p.m., and again at 9 p.m. We put him down to bed between 9 and 9:30.

Michael is the youngest of five children. He has "a G-tube [gastrostomy], a J button [jejunostomy], and a broviak [for the TPN], and a trach." His mother describes her day of caregiving:

> During the week, Michael gets up between 7 and 7:30. I have already taken my shower, two of the kids are already gone, two of the kids are getting ready. We kind of sponge him down because he wakes up soaking wet from his diaper. We disconnect his TPN, give him his breathing treatments, his meds, change dressings. . . . After the first wet diaper, we put his pants and shoes on him and hook up his pump, and then we get ready for school.
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> He gets tube fed for 4 hours a day. . . . Then he comes home, and he gets more medicine, more breathing treatments, another diaper change, goes to bed for a nap. Then we have to wake him up for therapy . . . so we get him up, change him again, and it's either speech, OT or PT, depending on which day of the week it is. Some days it's doctor's appointments. . . . We do that and then usually between 4 and 7 we're driving everyone else to their stuff, taking them to piano lessons or choir or scouts or whatever it is, ice skating lessons. . . . A couple times a week we give him a bath in the evening, and when we do that, we have to go through changing all of the dressings, which takes about an hour. About 8:30 he goes to bed. I'm usually up two or three times in the night suctioning him or something like that . . . so that is a typical Michael day.

These descriptions reveal highly structured days, filled with many caregiving tasks. Although most families with young children lead busy, highly scheduled days; these families' activities revolved around caregiving tasks and medical procedures, not recreational and social activities. The five families who received nursing care expressed how grateful they were to have professional assistance in caregiving, yet numerous medical and therapeutic procedures remained to

be administered by the parents. The families seemed to have incorporated these intensive caregiving responsibilities into their daily lives.

The Challenge of Always Being There. The children's medical issues seemed to require the constant attention and energy of the families. Five of the children cycled through infections brought on by their immobility, shallow breathing, and suppressed immune systems. The parents expected periods of illness and relied heavily on their nurses for care during these periods. When the children were ill, therapies and routine appointments had to be put on hold. The parents' activities were also cancelled, so that they could be home with their children. These times were discouraging because often the children would lose skills, and progress in learning new skills was put on hold.

Beyond the medical procedures and caregiving routines, the parents were concerned about their children's developmental growth and their abilities to engage in interaction with others. This concern about the child's involvement in play seemed to present the greater challenge to the parents. The parents recognized that time spent with the child in caregiving and medical procedures did not fulfill the child's need to play and socially interact.

Because these children had limited ways of expressing their feelings, interaction and communication required constant effort by the parents. Jeremy's mother said, "Our biggest challenge with him right now is trying to find a way for him to interact more independently and to communicate with us." The student with this family observed that when the mother played physical games with Jeremy, it was important, "to look for subtle signs, like a slight furrow of his brow or the pursing of his lips" to know when he was tired and ready to stop.

One student explained with empathy how Annie's mother worried about how she felt when she showed signs of illness:

> I was struck by the stress of wondering what was wrong with Annie. It is so hard to know since her communication is so impaired. She can't answer questions, speak, or communicate her thoughts using a device. She can activate switches with voice output . . . but her understanding of language seems to be limited to a small set of familiar words and phrases. I wonder if it would be beneficial to somehow to teach her words related to pain and discomfort. . . . I would find this [lack of communication] upsetting and terribly frustrating, knowing that a seizure was likely on the way and being unable to do anything to stop it.

Perhaps because Jeremy, Annie, and Katie could not play independently, their parents expressed that they felt guilty when their children were left alone. They tried many methods to engage them in independent play given their severely limited movement and vision. For example, several families had borrowed or owned switch-activated toys and easy-to-activate toys. Despite these efforts, the families had yet to discover methods for their children to play independently.

Katie's mother explained, "[the challenge is] keeping her entertained because she can not do anything for herself. . . . she likes to be entertained. . . . We're trying to find something that she can do independently . . . " The student noted that Jeremy's "participation in the world is through his family members." At age 6, "he is completely dependent on them for his every need."

The literature has identified the importance of a balance between meeting the child's developmental needs and managing the illness (Patterson & Blum, 1996; Tak & McCubbin, 2002; Turnbull & Turnbull, 1997). The parents seemed to make great efforts to maintain this balance, keeping the child's developmental skills a priority.

Change in Career Plans. Primarily due to their children's frequent medical appointments, illness, and hospitalizations, the parents changed their career goals. In six of the eight families, the mother left paid employment to become a full-time mother. In the family with five children, one with a rare genetic disorder, the father held three jobs to help pay for the medical expenses and allow his wife to stay home. In another family, the mother left her job to be home full time, and the father changed jobs to be home more of the time. One mother explained that she did not work outside the home because, "When [my daughter] is sick . . . everything stops because we don't know how sick she's going to get . . . she has seizures and sometimes she ends up in the hospital for a couple days, and if the respite worker calls off, I don't have anyone to watch her." These unpredictable events were not compatible with maintaining a job.

In one exception, a mother held a part-time position that allowed her and her husband to alternate days at home so that one or the other was at home with their child everyday. In a second exception, the father left his work to become a stay-at-home dad while his physician wife continued her practice. This father stated, "There were three people trying to deal with Carlie's feeding issues. So we made a decision that one of us had to stay home so that she would have a little more consistency." Both parents were pleased with the progress she had made since her father has been at home full time.

As in previous research (Barnett & Boyce, 1995; Crow, VanLeit, Berghmans, & Mann, 1997; Dunlap & Hollinsworth, 1997; Helitzer et al., 2002), these eight families had shifted their family occupations, devoting more time and energy to caregiving and less to socialization and work. When caregiving for children with specific needs requires that one parent stay home, the family's financial

well-being, and the parents' social network and self-identity can be negatively affected (Barnett & Boyce; Turnbull & Turnbull, 1997).

Making Decisions and Tolerating Compromises. Parents in this study were asked to make difficult decisions for their children on a regular basis—decisions about services, medications, and treatments that had important effects on their children. The parents were also frequently given advice and offered alternative treatments. Sometimes when asked to make decisions about treatments, they did not always feel that they were knowledgeable about the potential effects, risks, and benefits. Generally these decisions involved compromise that weighed the costs and benefits of several options.

For example, Jeremy had intractable seizures that needed to be controlled by medication. However, the medication made him drowsy, lethargic, and nonresponsive; therefore, his parents asked for less potent medication. As a result Jeremy was more alert, responsive, and communicative; however, he also had 30–40 seizures a day. His parents valued the ability to have daily positive interaction with their son at the risk of possible long-term consequence of the seizure activity.

Kevin's parents and physician agreed to the insertion of a baclofen pump to decrease his spasticity. By decreasing his muscle tone, his parents could easily position him with good alignment in his wheelchair. Unfortunately, the muscle tone inhibitor also affected his arm movement, such that he could no longer use his arms to reach and hold objects. Despite his loss of strength, his mother decided to continue the baclofen and hoped that he would regain some of his arm strength.

Another context for family decision making was the Individualized Education Program (IEP) meeting. In Kevin's IEP meeting, his mother decided that due to his seizure meds, sleep needs, and endurance, she would bring him to school late, that is, between 9:30 or 10:00. Although this later arrival time meant that Kevin would miss 2 hours of instruction, his mother negotiated this arrangement because she knew that if he became overly tired, his seizures would increase, and he would not benefit from the instruction he did receive.

In family-centered intervention, professionals recognize that parents are the primary decision makers when planning services for their child (Dunst, Trivette, & Deal, 1994; Humphry & Case-Smith, 2001). The Individuals With Disabilities Education Act Amendments (1997) reinforce this concept by specifically including the parents in every educational decision that is made for the child. Although professionals recognize that parents have these rights, they also acknowledge that good decision making requires deep understanding of the issues. At times, the parents felt that they were being asked to weigh options without adequate information and without knowledge of the costs associated with each option. The parents in our study discussed the compromises that they had needed to make when planning medical and educational interventions. These decisions seemed to weigh on the parents and they expressed anxiety regarding whether or not they had made the best choice.

Maintaining a Social Life

As discussed in the previous section, socialization was affected by the parents' inability to find a sitter and the lack of respite care. When families, including the child with a medical condition, attended recreational or social events outside their home, extraordinary planning and creative adaptability were required.

Where Do We Find a Sitter? Most of the families did not use child-care providers given the extensive caregiving demands of their children; therefore, the parents had limited options for leaving home. Five of the children had poorly controlled seizures, four had compromised immune systems, two vomited frequently, and two had very low endurance for activity. In several of the families, one extended family member took care of the child for short periods if the parents needed some respite. For Annie's parents, "Basically the only people that help are Dan's parents . . . no one else has taken the time to learn how to do the medicines."

Although several of Jeremy's extended-family members had indicated an interest in learning his medical treatment to help care of him, these arrangements had not been made. Sean's family also did not have any help with respite other than nurses; "I would say the only extended family that really helps is [my husband's] mother, and mostly when we are not home and people need to drop off supplies. When we are in the hospital [with Sean], she will watch our daughter . . . so the only respite that we have had is the nurse." In general, the families only attended community activities in which the entire family could participate.

These parents, like those described by Kirk (1998) and Murphy (1997), rarely accessed respite. The parents did not complain about lack of respite and seemed to accept their situations. In some cases, the child's care could be taught to others, but the parents seemed reluctant to take the chance that problems may occur.

Anticipating the Unanticipated. Because the children in this study had multiple and often unpredictable needs, parents felt that they had to carefully and extensively plan each activity outside the home. Unanticipated events and preparing for them was a dominant theme in each family's social life.

When Jeremy's family went swimming or bowling, the parents had to check the facilities' accessibility before the visit. His father prepared for a bowling outing by researching the facility's accessibility and its least busy times. This family organized the equipment and supplies needed before every event. They developed plans "A" and "B"—"A" hoping that Jeremy would tolerate the activity or "B" fearing that he would not and they would need to return home. Carlie's reflux required that her parents take two to three changes in clothes with them on outings. They always had an "escape plan" in case she began to vomit. Carlie had a very low tolerance to noise so her parents used headphones at birthdays and in restaurants. The headphones allowed Carlie to enjoy the activity without being overwhelmed.

David's parents often had to curtail social events and outings because his endurance was poor. "We mainly have problems because David gets tired faster, he gets colds easier, and if he gets any type of cold we pretty much have to stay in the house. We have to do what he can do. So if he gets worn out we just have to go home . . . he has asthma and when you can't breath and you have a weak heart, it is double trouble." David's mother further explained:

> You make plans with friends, but you really don't know if you're going to be there until you're there . . . because he can get sick, he can have a seizure, his respite provider may not show up . . .

In general the families made careful decisions about their outings and the social events they attended. They weighed the costs and benefits, they decided whether or not they had the energy, then they planned carefully what supplies and equipment would be needed. Each had mastered packing all of the equipment and supplies that may be needed, including headphones, medications, extra clothing, and medical supplies. As well-supplied as they were, they also prepared to return home quickly, curtailing their attendance when problems arose. Several parents voiced that they hoped that relatives and friends understood their frequent early departures.

Perhaps these parents persevered in making efforts to participate in social events in order to maintain a balance and a semblance of typical family functioning. Gallimore et al. (1996) discussed the ongoing importance of family flexibility and adaptability to balance family functions when children have developmental disabilities or medical chronic conditions.

Maintaining a Self-Identity

With the level of care required by these children, it is not surprising that the disability became a prominent aspect of the family's identity and social–emotional selves. Through many of the conversations with the parents, it became apparent that the families viewed their self-identity in a positive way, to the extent that they made opportunities to support others in similar situations.

Celebrating Life. An important element of the parents' attachment to and feelings about their child was that each had faced the very real possibility that the child would die. Each child, at some point, and usually not at the time of birth, had reached a state of critical medical condition. These times, when their children were critically ill and in ICUs, left the parents with indelible memories. Although the students did not specifically ask about these traumatic times, the parents provided detailed accounts of medical crises when they thought they would "lose" their child.

David's parents described his heart surgeries during his first 2 years. During the last heart surgery, he had a stroke and was in a coma for several days. Michael's genetic disorder is known to result in early death, and he has been critically ill a number of times. Carlie spent the first 2 months in the neonatal ICU "barely holding on to life." Jeremy had been a typically developing infant until an accident in which he was almost strangled by slipping through his highchair. He was very close to death in the 24 hours following the accident.

Parents seemed to respond to these experiences of critical illness or severe injury by vowing to be continually grateful for their child's survival and life. Several of the parents referred to their child as a gift who allowed them to appreciate life. About half of the parents continued to live with the knowledge that they may yet lose their child. However, rather than grieving, this knowledge seemed to make them to appreciate the time that they had with their child and the joys that he or she brought to the family. Michael's mother explained; "Michael has given us so much. His brothers and sisters love him. They've learned about what it's like to be different. . . . They've changed. My husband and I have changed . . . because Michael has these issues, we enjoy every little thing he does."

The parents described ways that they had become more sensitive to and tolerant of individual differences. They seemed to appreciate life more, having almost lost a child and knowing how tenuous life is.

Becoming an Advocate. The families actively participated in advocacy for children with disabilities and had joined advocacy organizations or support groups. For example, Sean's mother belonged to two support groups, a transcutaneous peritoneal nutrition support group and a support group for children with genetic disorders.

Two other mothers worked part-time for advocacy groups. Mary, Jeremy's mother, worked part-time for a state family advocacy agency. Her role was to maintain a Web site for families with children with disabilities. She also

belonged to a parent organization that matched parents throughout the United States who had similar children and established long-distance communication. Michael's mother also worked a few hours a week for an advocacy group. "You know, I finally feel like I have a purpose. I'm on the family advisory council at the hospital."

Helitzer et al. (2002) suggested that mothers of children with disabilities assume roles that bridge the world of medical and educational professional with everyday home life. These support groups may replace some of the social activities that the parents have lost or can not sustain. The personal satisfaction that they achieve through their advocacy occupations may fulfill their interests in leadership and professional interaction that they may have otherwise experienced in a career.

The findings of this study suggest that the identities of these parents revolved around their preschool children with chronic medical conditions. The parents felt competent in caring for their children, who had survived life-threatening trauma or illness. They had accessed a full range of services and had joined advocacy and support groups. Each family felt that sharing their stories and their experiences was important as they told their stories in detail to the students and opened their homes to the students for 6 months. Parents communicated that the child had a positive effect on family members who had become more sensitive to and accepting of disabilities. They also seemed to feel more appreciative of each other and of life itself.

Occupational Therapy Practice Implications

Practitioners can help families maintain a balance of family functions, by problem solving to find ways to enable children with severe disabilities to play and interact and suggesting efficient ways for parents to manage their daily caregiving routines. For example, recommending use of assistive technology, such as adapted switches or augmentative communication devices, can allow children with limited motor function to access toys that provide auditory and visual stimulation. Assistive technology is most helpful when it fits well into the families' values and style of communication and provides meaningful play to the child (Deitz & Swinth, 1997).

The medical and educational decisions these parents faced were difficult to make, and often the parents felt that they were without one clearly best choice. Sometimes these parents had to choose the least detrimental option among several potentially negative scenarios. Professionals can support parents in their decision making by providing them accurate, relevant information (King et al., 1999; Patterson et al., 1994) and supporting their decision once it has been made. Parents should be prepared and informed as much as

possible when asked to prioritize intervention and treatment options. Once parents have made a decision, professionals should not only honor it, but embrace and implement the decision so that it can serve the best interests of the child and family. Parents in early intervention have expressed that they wished professionals were nonjudgmental and would think the best of the choices they made as parents (McWilliam, Tocci, & Harbin, 1998).

To help parents balance their caregiving responsibilities with social and recreational activities, practitioners can identify sources of respite that parents can use, acknowledging that competence in nursing and medical procedures would be necessary. Professionals can encourage parents to teach the child's care to extended family members. Extended family often want to help but do not know how. When they participate in the child's care, they gain a better understanding of the parents' experiences and can offer more emotional support.

Practitioners should encourage families to participate in recreational and social activities (Dunst et al., 1994). Practitioners can help by identifying community recreational facilities that are accessible and suggest methods to make outings successful. An occupational therapist's role is to listen and to provide parents with information on support and advocacy groups, including those on the Internet. They can also encourage families to establish identities in organizations and with social groups beyond those focused on disability (Dunst et al.; Turnbull & Turnbull, 1997).

Limitations

This sample of families was homogeneous across a number of dimensions, including race, socioeconomic status, and composition. The homogeneity allowed for in-depth exploration of their similar experiences and functions. The strong cohesion among family members may be unique to the participants who were studied and who volunteered to participate in a graduate student training project. All of the families had financial resources and medical insurance; the study's findings can not be generalized to families without these resources.

Recommendation for Future Research

Inclusion of a larger and more heterogeneous group of participants would increase the generalizability of the study's findings. Future qualitative research should explore family occupations when children have other types of disabilities, such as behavioral problems. The siblings' experiences should also be explored because the research literature investigating sibling experiences is minimal. The shifts in parents' roles and their methods of adapting to their children's caregiving needs should be further analyzed using

quantitative research methods. Analysis of measures of coping strategies, social supports, perception of stress, and adaptability in parents with children with chronic conditions can produce predictive models of family adaptation and resiliency to further extend and validate the findings of this study.

Conclusions

These families had round-the-clock demands and responsibilities to care for children with significant chronic medical conditions and developmental disabilities. The parents had shifted their occupations from work outside the home and social activities to caregiving activities and frequent interaction with health care professionals. When children have chronic medical conditions, practitioners can help families balance the child's medical needs and developmental needs. They can also support families in balancing caregiving responsibilities with social and recreational activities. Resilient families, such as those who participated in this study, give us lessons to pass onto other families in similar circumstances.▲

Acknowledgments

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