Mothering a Child With Hidden Impairments

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• human activities and occupations
• normalization
• qualitative research

When a mother has a child with a chronic impairment, the occupational demands of mothering extend to address the specialized needs of that child. This research explores how the type of hidden impairment in a child influences family routines and occupations. This qualitative study consisted of interviews with 22 mothers of children with attention deficit hyperactivity disorder (ADHD), a behavioral disorder, and 22 mothers of children with cystic fibrosis, a physical disorder. Open-ended questions were used to explore family demands, resources, time use, routines, concerns, and support.

The transcripts of these interviews were analyzed in terms of consistency with existing literature on parenting the child with hidden disability, and for emergent themes. In this analysis the experiences of mothers of children with cystic fibrosis were consistent with research findings on other chronic conditions, with these mothers reporting that family provides them with extensive physical and emotional support. Although mothers of children with cystic fibrosis reported a persistent emotional sorrow, they felt they were able to "normalize" their daily routines. In contrast, mothers of children with ADHD reported little family support, high perception of child-related demands, and less confidence in their success in mothering these children. In describing their daily routines, these mothers often stated that there was no such thing as a "normal" day. They felt constantly "on alert" and did not feel that they had "normal" routines. Based on this study, mothers of children with ADHD felt distress because their child did not easily conform to social standards, and were likely to express exhaustion in their role as "mother." The pattern of responses offered by these participants differs significantly from that of the participants whose children have cystic fibrosis, and from the usual pattern of coping with chronic childhood disability documented in the literature.


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Issues of parenting and, in particular mothering, "other-than-normal" children have been a focus of research in several disciplines (Nelson, 2002). In her meta-synthesis of mothering studies, Nelson states that "the combined effect of social trends and health reform has put mothers of other-than-normal children at risk for a parenting crisis" (p. 515). There is much research pertaining to family stress associated with childhood disability. Much of this research focuses on a unidimensional difference faced by the mother, for example a child with cerebral palsy or a child with muscular dystrophy (Bouton, 1983; Bouma & Schweitzer, 1990; Kendall, 1998; Segal & Frank, 1998). Few studies have included a comparison group, or distinguished between "visible" and "invisible" conditions.

Although the acceptance of the child's disability itself may be a major stress, as the disability persists, it has been demonstrated that families begin to see the lifestyle changes caused by a medical condition as "ordinary." This process is called "normalization" and is viewed as a positive adaptation in parenting a child with special needs (Deatrick, Knafl, & Walsh, 1988). Successful normalization has been described in conditions as varied as asthma, diabetes, cancer, arthritis, and muscular dystrophy and involves incorporating the child's illness into routine child and
family occupations (Knafl & Deatrick, 2002). Normalization is a construct that reflects an internalization of the specialized habits and routines associated with a disorder to such a degree that they are integrated as ordinary personal and family occupations (Knafl & Deatrick, 1986). Because of the effects of normalization, families dealing with chronic medical problems in their children often do not differ from families with more typical children on surveys and Likert-type stress measures (Walker, Van Slyke, & Newbrough, 1992).

Distinctions have been made between behavioral and medical disorders in clinical research on stress, with significantly more family stress documented in the presence of behavioral disorders such as autism (Bouma & Schweitzer, 1990; Donenberg & Baker, 1993). Early research on normalization did not distinguish between medical and behavioral conditions, although there was evidence that families responded differently based on the type of condition (Deatrick, Knafl, & Walsh, 1988).

Attention deficit hyperactivity disorder (ADHD) is a disorder of behavior that may include a short attention span, poor impulse control, difficulty completing tasks, high levels of motor activity, and poor interpersonal awareness (Aust, 1994). Children with ADHD may take oral medications such as Ritalin™ to control the effects of the condition (Leung, Robson, Fagan, & Lim, 1994). Other recommended interventions include special education, counseling, and occupational therapy. Research on parenting children with this condition describes family life as “chaotic, conflictual, and exhausting” (Kendall, 1998, p. 839). Lewis (1993) found that parents of older children with ADHD reported poorer family functioning than parents of young children with the condition, suggesting that functioning may deteriorate as the family members interact over time. Segal and Frank (1998) reported that the symptoms of ADHD have the potential to disrupt family routines and challenge social norms.

In cystic fibrosis, a contrasting physical condition, the body produces an abnormal mucous that leads to progressive degeneration of the respiratory and digestive systems. Although regarded as a terminal medical condition, with current technology most children with cystic fibrosis live into adulthood, with chronic, though relatively stable health concerns throughout childhood (Cystic Fibrosis Foundation, 2003). The treatment of cystic fibrosis in children varies based on which organs are involved. When the lungs are involved, children may require vigorous percussion on the back to dislodge the thick mucus from the lungs and frequent courses of antibiotics. The antibiotics may be administered intravenously or orally. When cystic fibrosis affects the digestive system, the body does not absorb enough nutrients and the child needs to take replacement vitamins and enzymes. While these treatment regimes may be extensive, they are constant and often develop into routines (Angst, 1992).

The Research Purpose

The purpose of this research is to describe the variability in occupations of mothers dealing with different types of childhood conditions in order to better support the occupations and the optimal development of the child and parent. Mothering is an adult occupational role that is both personally and socially constructed. The role of mother is value-laden and includes both the daily work of child care and the larger social meaning of having children (Boulton, 1983). Societal images of motherhood include that (1) a mother enjoys her child, (2) a mother intuitively knows what to do for her child, (3) a mother cares for her child without ambivalence, and (4) the mother devotes herself first to her child’s needs (Thompson & Walker, 1991). Mothering is a dynamic occupation that changes with both the age of the child and societal demands. Francis-Connolly (1998) describes mothering as a lifetime occupation that is central to the mother’s self-perception. Studies of occupational science and occupational therapy have promoted the study of both family and maternal occupations (Segal, 1999). Published studies have included both typical families (Francis-Connolly, 1998; Pierce & Frank, 1992) and families of individuals with special needs (Kellegrew, 2000; Segal, 1999).

ADHD was chosen as a focus for this research because of the many mothers encountered by this researcher were trying so hard to parent in the face of social censure. ADHD is a hidden impairment in that it has no obvious physical manifestation, and it is a disorder of behavior rather than a disorder of body function. In order to successfully compare this behavioral condition and its influences on the mothers’ self-perception, the comparison group needed to be dealing with a physically limiting condition in which the physical condition is hidden. Cystic fibrosis was selected as an example of a hidden medical condition.

Method

These two conditions, ADHD and cystic fibrosis, were the child impairment variables chosen for this study because both are chronic, present at birth, and invisible to the casual observer. Although cystic fibrosis is regarded as a terminal condition resulting in early death, mothers recruited for this study were dealing with the “well” child with cystic
fibrosis, rather than an ill or hospitalized child. The premise of this study is that the childhood behavioral deviations and social sanctions associated with ADHD limit the child and the child’s mother’s abilities to participate in typical occupations and succeed as “normal,” compared to mothers of children with cystic fibrosis who are not typically dealing with either behavioral deviations or social sanction.

A qualitative research interview was selected as the data collection method that would allow access to the perceptions and life experiences of the mothers (Kvale, 1996). The theoretical approaches that guided data collection and analysis were the concepts of roles, habits, and routines from occupational science (Zemke & Clark, 1996), the idea of socially constructed roles (Berger & Luckmann, 1967), normalization theories (Deatrick, Knafl, & Walsh, 1988) and family stress and adaptation theory (McCubbin & Thompson, 1991).

Informants

Informants for this study were recruited from specialty clinics, regional chapters of CHADD (Children and Adults With Attention-Deficit/Hyperactivity Disorder), a support group for families with ADHD, and CF-Sharp, a support group for families with cystic fibrosis. To be included, a mother needed to be more than 18 years of age, be fluent in English, and have a child between the ages of 5 and 18 years diagnosed with either cystic fibrosis or ADHD. “Mother” includes biological, adopted, foster, and stepmothers. Consenting participants were interviewed during the child’s clinic visit, or interviews were scheduled for a later date. The ADHD data were highly variable, and recruitment continued until there were 22 mothers of children with ADHD when the researcher felt confident of data saturation. With the matching group of 22 mothers of children with cystic fibrosis, a total of 44 participants were included in the study.

Procedure. Data collection consisted of either one or two interviews with each informant. The interviews were done by the researcher, and each interview lasted between 1 and 2 hours. In the interview the informants were asked general information about family structure, resources, and demands. They were asked for the history of their experiences as mothers both prior to and since their children were identified as having impairments. Additionally each informant was asked to provide a detailed summary of her “typical” day and to provide a list of persons who were helpful in dealing with their child’s special needs and the type and frequency of support that they offered.

All of the interviews were audiotape recorded and transcribed by a professional transcriptionist. The data collection period extended for 6 months. After the first 10 interviews were completed, a preliminary analysis was done and a closing question, “Is there anything I should know about what it is like to live with and parent a child with ADHD [or cystic fibrosis] that we did not discuss yet?” was added. Interviews with each mother were treated as single cases. Interviews of mothers of children with cystic fibrosis were planned to match the number and age range (both child and parent) of mothers in the ADHD group.

Analysis

A list of constructs identified in the literature was created and imbedded in the interview format prior to data collection. As data were acquired and reviewed, recurrent patterns discussed by study participants were also identified and added as emergent constructs. Each construct was assigned a “code” that was embedded in the transcript to aid analysis. For example, in Gallimore et al. (1989) the social construction of “ecocultural niches” by families of children with developmental disabilities was described. Findings from the studies reported by Gallimore and Lopez (2002) suggested that families build specialized environments (niches) in their homes and communities in which their child with a developmental disability was able to successfully function. In the interview data for the study reported here, following any description of highly “parent-structured” environments of this type the code word “Niche” was inserted in the text in brackets. Bracketed code words of this type were added as new themes emerged in the data, and previously coded transcripts were continually updated to include the more current coding schemes. This reflexive strategy is called open coding (Strauss & Corbin, 1990).

Axial coding is “a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories” (Strauss & Corbin, 1990, p. 96). The focus of this procedure is to integrate the codes from diverse theories and emergent themes to accurately reflect the intent of the informant and clarify relationships in the data. Five interview transcripts, with no analytic codes inserted, were circulated to specialists in cystic fibrosis, ADHD, and qualitative research for review. Coding strategies were discussed with each of these persons prior to this researcher’s further analysis of themes and patterns in the text. A table of summary coded information was generated for each interview and patterns in the data were analyzed by hand.

During each interview, the researcher kept notes that included comments about the context, the time of day, and general impressions of the informant. These field notes were analyzed with the transcript data to determine the frequency of and context within which that topic was mentioned. When a pattern appeared consistently in the completed
transcripts, the researcher used the subsequent interviews to confirm or refute the perceived pattern of responses. Following initial analysis of all of the data, two interview subjects from each disability category were given the summary information and data analysis for content validation (Gilgun, Daly, & Handel, 1992).

Additional analyses needed to make and validate statements of relationship were completed after the interviewing was complete and the final transcripts were available to code (690 pages of interview transcripts and 22 pages of field notes). The transcript data were then separated into demographic information, mothering roles and occupation, and daily routines. In some instances comments were assigned multiple codes, and some codes such as [emotional demands], [medical procedures], and [home programs] were collapsed into the broad category of [child-focused demands]. The results of the analysis of the interviews about mothering roles, routines, and occupations in these two groups of informants are discussed below.

Findings

Table 1 provides basic demographic information on the two participant groups. The two groups were similar in terms of family size and structure. A larger proportion of mothers of children with ADHD were employed more than 25 hours per week. This difference probably reflects a regional idiosyncrasy in the eligibility system for obtaining medical services. Families in lower income brackets received a higher level of medical support for children with cystic fibrosis than was available to families in middle-income groups. For this reason, many previously employed parents left paid employment to secure better care for their child with cystic fibrosis. As Table 1 indicates, the family income for families of children with ADHD was far below the family income of families with children with ADHD.

Three themes were consistent in these data. The first was that family appraisal seemed to be influenced by the participants’ perceptions of personal control. Second, participants seemed to feel more like “good mothers” when their children were able to participate successfully in “normal” childhood activities such as school, worship, and parties. The third theme was that the ability to maintain daily routines seemed to contribute to the participants’ sense of personal control and personal well-being.

**Family Appraisal.** Family appraisal is described as “…the family’s subjective definitions of their demands, their capabilities, and of these two factors relative to each other” (McCubbin & Thompson, 1991, p. 20). Positive family appraisal includes an overall sense of personal control and little ambiguity about role expectations and the action required to cope with the challenge. Specific threats to a positive appraisal are “role strain because one can’t meet the high expectations set for oneself…[and] lack of a clear definition about how to cope” (McCubbin & Thompson, p. 20). Research on family stress and adaptation reports that higher scores on family appraisal measures are associated with more positive child outcomes (McCubbin & McCubbin, 1993). For this reason, family appraisal can be interpreted to reflect perceived success in family occupations and in meeting personal expectations for role performance.

In general, the mothers of children with cystic fibrosis described themselves as optimistic, detailing their children’s successes, extracurricular activities, and new medical advances that might slow the progression of the cystic fibrosis. This pattern of response differed markedly from that of the mothers of children with ADHD. Much variability in the tone of the interview existed in this group of participants. A range of personal styles was demonstrated, ranging from an optimistic view (similar to the predominate view in the cystic fibrosis group) to a depressed and withdrawn attitude. Regardless of the mother’s general affect, most mothers of children with ADHD reported frustration with the controversies involved in identification, medication, and service provision that they had encountered. Many of these mothers were openly angry and reported that their interactions with both the health care system and the school systems were strained.

Unlike the participant mothers of children with cystic fibrosis, mothers of children with ADHD reported a persistent censure. They were distressed by the controversy surrounding the diagnosis and treatment of ADHD. These participants reported that no matter how carefully considered their decisions were, they were continuously challenged by well-meaning acquaintances and even the popular press. They also reported that ambiguity about “best care” for children with ADHD supports these challenges and leads to the implication that they were poor parents. The fear of being considered a “bad mother” was frequently cited in the interviews with mothers of children with ADHD. These mothers reported an ongoing search to learn all they could in order to make good decisions, as one participant stated:

**Table 1. Demographic Summary of Informant Groups:**

<table>
<thead>
<tr>
<th></th>
<th>ADHD</th>
<th>CF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean number of children in home:</td>
<td>2.32</td>
<td>2</td>
</tr>
<tr>
<td>Mean age of child with CF or ADHD (years)</td>
<td>9.7</td>
<td>11</td>
</tr>
<tr>
<td>Mother’s mean age (years)</td>
<td>41</td>
<td>37</td>
</tr>
<tr>
<td>Mothers employed more than 25 hours/week</td>
<td>62%</td>
<td>48%</td>
</tr>
</tbody>
</table>

Note. ADHD: Attention deficit hyperactivity disorder. CF: Cystic fibrosis.
Your life accommodates them. The running around, and the special appointments, and the stacks of papers that go with it and the information that you seek out and read. But it all depends on the person, too. I’m a person that has to research what’s going on. I may get too much or I may get too little, but at least I’m going to know something about what’s happening. And I’ve read many books.

All 22 of these mothers reported social sanctions and high demands placed on them by the school or medical communities. One participant commented:

And so their [the schoolteachers] attitude is that you’re just a lousy mom if you can’t spend 2 or 3 hours a night with your child working on this specific thing. That’s not real, and it’s a real barrier block. They’re not up to date on what the life is like for the parents out there. I won’t get on my soapbox. I pick up my kids at 5:30. By the time we went home and get out of the car it’s closer to 6:00. I have to make dinner. By the time I pick them up, [Dana and Leon (pseudonyms)] are both completely off their Ritalin….Trying to get an ADD student who’s working below level to sit down and do his homework every night….And that’s if you can sit with them and say, “Stay focused. Okay, concentrate on what you’re doing. Now what’s next. Now what do you have to do?” The reality is, I’ve got two other kids that are running around screaming and jumping that need some attention, need food, need baths, need me to look at their stuff. I don’t, it’s not feasible. And so it becomes this huge war.

The mothers of children with ADHD in this study reported much frustration associated with the awareness that their child did not function as well as peers in many settings. None of the mothers interviewed felt that they were entirely to blame for their children’s difficulties in school or social settings. Yet as one mother in the study reported:

We’re always blamed for it. People think you should be able to control your child. I used to feel the same way, with my other children, when I’d see a child misbehaving. I’d think, “What’s wrong with this parent? Why can’t she control the situation?” I didn’t know. I was just like them.

This experience is very different from that reported by participants dealing with cystic fibrosis. These participants had a well-defined set of behaviors and routines expected of them to maintain their child’s health. Following these routines, they felt that they had happy well-behaved children who could participate in regular childhood activities. These mothers reported confidence that they were “good mothers.” Most of these mothers focused on how “normal” their child and their family were, and responded with confidence in their appraisal of their child’s condition. As one participant commented:

[After you got used to the diagnosis of cystic fibrosis, how do you feel about the problem?] I got used to it. After I found out more about it, it’s not as bad. When you get to watching films and reading on it and stuff, it’s not too hard to deal with. When you first find out about it, and you don’t know much about it, but you know that your cousin had passed away because of that, it’s scary, but once you find out you know, well, they were, one was thirteen, the oldest one was thirteen when he passed and the younger one was fifteen. And you know, the more the years go by, the more they know about it, and it’s a lot more easier now than it was back then. So that was a relief to know that they live longer too. In his day and time, they’ve got a better chance….He’s just a normal, happy little boy.

Normalization. The quote above was typical of the comments of participants who had children with cystic fibrosis. In this group the frequency with which the words normal, ordinary, and routine occurred was striking. It was especially striking when compared to how seldom those words were used in the ADHD interviews. The fundamental premise of normalization is that individuals make sense of chronic illness and life disruptions by constructing a “life as normal” story that includes a past, a present, and a future (Deatrick, Knafl, & Walsh, 1988). Cystic fibrosis, in many ways, is conducive to this sort of story building. When asked, “Tell me the story leading up to your child’s diagnoses,” mothers of children with cystic fibrosis usually had a short coherent tale such as the following:

She was doing great. She was growing. She was gaining weight. She was doing good and then I got like strep throat, ear infections, I just got real sick, running real high fevers and for a long time, like a week and a half, 2 weeks, my milk kind of dried up from lack of being able to eat and keep stuff down and drink and stuff. But anyway, we had to start putting her on formulas. And that’s when our problems started. She started throwing up and having diarrhea and that was at 3 months. And then finally at 6 months, everything just clicked. They had diagnosed her as failure to thrive. And then we started noticing the true-blue symptoms of cystic fibrosis. And we kind of just fell in together. And we had her sweated and she turned out positive. And it was a rough 3 months. After you got used to the label, how do you feel about the problem? Its just part of life.

Mothers of children with ADHD had a longer period of dealing with their child’s problem without health care support. Whereas, the health crises posed by cystic fibrosis led these mothers into early and intensive medical interventions, the participants who had children with ADHD had very different stories. A major theme in the ADHD stories was the amount of vigilance and the stress that vigilance caused as mothers tried to keep their child safe and out of trouble. For example:

He never stopped, ever. He was always on….And I always thought, “Wouldn’t it be wonderful if he had a little switch
to turn him off and stick him in the drawer and put him away for the rest of the night.” But he was just real different from the other kids. The other kids would be like bumps on a log and here was this kid that just wouldn’t stop. And then sometimes he really got so wound up that it was pathetic…he was just like this little top out of control. You know, and I knew he didn’t understand what was going on….In kindergarten, at the point that the teacher told me, I knew that she was right and that there was something. He just couldn’t sit in his spot and he wasn’t being malicious or anything, but he just couldn’t do it.

This mother was so involved in managing her child’s behavior that she was unable to do more “normal” things. Her frustration with this constraint is illustrated in her response to the question “Have your interests changed since you have been dealing with your child’s special needs?”. It would be nice to shave my legs and stuff once in a while….Like I say, I truly felt, not a joke, that my life was being sucked away. I spent all the time with this kid after school. I was working these crazy hours, 4:00 a.m. to 2:30 in the afternoon, so I would be there to pick up these kids. I’m a medical technologist. To pick them up so they don’t have to go to after school care so they can go straight home and do all this junk for school. And then I neglected totally my older son, which then now he’s going through all of these puberty and everything else, and it’s just like, you know, I’m overwhelmed. And, you know, you feel guilty….I did this for a couple of years, like 3 years almost, and I started getting insomnia, and things just started cracking. And at that point in the afternoon I was worthless anyway. I only was working three times a week. But it took me a day to recoup. It was just awful. I was horrendous and I was getting insomnia on top of everything else. I said, “That’s enough, that’s it, that’s it, that’s it.” I cut back my hours AT HOME and I’m working 5 days a week now.

The process of normalization has several component parts. First, to construct a story of life as “normal” there needs to be acknowledgement that there is a chronic condition. Both participant groups recognized the presence of a chronic condition. The second aspect of normalization is that the problems associated with the chronic condition are accepted but minimized. With cystic fibrosis, there are rigorous and aggressive interventions needed to maintain the child’s health. These interventions include tasks such as serving frequent high calorie meals with enzyme supplements and limiting exposure to common colds and infections. To manage cystic fibrosis the mothers were able to develop strategies and had predictable patterns of behavior that allowed their child to participate in many “normal” childhood activities. One of the common strategies of “doing normal things” is a focus on discipline and treating the child “like any other child.” This was commonly mentioned in the cystic fibrosis interviews. “Special” treatment at school or from family friends was frowned upon. Many of the participants with children with cystic fibrosis put a lot of energy into “covering up” and minimizing the focus on the life changes caused by cystic fibrosis. This is consistent with the pattern of normalization described in the literature (Knafl & Deatrick, 1986).

For the participants who had children with ADHD, the aspects of the condition were accepted, but continuously intruded into and limited both the child and the mother’s ability to engage in social and personal activities. The strategies devised by mothers of children with ADHD may have helped the children perform in school, but they interfered with each mother’s ability to participate in her own daily occupations. As demonstrated in the previous quote, these participants often cited common tasks, like “shaving my legs” as luxuries, and these same mothers often described needing to choose between their own and their child’s needs. As with cystic fibrosis, discipline was a major parenting focus. In this case, rather than insisting on “like normal,” many mothers reported that they had “lowered their standards” or that they “chose their battles.” In the case of ADHD discipline was sometimes sacrificed in order to maintain a level of family conflict that allowed other family members to function “normally.” In attempting to minimize or “cover-up” the behavior problems associated with ADHD, these participants went to great lengths. Here is one mother’s report of her daughter’s support services recruited to help her daughter participate in the school setting:

She has occupational therapy twice a week privately at [local clinic], plus she received occupational therapy at school as well….I know at least once a week, but it sounds like periodically she sees that person more often. She receives speech language…I don’t know how often….She goes to [local behavioral psychologist] once a week. She gets individual counseling. Plus, we go as parents every other week for parental guidance training, whatever you want to call it. And I think there are people in the class in the school who periodically do things with her, but there isn’t like a set psychologist who sees her.

Maintaining a Routine. Routines were important to the perception of normalization in both groups. Mothers in both groups who described their lives as routine seemed consistently positive and those who described their life as chaotic seemed negative in their family appraisal. A typical response to the question, “Describe your typical day to me including the whole 24 hours” for the participants with children with cystic fibrosis follows:

Day after day, same time every day practically doing the same thing. Our routine very rarely changes without something happening. In the beginning, of course you start…it was a matter of getting used to it. You do have to get used
to it. But he is going to be 12...it's been a lot of years. It's really a pattern. That if we are on vacation or something, and it's not routine, we can get disturbed...because we're not used to that. You can get very dependent on that...and that is the way we live. Anything else throws you off...Because of need for medications, meals are at certain times...snacks pretty much certain times too...When I talk to you about it, I realize that everything is very routine...highly. I just never thought of it that way.

The participants dealing with children with ADHD often had much difficulty describing a "typical" day. Often the question "describe your typical day to me" resulted in several questions from the mothers, including "a school day or a weekend day?" and "on or off medicine?" The lack of routine was the most consistent pattern in this group of participants. Their answers were often lengthy and included detailed description of their frustrations. An example of this follows:

I get up at 6:00, but my husband doesn't get up. We don't wake the kids up until quarter to 7. We leave the house at 7. And I say, "We've got to get these kids up earlier." And he says, "What for? We'd have to deal with [Nathan] all that much longer." We just get him up, we just deal with him for 15 minutes, and that's it. Get dressed, put your shirt on, put your shirt on. You know, you tell him, put your socks on. And he's not on—obviously, he takes his medication, but that's not going to kick in for quite a while, 45 minutes. I've been tempted to get him up and give him medicine and then put him back in bed. It's horrendous. Those 15 minutes. You know, you're screaming like an idiot, "You don't have your shoes on. I told you to get your shoes on." Because you're just trying to get out the door at 7:00. And it doesn't matter. You can wake him up at 6:15 and you still go through this. You just have 45 minutes of this. So I don't know. Yeah, the mornings are definitely the most horrendous."

Mothers of children with ADHD aspire to, but seem to have more difficulty attaining, a semblance of normalization. The impulsive and erratic behavior of many children with ADHD makes it difficult to sustain daily routines. A recurring issue was the high demand for parental vigilance. This need for vigilance limited the participant's ability to participate in her own daily occupations. Many strategies for dealing with this were described. Most, like the ones that follow, were distressing for the mother.

...we're forever doing like behavior modification programs, like the modification program the last couple of months that we're trying is these boards, write on--wipe off boards that we have where she gets check marks for accomplishing (1) getting dressed in the morning, (2) brushing her hair in the morning, and (3) eating. You know, very elemental, very basic things. And then at the end of the week, we give her rewards not necessarily based on number of check marks but just general gestalt. We were doing a more direct point system with rewards and that got to be a big battle. Every point was battled for. It was like, you know, she wouldn't want to do the work, but she wanted the points so she got the tokens. And that got to be a hassle. But we're constantly going through different revisions of behavior modification.

One of the things that seemed to interfere with the development of routines was the children's dependence on their parents to organize them with routine tasks. The children did not seem to develop or manage daily routines well. As one mother commented of her 10-year-old, "Oh, he's definitely very dependent on me. Very, very, very." Another mother commented, "Even at 18 months [Mary] was active and getting into things. We could not sleep at night for fear that she was going to get out of bed and tumble down the stairs. Or go outside the house. She'd wake up and she'd be ready to take on the world. In order to get any sleep, we used to lock her in. We must've been totally stressed."

**Occupational role behavior.** The "mother" role has unclear parameters in our society. Rather than a prescriptive set of expected behaviors, mothering is a fluid role that seems to vary according to personal, social, and environmental pressures on both the child and the mother (Nelson, 2000). The children's abilities to perform well in social venues such as school, church, and sports were consistently mentioned by all participant mothers as evidence of their successful mothering. In the case of mothers of children with cystic fibrosis, they spoke with pride about their children's good grades, roles in the school plays, and performances as cheerleaders. The mothers of children with ADHD also took their children's successes and failures personally. For example:

I don't know, maybe just because I'm sensitive about it or something, but sometimes I think he doesn't have a lot of friends, even though he's been in this school forever...he doesn't get invited a lot of places. And he doesn't have that. But he doesn't seem to mind, either, so I quit worrying, or tried to quit worrying about it. But I think some of it is the parents can't deal...Although, you know, I would give him a dose, you can invite him. It makes me sad.

Because a child's social participation is to some extent outside a mother's control, mothers of children with chronic conditions must respond with increased involvement in their child's school and leisure activities. A recurring theme was the need to keep up with everything that was happening to their child. Mothers in both groups described the sense that their child was "a time bomb ready to go off." Mothers either by themselves, or in response to environmental press, become very invested in their maternal roles as caretaker, protector, and cheerleader. Mothers in both groups described their spouses as "good fathers" but not as involved in the day-to-day management of child-care rou-
times. These mothers often centered their lives around their children, for example, in response to the question “How has your lifestyle changed to accommodate [Anna]?” one mother said:

I'm more leery of taking them [Anna and her brother] in public. You definitely don't want to take two of them together if you don't have to, like to the grocery store, you know, when you're trying to do things and they're here and they're there and all over. And it's really harder to take them to public things because of their hyperactivity and their impulsivity and they talk back to you, and other people look at you, like you're letting them do this.

Participant mothers of children with ADHD described distress, exhaustion, frustration, and worry for their children in the adult world. These mothers spent much of their day in direct interaction organizing and supporting their child so that he or she could participate at school, and about half of the mothers interviewed felt that the need to do this interfered with their ability to engage in other important occupations, such as homemaking, keeping up with friends, and leisure. The participating mothers of children with cystic fibrosis also spent much of their day organizing and supporting their children, managing complex medical regimes. The descriptions of daily routines suggested that the time spent in child-related activities was similar in both participant groups. Unlike the mothers of children with ADHD who commented that their “life was being sucked away,” the mothers of children with cystic fibrosis felt that there was no better or important competing way that they might spend their time. The terminal nature of cystic fibrosis seemed to have a pervasive effect on personal decisions resulting in a tendency for these mothers to subjugate their interests in order to be an idealized “super-mom” who was always there. Ungrudingly the participant mothers of children with cystic fibrosis described accommodations for their children that ranged from moving to a better climate to putting their children’s clothes in the dryer a few minutes every morning so that they don’t have to dress in cold clothes.

Discussion

This study explores how type of hidden impairment in a child influences the child’s mother, and influences the mother’s daily routines and occupations. The perceptions and the structured routines described by the participant mothers living with children having cystic fibrosis were consistent with other research on chronic illness (Deatrick, Knafli, & Walsh, 1988). They had many additional daily demands, but these were repetitive and soon became seen as “normal.” The responses of mothers of children with ADHD were very different. Their daily routines were highly variable, with no clear pattern emerging from the several pages of notes describing each “typical” day. As with cystic fibrosis, many additional daily tasks were needed to keep their children participating in school and social environments. These mothers reported feeling overwhelmed, yet felt isolated from social support.

Mothers of children with cystic fibrosis said they “treasured the family moment” and were very child-focused in their daily choices and routines. These mothers reported that they sometimes felt overwhelmed, but found support in their family, their community, and the health care system. These mothers had strong, clearly defined daily routines that seemed to help them manage their complex demands, to feel “normal,” and achieve a sense of accomplishment. In contrast, for mothers of children with ADHD, the impulsive and atypical behavior of their child led to social censure and self-doubt. These mothers said that they “got by minute by minute” and that they were careful to “pick their battles”…Dyck (2002) noted that the responses of women with multiple sclerosis to the question “describe your typical day” were “cast with an overarching theme about how well or how ill they might feel.” This response seems similar to the uncertainty described by mothers of children with ADHD to their uncertainty about the kind of day their child might have.

Segal (1999) describes family occupations as “culturally meaningful chunks of activities” (p. 53). Much of the occupational therapy literature on family occupation has focused on specific activity contexts such as meals, homework, self-care, play, and leisure (Segal; Kellegrew, 2000; Leipold & Bundy, 2000). The analysis of family routines in this study suggests that success in social participation in valued social realms, such as school, church, and sports was closely linked to the mother’s subjective sense of personal competence. While meals, homework, and self-care routines were discussed in detail, the affective responses of the participant mothers in this study were more linked to their children’s social participation.

Consistent with normalization theory, mothers in this study had a more positive appraisal of themselves and their children when the disability of the children could be hidden from public view by specialized daily routines. When the condition could not be managed by routines, and the child was socially identified as “different,” the mothers had a more negative view of both themselves and their children. Larson (1998) indicated that central to the emotional coping of mothers of children with disabilities was the paradox of accepting their children as they were, while continuing to hope for improvement. The overriding sense of hope that was present in the interviews of mothers of children with cystic fibrosis in this study was not common in the inter-
views of mothers with children with ADHD. The mothers dealing with ADHD were more likely to express exhaustion and futility similar to that described in Boydell's study of mothers of adult children with another chronic condition, schizophrenia (1996). In her metasynthesis of mothering research Nelson (2002) noted that a sense of exhaustion was reported only by mothers of children with ADHD and with mothers caring for adult children with schizophrenia. The other types of mothering experiences she reviewed, including the experiences of mothers of children who were technologically dependent, had cerebral palsy, were brain-injured, and had asthma did not include this feeling.

Kellegher (2000) commented, “….a mother’s view of her child’s future played a pivotal role in the types of daily routines constructed” (p. 258). In this study, concerns about the children’s futures were expressed by mothers in both participant groups. The reports of mothers in this study suggest that their appraisals of themselves and their children (positive or negative) reflect their own visions about what they see in their children’s future. Occupational therapists are in a powerful position to influence the visions and help mothers support the development of positive daily routines. In the interviews, the descriptions of daily routines were rich, and often seemed to be “eye-opening” for the respondents. Future research into child treatment interventions that are enmeshed in family routines and interventions aimed at enhancing “normalization” may enhance our understanding of occupational behavior within the family group.

A recurrent source of exhaustion and frustration described by mothers of children with ADHD was their relationship with the children’s schools and with the health care system. Nelson (2002) describes acquiring skill in negotiating the health care system as a positive adaptation seen in mothering other-than-normal children. The participant mothers whose children had cystic fibrosis found support and comfort in their health care providers. This was not the case of many of the mothers of children with ADHD. The social and medical controversy about the “existence,” etiology, and best treatment for ADHD contributed to the mother’s distress.

The heterogeneity of the demands on mothers of children with these types of conditions made them difficult to compare, yet yielded some important insight into the strategies that mothers used to cope. This researcher observed that in both groups of participants, there was a tendency to gloss over or underrepresent the burden and special care needs of their child. This suggests a need for health professionals to take time and ask questions about family routines and habits that will give insight to the daily lifestyle. Sensitivity to the demands and needs of the family should enable the occupational therapist to have a more client-centered focus. In addition, by increasing the treatment emphasis on skills that will support the development and maintenance of daily routines occupational therapy interventions are more likely to be meaningful and supported by the family and understood by others in the family constellation.

Conclusions

The purpose of this study was to explore how the hidden impairments of cystic fibrosis and ADHD in the child influences family routines and occupations. I found that mothers’ abilities to organize and maintain routines seemed to contribute to their sense of well-being and efficacy in their roles as mothers. Normalization theory was useful to understand how the ideal of being a “normal” family supported the participants with children with cystic fibrosis. By hiding the condition, through routines and selective sharing of information, these mothers seemed to feel that they had learned how to best “mother” their child and felt societal approval for their successes. Participant mothers of children with ADHD also maintained the ideal as being a “normal” family, but saw that as a goal rather than a current state. Barriers to normalization for those mothers included the overt and unpredictable behaviors of their children, the often antagonistic relationship with the health care system and the schools, societal judgment, about public behavior, and the controversies associated with the recognition of ADHD as a “real” condition. This study lends support to the finding of Helitzer, Cunningham-Sabo, VanLeit, and Crowe (2002) that “caregivers’ daily routines and activities, life demands, social support, and coping mechanisms need to be strongly considered when planning intervention for children with special needs” (p. 32).

References


