
Mothers With Disabilities: In Their Own Voice

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Objectives. The purpose of this study was to gain an understanding of the personal experience of women with disabilities engaged in the occupation of mothering and their perceptions of their interpersonal environment, including interaction with family, professional caregivers, and the community.

Method. In this qualitative study, in-depth interviews were conducted with a diverse sample (n = 8) of mothers with disabilities or chronic illnesses to uncover the nature of their mothering experience. Data were analyzed for themes with the constant comparison approach of grounded theory.

Results. The quality of the participants' experience varied with the degree of perceived similarity or dissimilarity with other mothers and acceptance of these differences. In addition, their perception of the supportive or nonsupportive nature of their interpersonal environment had an impact on their mothering experience.

Conclusion. The results suggest that mothers with disabilities tend to value the importance of performing maternal occupations according to a perceived culturally common way, although self-acceptance of their own unique differences in performing these occupations facilitates maternal engagement as well.

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Parenting, a central human occupation, has profound personal meaning and requires an orchestration of many components. Erikson (1980) theorized that becoming a parent (an expression of generativity) was a normative adult developmental experience, and researchers have examined the way parenthood shapes and organizes adult personality qualities (Gutmann, 1975). Parents are expected to engage in many diverse activities, ranging from the provision of their child's concrete needs for sustenance, shelter, and safety to the provision of an enriching psychosocial environment for their child's overall development and socialization (Maccoby & Martin, 1983). Although being a parent can influence psychological well-being both positively and negatively, for many people it gives meaning to life (Umberson, 1989; Umberson & Grove, 1989). Becoming a parent is an experience that many persons assume will be accessible to them. However, this has not been true for persons with a disability.

In the past, persons with disabilities were generally not recognized as persons who could nurture future generations (Sprill, 1987). As a result of technological and biomechanical advances within medicine, persons born with disabilities are leading longer and fuller lives that could include the conceiving, bearing, and nurturing of children. Other persons are acquiring and living with disabilities during prime child bearing and child rearing years. In addi-

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tion, the sociopolitical and legal changes promoting full inclusion have fostered a more open attitude toward persons with disabilities participating in all aspects of life. All of these factors make the examination of parenting with a disability a timely pursuit.

The unfounded belief that persons with disabilities will be “unfit” parents has been entrenched in our culture as well as in our legal system (Asch & Fine, 1988; Gilhool & Gran, 1985). Laws prohibiting persons with disabilities (e.g., epilepsy, retardation, psychiatric illness) to marry or have children existed in many states (Asch & Fine, 1988). Although there have been social and civil rights trends toward full life involvement of persons with disabilities, there are still “only a handful of progressive states that refused to treat disability as *prima facie* evidence of parental unfitness and possible detriment to the child” (Gilhool & Gran, 1985, p. 30). Persons with physical disabilities continue to have their right to child custody legally challenged. In an interview with Stephen Greenspan, a psychologist who conducts research in child custody and disability issues, he stated that “because a parent has a disability, the system throws all kinds of roadblocks in the way” (De Angelis, 1995, p. 39). This bias also occurs in the psychological assessments of parents that courts use. A fair evaluation includes examining the parent and total family environment and support, not relying exclusively on scores of a psychological test.

On a personal level, many women with disabilities may be “discouraged by their families, friends and health providers from considering the option of parenthood” (Asrael, 1982, p. 214). From a societal perspective, Westbrook and Chinnery (1990) discussed the negative attitude toward women with disabilities having children. They view this as a part of a larger social bias toward persons with disabilities that focuses on deficits instead of abilities. These authors believed that this negative attitude affects women with disabilities who choose to parent by “depriving them of relevant information and support and fostering feelings of guilt and inadequacy” (Westbrook & Chinnery, 1990, p. 17).

In her review of research on this topic, Meadow-Orlans (1995) suggested that studies of adults and children with disabilities tend to be driven by a deficit rather than a coping perspective, “ignoring the natural adjustments made by the human organism to biological risk and disability” (p. 64). Earlier literature on the effects of parenting with a disability generally concluded that having a parent with disabilities in the home adversely affected the child’s development in areas such as gender–role identity, interpersonal relationships, physical health, and so forth (Buck & Hohmann, 1981, 1983). Many of these initial findings may have been based on speculation rather than on research-based evidence. According to Buck and Hohmann (1983), much of this previous research was problematic because of the absence of control groups; the combining of

dissimilar parent groups, such as those with psychiatric and physical disabilities; less reliable instrumentation; and other methodological flaws that may have confounded the results. Using a more sophisticated research design, Buck and Hohmann (1981) found that children with fathers who had spinal cord injuries were not adversely affected on a number of psychological variables as previous research had suggested. Coates, Vietze, and Gray (1985) stressed the importance of examining multiple influences, including family process variables (e.g., communication, power, problem solving) on the study of parenting with a disability. They underscored the importance of including family system processes as either a predisposing or mediating factor on how the disability will affect the child.

The Mother With a Disability as a Part of an Adapting Family System

Parenting with a disability cannot be separated from the context of the family system as well as from the family’s unique adaptational processes. In addition to the relationship with her child, the mother is an integral part of the marital or extended family system, which in turn is intrinsically connected to other social systems (Weeks, 1994). Because the family is a growing, open system, the interdependent parent–child system also continues to change over time (L’Abate, 1994). Parenthood involves a continual adaptation process in which the parent changes simultaneously with the growth and development of the child (Cusinato, 1994). Parents with disabilities, like all parents, go through this continual adaptational process.

Within the family system itself, the ability to adapt and respond to predictable and unpredictable changes, stress, and adversity has been studied as a normative “self-righting” phenomenon that is based on the interaction of complex family relations. According to Crnic and Acevedo (1995), parenting stress includes normative daily “minor parenting hassles” of continuous caregiving that can vary in frequency and intensity as well as in duration. Multiple factors (e.g., the individual child’s or parent’s attributes, the quality of the marital relationship, family interaction patterns) determined the effect of these minor stressors over time. McCubbin, Thompson, and McCubbin (1996) also discussed the family’s response to stressors, with the assumption that hardships and change are a normal and regular part of family life over the life cycle. They believed that resilient families develop competencies and capabilities to minimize the disruption of these events and maximize well-being of the individual family members and the family as a whole. These adaptive processes can occur in families regardless of the disability status of the parent, and there is little written about them.

When there is a disability in the family (particularly of the parent), additional components must be considered. The adaptation must take into account the onset of the disability (sudden or gradual), its timing within the individual

and family life cycle, and its progression or constancy (Rolland, 1994). On the basis of the nature of the parent's disability, the family may have to adjust to additional unexpected changes or make continual adaptations, taxing resources. In addition, community resources and networks of relationships, which are important for family resiliency (McCubbin et al., 1996), may not be as physically or attitudinally accessible to families in which the parent has a disability.

The experience of mothering and the family system itself also are affected by the individual's history as well as the larger sociocultural context. For parents with disabilities, Hanna and Edwards (1988) wrote:

The way in which parents care for and discipline their child is influenced by...how they were cared for as children, their own maturity, their feelings about self, their relationship with each other, their values and philosophy, and stresses that arise. (p. 40)

Larger sociocultural forces, such as the women's movement, also have effected a change in the image of motherhood, from an exclusive mother-child-home focus to a broader focus that includes both work and family occupations (Farber, 1993). The disability rights movement, which has advocated for full inclusion in all activities, may facilitate fuller parenting involvement by those who had previously been limited or discouraged in their involvement, by establishing a new cultural norm.

Occupational therapy literature that examines mothering with a disability is relatively limited. Crist (1993) suggested that there is a need for more knowledge about this important life role. Llewellyn (1994) believed that this occupation has been "neglected" and that examination of its "meaning, value and intentionality" (p. 173) has been overlooked. Therefore, she recommended that the parent's perspective and voice be included in future writing on parenthood. Understanding the self-stories of persons with disabilities provides an opportunity to appreciate the unifying identities that contribute to their functioning (Polkinghorne, 1996). Because there is need for further research about mothers with disabilities, as well as a need to include the mother's voice in this perspective, the intent of this study was to describe the parenting process from the decision to have a child or continue a pregnancy to the actual pregnancy, birth, and years of parenting as well as

parents' sense of others' influence in their lives.

Method

A qualitative research methodology was used to uncover the "nature" of the mother's experience (Strauss & Corbin, 1990) and to explore possible previous biases in earlier conceptions (Cresswell, 1994). Because little had been written from the perspective of the parent with a disability, three "experts" in the disability community (who were involved with advocacy or services for persons with disabilities), who were themselves mothers with disabilities, were individually consulted in preparation for this study. One was known to the investigator professionally, and the other two were recommended by the first. Similar to what was mentioned in the literature (Buck & Hohmann, 1983; Westbrook & Chinnery, 1990), the interviews of these experts conveyed a pervasive theme of negative societal bias toward or nonacknowledgment of their own (and other mothers') parental status. They suggested four abilities that were important for successful parenting with a disability:

1. The ability to psychologically create one's own role model
2. The ability to be adaptive and inventive in the pragmatic aspects of parenthood (i.e., managing a baby from a wheelchair)
3. The ability to prevent the internalization of societal biases toward parenting with a disability or the nonacknowledgment of their role
4. The ability to redefine for oneself what is important in being a parent

This information influenced the development of the interview guide used with the sample.

Participants

The study participants were recruited with the snowball sampling technique. Contacts among persons with and without disabilities (within a large urban university and a university hospital) were asked to recommend mothers for the study who had a physical or sensory disability and who were currently parenting and living in the community. These identified mothers were then asked to refer other mothers with disabilities. Mothers with various disability types were included in the study sample to secure a diversi-

Table 1
Demographics of Mothers With Disabilities

Case	Number of Children	Age of Youngest Child (Years)	Age of Mother (Years)	Race	Condition
1	1	9	44	African-American	Cerebral palsy
2	2	10	36	African-American	Scoliosis/kidney disease
3	1	12	47	Caucasian	Parkinsonism
4	1	7	43	Caucasian	Multiple sclerosis
5	2	4	31	Caucasian	Multiple sclerosis
6	1	4	35	Caucasian	Multiple sclerosis/diabetes
7	2	0.75	39	Caucasian	Fibromyalgia
8	4	11	55	Caucasian	Retinitis pigmentosa (blindness)

Note. $n = 8$.

ty of experience and to accurately reflect the complexity of the experience of parenting with a disability (Morse, 1993). Potential participants were called and told about the study, and their voluntary participation was requested.

Eight mothers reached by phone consented to participate: two African-Americans and six Caucasians (see Table 1). The participants' ages ranged from 31 to 55 years ($M = 41$ years), and the ages of their youngest child ranged from 9 months to 11 years of age ($M = 7$ years), although one participant also had grown children from a previous spouse. Four participants had one child, three had two children, and one had four children. Some participants had more than one disability or condition: two had congenital disabilities (cerebral palsy, musculoskeletal disorder, kidney disease), one had retinitis pigmentosa since 6 years of age and was now considered legally blind, three had multiple sclerosis before the birth of their only or last child, one received a diagnosis of connective tissue disease and fibromyalgia before her children were born, and one received a diagnosis of Parkinsonism concurrently with the advent of her pregnancy. Six of the eight participants had been diagnosed with their disability or condition before the pregnancy of their first child, one was diagnosed before the pregnancy of the second child, and one was diagnosed concurrently during her pregnancy. Six were married, and two were single parents. Seven lived in their own homes, and one single-parent participant lived with her extended family.

Data Collection and Analysis

Using a grounded theory approach, data collection, analysis, and interpretation occurred concurrently (Cresswell, 1994). Each participant was interviewed once in her home for 1 to 2 hours. The "grand tour" research question was: What is the experience of being a mother with a disability? The participants were asked the following specific questions:

1. Tell me about your decision to have a child.
2. How did those around you respond to your decision to have a child?
3. What was it like for you as a parent in the beginning?
4. What is it like for you as a parent now?
5. How did those around you respond to you being a parent (then and now)?
6. What do you enjoy most and what do you enjoy least about being a parent?
7. What do you think is most important for anyone to know about parenting? (The words "with a disability" were added to get more specific information.)

All of the interviews were audiotaped and transcribed. Notes were made in the margin of the transcriptions using the participants' own words, when possible (to more closely capture the essence of the participant's meaning (Strauss & Corbin, 1990). Provisional categories were developed

through the initial reading of transcripts and during subsequent reading and analysis. Information from interviews with new participants was compared and contrasted with content from interviews with participants previously conducted, using the constant comparison method of grounded theory (Strauss & Corbin, 1990). Memoing was used to record the researcher's ideas and thoughts of possible relationships within the data (Miles & Huberman, 1994), and an audit trail was created to document changes in interview procedures.

The data were first examined within the following stages of the parenting process: decision to have a child, the pregnancy, parenting during the child's infancy and early years, latency age, and preadolescence. At the completion of all the interviews, transcripts were recoded line by line to reconfigure data within this developmental schema. Verbatim sections of text were compiled under each stage. However, two main themes emerged that appeared to transcend this schema. These themes concerned the participants' description of themselves as mothers and their perceptions of their interpersonal environment.

To verify data, member checks were used. Participants were contacted by phone to discuss and clarify the researcher's interpretations of the central themes and participants' supporting quotes. In addition, two of the three original experts (and an additional one) were contacted to confirm or refine themes found.

Finally, participants' narratives were compared with the narratives found in anthologies of stories of women with disabilities published by the alternative press (Finger, 1985; Hyler, 1985; LeMaistre, 1985; Matthews, 1983) because these other stories had influenced the formative process of this study.

Findings and Discussion

Two major themes emerged that appeared to transcend the stage of parenting and age of the child: (a) maternal self-description, including feelings of being *just like other mothers*, *unlike other mothers*, or *unlike other mothers but it is okay to be different* and (b) perception of interpersonal environment, including experiences fostering normalization and adequacy and experiences stimulating feelings of marginalization or inadequacy.

Maternal Self-Description

The participants' maternal self-descriptions seemed to color their momentary or recurring experiences. These descriptions conveyed the primacy of having a disability (or being different) and being a mother and revealed the degree of acceptance or nonacceptance of self with a disability. Self-acceptance is considered a beneficial psychological characteristic in persons with a disability as well as an important factor in parenting (Hanna & Edwards, 1988). Parents with disabilities "who view themselves positively

are better equipped to cope with disability and establish healthy personalities” (Hanna & Edwards, 1988, p. 42).

The participants’ self-descriptions were presented as a source of pride and comfort, as a painful longing, or both. Some mothers spontaneously emphasized how they were *just like other mothers*. One participant with cerebral palsy who used crutches to walk when her 8-year-old child was born, but who currently depends on a wheelchair for mobility, revealed her reaction to finding out she was pregnant: “There’s no difference between me and ‘Joe Blow’ over there, except for I have a little disability. But the disability does not stop me from being the parent that I am—the good parent that I am.”

The participant with a visual impairment described how comforted she was by feeling that she was like other mothers:

I got into a nursing co-op....I’ve discovered they [mothers without disabilities] were all having...a lot of the same problems. It kind of like shrunk it back down and normalized things. Like it’s not because I can’t see. It’s just hard being a new mom and not getting any sleep. And it helped me kind of focus on what the real issues were with the disability. There was like parenting issues and there was the disabled parenting issues, and it helped me...deal with them more appropriately.

Another participant, who has multiple sclerosis, responded this way when asked how it was in the beginning being a parent: “Just the lack of sleep....I was still walking, so I could still stand to diaper him, but it was just hard as it’s hard for everybody...just compounded by the MS and the easy fatiguing.”

Other participants emphasized how they were *unlike other mothers*, and this recognition appeared to cause pain at the loss experienced. The mother with Parkinson’s disease spoke about her 11-year-old son:

I was a good skater....He’s into skating. I would love to skate with him. But I can’t skate....When he was younger, I was always afraid that something was going to happen to him....I wouldn’t be able to rescue him. So I avoided doing a lot of activities that other mothers could do. I really missed being able to do what other mothers were able to do with their kids.

Another participant, with multiple sclerosis, stated:

My daughter...only has known me having MS...because she was only a year old before I was diagnosed so she really doesn’t know any different....One day, specifically, she asked me to put her hair in ponytails and then she was really yelling at me...that she guesses that the only time she’s going to be able to have ponytails is if her aunt or grandma puts them in for her because I can’t do it. Well, that made me feel like crap...she doesn’t understand. She knows. She just doesn’t want to hear it. She’s 6.

These first two categories of maternal description (“like other mothers” and “unlike other mothers”) were not mutually exclusive but seemed to be primary modes of presentation of self in that although the participant shifted between categories within the interview, she returned to one of the predominant categories. During the member checking, changes were noted in both directions because of situational reasons; for example, one participant had just participated in a multiple sclerosis walk and was feeling much better

about herself in general. It is also possible that for the two previously quoted participants, the predominant sense of loss associated with feeling unlike other mothers may be because of the concurrent appearance of their disease with early parenting, not allowing enough time to fully integrate the idea of having a disability with the process of becoming a parent. However, not all of the participants with acquired disability emphasized this category.

The reality of these participants’ lives was that their lives were both like and unlike that of other mothers. These somewhat contrary experiences are paradoxical. Some participants described their reconciliation of the two opposing experiences (sadness in not being like other mothers and the acceptance of the adequacy of their unique mothering style). Larson (1997, 1998) identified a similar phenomenon of women living with contradictory feelings toward their child’s disability. She called this process “embracing the paradox.” Larson (1997, 1998) posited that the tension between the position of loving the child unconditionally and maintaining optimism and the position of “wanting to erase the disability” (Larson, 1998, p. 865) and battling their own fear, creates energy to engage in the mothering role. This process is similar to the dialectic understanding of development, which explains that contradictory forces provide the impetus for growth (Bopps & Weeks, 1984). The following quotes demonstrate one participant’s reconciliation of feeling unlike other mothers with the feeling that it is okay to be different. This participant’s multiple sclerosis affected her balance and energy.

The biggest sadness is that I can’t do things with him, like go to the park. I see mothers throwing Frisbees™, [playing] kickball, soccer, whatever—and I can’t do that. I can’t be a part of “let’s go to [the toy store],” or “let’s go walk around.” I don’t shop...so that’s sad....I can’t be the parent that’s playing ball or kicking around with him and stuff like that. That’s the sad part.

However, when asked what she thought was important for parents with a disability to know, she responded:

Not everybody’s the same....My son could have a wonderful time learning....I could teach him a lot of things regarding the zoo, for example. Doesn’t mean we have to go. There’s videos. There’s storybooks. We read a lot of books...[and] we talk about it. He just went last year for his first time. Now, he happened to know other kids from his school, they’re 4, they’ve gone twice a year since they were born....I could look at that and say, “Oh, my God, I’m not being a smart parent.” [But] that’s doing it differently....we can get the same thing accomplished. *It’s the same end, different means.*

Not being able to drive was an issue for a number of the participants. They either felt bad about depriving their child of an experience or came to some acceptance of their mobility limitations or did both. As the participants with impaired vision described:

My kids had to learn to take public transit or walk....it wasn’t so horrible but...they didn’t appreciate [that] Mom couldn’t jump in the car and take them to scouts. There were things they couldn’t participate in...because I couldn’t transport them around in the car....One of them is still angry that she is not an Olympic gymnast because I couldn’t take her....I had to let them go maybe further afield on public transit than

other parents would have. They sometimes complained. They got wet. They got cold. It took more time and...I would say, "Yeah, I know, but at least you will be able to drive someday, so it's not forever."

A participant with multiple sclerosis who needed a wheelchair stated:

There are so many things I would want to do with and for him...I don't have that freedom that most mothers have to jump in the car...It's very frustrating because I'm fiercely independent. I've always been. And not having the physical stamina or the physical wherewithal to exercise that independence....So we sort of prioritize the things that we can do together. It's a little bit more restricted. We work on the computer together. We do a lot of reading together. We do artwork.

As a result of logistical constraints, I haven't met his teacher this year yet. They had back-to-school night. I couldn't go that night. My husband went. But, ah, usually we both go....Hopefully, within the next year, we'll get a van that I can drive the cart into, which would make it so we can go places together...which will be nice.

The ability to see the positive side of a difficult situation is associated with the characteristic of resilience. Resilient persons have the ability to "negotiate significant challenges to development, yet consistently 'snap back' in order to complete the important developmental tasks that confront them as they grow" (Higgins, 1994, p. 1). Resiliency permits these participants to acknowledge "significant psychological pain" (Higgins, 1994, p. 2) yet not let that experience interfere with their ability to be loving.

Polkinghorne (1996) described both agentic and victim identities. Agentic identity is based on an active, proactive orientation (e.g., resiliency) versus a feeling that one is a victim of outside forces. Occupational therapists can help persons with disabilities to move from a position of victim to a proactive position of agent throughout the course of rehabilitation by fostering proactive interaction with spouse, friends, or family of origin regarding their needs. Therefore, it is important to educate the family regarding the facilitation of a more agentic position.

Perception of Interpersonal Environment

Informants described different experiences regarding role sharing or accepting help and had a different sense of community. Nonetheless, two main categories were identified: *experiences fostering normalization and adequacy and experiences stimulating feelings of marginalization or inadequacy*. Strategies that fostered normalization and adequacy included (a) being willing to provide or actually providing complementary or supplementary parental activities (i.e., role-sharing), (b) giving support, and (c) having a facilitative attitude. In contrast, sometimes the participant felt ambivalent toward the assistance or role-sharing, especially when she was perceived as highlighting her inadequacy or feelings of being left out. The perception of role-sharing or receiving assistance from the spouse and children, professional caregiver, and sense of community is discussed.

Spouse. One participant described a poignant discussion with her spouse regarding future role-sharing before

making the decision to have a child because of the uncertain course of her illness (multiple sclerosis) and the need to establish contingency plans:

If I was going to do this [have a child] and we wanted to do this, we needed to prepare for whatever was going to happen. My husband was willing to be full time, meaning that he would do everything....So he put 100%, actually 150%, of himself into this....if necessary he would do whatever he had to do to take care of the child....He would be part of the things that stereotypical fathers don't do....If I don't have the energy to do the dishes or make dinner...either we order out or he would do it....[This commitment] provides you with confidence. It provides the child with the help that they will need that you can't provide. So if mother and father are both together, then the child gets 100%.

The explicit discussion of responsibilities before this couple decided to have a child was important to the participant. According to Rolland (1994), "Effective communication is absolutely vital to family mastery of illness and disability" (p. 71).

Another participant, with a visual impairment, described the positive importance of role-sharing and support to her comfort as a mother:

My first husband would never read to me. My second husband would, so we read things together when we had a baby, so I was kind of a little better prepared [for delivery].... My second husband was more comfortable with me as a visually impaired person, and I was more comfortable.

More conflicted feelings emerged from other participants regarding role-sharing. A mother with multiple sclerosis described the following mixed feelings:

Their dad kind of has filled that gap. He usually jumps if they want to go to the park. He takes them....I don't know if he had a conception in his mind on what a father was supposed to do or be, but based on my performance as a mom, it's been wonderful. Almost too wonderful...because then the kids can't separate that...."Daddy does this for me, why can't you." You know, so then I feel like we're in competition....Last year, he insisted on taking the kids canoeing....I opted to stay home. The kids wouldn't let me forget that...."Why didn't you come canoeing? We had so much fun."...I don't like it when it's hot, and I was going to have to row a canoe with all four of us in it. Well, Daddy could have done it. You know, well, Daddy can't do everything. So that's hard, too.

While reflecting on these words, this participant said that she was truly grateful for her husband's help, but his ability to do things reminded her of what she could not do and brought up feelings of loss.

The child. The child's interaction with the parents changes with the child's age and development. Children progressively take on more family or household responsibilities as they get older. When a parent has a disability and needs specialized help, breaches can occur in the boundaries of the traditional, hierarchical parent-child helping relationship (Rolland, 1994). These breaches may be necessary for family functioning and only become dysfunctional if role expectations are rigid and age inappropriate. The following mother with multiple sclerosis described her 8-year-old:

He's a big help. He has dubbed himself my royal footman, and there are times when I need help with things with my feet, like getting into

bed....When he was about 3 and a half...I couldn't get into his room and sit down on the rocking chair to read to him anymore. Since then, we've been reading at night in my bedroom, and so he helps me get into bed. Sometimes I need assistance.

Three participants described their child's response to the parental request for assistance as one of ambivalence. This ambivalence may be especially accentuated by age or gender with the accompanying need for individuation, as illustrated by a mother with Parkinsonism and her preadolescent son:

He has two phases. When he's in a sweet phase...he's just wonderful. He helps me. He does things for me....On the other hand, he's got this other phase where he resents having to do everything for me, and he feels like he's getting nothing back....Who's the parent and who's the child?...This little boy has had to take on responsibility...for taking care of me. When he was 7 years old, he felt responsible for me because my husband wasn't here some nights...that really put a lot of stress on him.

Professional caregivers. In families who have a member with a disability or chronic illness, professional caregivers become part of what Rolland (1994) described as the "health-related family unit" (p. 65). The potential for auxiliary parental support from caregivers was described positively by some participants. A participant with a visual impairment stated:

I had a baby nurse who was very helpful 'cause she showed me a lot of things that you need to learn when you're a new mom. And she was aware that...I had a vision problem, so that was very helpful to me....She was very supportive and said, "You'll be fine...you're experiencing being a new mom pretty much like any other new mom," and that was very helpful, but she took care of the [umbilical] cord and things that I hadn't thought about or ever occurred to me, and those are things that you need to do.

One participant with a movement disorder described this poignant scenario, which was mostly favorable but tinged with envy:

Once I went back to work, [the child care provider] was able to give [my son] what I couldn't. It meant a lot to me...that he was getting physical attention from her that he couldn't get from me. What was important to me was that she loved him and, and she gave him that....When I'd come pick him up, I could look in the window and see before I'd ring the bell. Sometimes I'd see her walking around with him, carrying him on her hip, and I was kind of envious....That was something I couldn't do. But...it made me happy to see him getting it from somebody.

Several participants reported instances when persons (family and nonfamily) gave unnecessary help without asking or "beyond" what was asked. This was described as an "invasion of boundaries" by some participants.

Sense of Community

Participants conveyed a range of feelings about their communities and subsequent involvement in their communities either for themselves or for their children. Social integration, a component of community integration and social support, has been found to be related to life satisfaction in persons with disabilities (Burleigh, Farber, & Gillard, 1998; Fuhrer, Rintala, Hart, Clearman, & Young, 1992).

Three participants who depicted a positive sense of community described intact groups as providing opportunities for shared individual or family activity, such as groups of artists with disabilities, play groups, or the Multiple Sclerosis Society Walk fund-raiser. These community group endeavors allowed others like themselves (i.e., mothers, artists, persons with disabilities) to interact and do shared activities.

Three participants described aspects of communities as nonsupportive and "potentially hostile," especially in families where children had peers who were adolescent or preadolescent. To prevent their children from being stigmatized because of the mother's disability ("kids can be cruel"), some participants used humor or taught avoidance techniques to their children to circumvent or deal with teasing. One participant with a visible disability described a verbal confrontation with a stranger regarding her disability and an incident in which her 8-year-old son and another child had a physical altercation. Another felt marginalized by her community of fellow workers. She described the experience as living in "two separate worlds," one with disabilities and one without.

Three participants with "invisible" disabilities in which unpredictability of energy was an issue described feelings of *being out of synch*. They felt bad for not being able to participate in a cooperative nursery school or a carpool in a regular way. When their requests for more flexibility or accommodations were not responded to affirmatively, it added to their feeling of being *unlike other mothers*.

Implications and Conclusions

Parenting is a valued and complex human occupation. The decision to become a mother was very compelling for the study participants, who consciously chose to have a child even though they were possibly putting their health at risk or who had an uncertain disease course. Although the findings of a qualitative study such as this one are not generalizable, the rich descriptions may be useful as a future resource for occupational therapists working with mothers with disabilities. To help mothers with disabilities maximize function and quality of life, occupational therapists need to be aware of the range of experiences that mothers have and design individualized treatments that maximize the mothers' meaningful occupational engagement.

Mothers with disabilities have both strengths and vulnerabilities comparable to mothers without disabilities, and they have unique challenges. All 8 participants either were well-educated, had some financial resources, or were able to participate in meaningful employment at some time in their lives. In general, they were resourceful and brought this trait to their parenting. Although at times these mothers wrestled with frustration, sadness, guilt, or an internalized negative view of self with disability (feeling *not like other mothers*), they also showed great pride in meeting the challenges of parenting.

Mothers differ in what they value within the complex range of maternal occupations. Being *like other mothers* seemed important to many of these mothers, and they appeared distressed when they were *unlike other mothers*. It is possible that mothers intuit unique and common images of appropriate maternal occupations from the culture (i.e., a mother braids her daughter's hair; a mother skates with her children) that they feel compelled to enact. In addition to participation in maternal occupation and fulfilling the expected role behavior, doing certain maternal occupations may induce the profound feeling of universality, or being just like other people, that Yalom (1975) described as a curative factor in treatment. Because of the saliency of this experience, further exploration with clients and in research is recommended. In her study of the occupation of mothering, Francis-Connolly (1997) found that the women in her study had an "illusive ideal" of the perfect mother that was socially constructed. Her participants were constantly comparing themselves to this ideal and, at the same time, feeling guilty for not being perfect. Ironically, the mothers with disabilities in the current study are more like typical mothers in their self-comparison to an illusive ideal. However, this "quest" for maternal perfection may make the process of mothering particularly poignant for women who are simultaneously grappling with their experience of disability. The challenge for the occupational therapist is to help the client sort these feelings out and plan for unique adaptation, not the illusive maternal perfection.

Some parents in the current study made the adaptations they needed without professional help. Mothers with disabilities may need different types of assistance. For those who felt *just like other mothers* most of the time, adaptation seemed effortless and seamless. However, for those who felt predominantly *not like other mothers*, both the subjective experience of parenting and limitation in parental occupational engagement seemed more apparent in their story. It would be important for the occupational therapist to explore what it means to the mother when she does not feel like other mothers. Does she need help accepting her difference and her unique way of parenting? Does she need to redefine what is important in being a mother? Does she need to share the role with others for safety or efficiency? Or does she want to be helped to make physical adaptations (through activity adaptation or adaptive equipment) to facilitate personal hands-on maternal care occupations? In the event that the physical condition limits the physical adaptation, it may be important to explore ways of helping the mother achieve psychological connectedness to her child through play or the sharing of community activities, in person or through new technology (i.e., video, "see-me-see-you" cameras).

Because of the particular sensitivities discovered in this study, the occupational therapist may need to assist parents with disabilities in accepting the fact that they may need to

use different means to accomplish the same ends and to normalize role-sharing (as used by working mothers). This may include reframing the acceptance of help (mechanical or human) as a strength, not as a deficiency. Additionally, in disabilities in which fatigue is a problem, assisting the client to think about reprioritizing essential mothering activities and teaching energy management techniques (when appropriate) can be helpful in facilitating the client's participation in the maternal occupations that she considers most meaningful.

From this study, it appears that the quality of the mother's experience was closely tied to her perception of relational support and community. The occupational therapist may educate and encourage the client and her family to develop mutually respectful ways to share parenting and family roles that promote the mother's autonomy and occupational involvement. Lastly, because of the relative newness of persons with disabilities being recognized as parents, it is important for occupational therapists to be inventive in developing roles in the community to facilitate physical access (e.g., to schools and playgrounds) and to educate persons in the community to promote their willingness to make both physical and attitudinal accommodations. ▲

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