Mothering Young Children With Disabilities in a Challenging Urban Environment

Judith Olson, Susan Esdaile

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Objective. This study examined the occupations of mothering very young children with physical disabilities.

Method. Two single, urban, Black mothers in their mid-20s were interviewed with a semistructured protocol. The audiotaped, transcribed data were analyzed with a phenomenological method.

Results. The context of the challenging urban environment was a constant influence that shaped the participants’ occupations of mothering. The major overarching theme derived from the data was that mothering was “what I got to do” in relation to their particular child. Two subthemes were identified: (a) mothering as caring and (b) the impact of social supports on the occupations of mothering.

Conclusion. To plan meaningful, effective interventions, occupational therapy practitioners need to understand the context in which mothering occupations occur and to ensure that mothers’ caring occupations and social support needs are addressed in the therapeutic partnership.


Mothering is a pivotal occupation for many women. In occupational therapy practice with children with cerebral palsy and other developmental disabilities, the occupations of mothering may be unseen as they form a silent backdrop against which therapeutic efforts on behalf of a particular child are provided. What about these mothering occupations, and what do mothers have to say about them? In this qualitative study, we examine mothering occupations as two mothers living in a challenging urban environment have experienced them in relation to their children with disabilities.

Literature Review

Numerous studies published in the occupational therapy and occupational science literature have described mothering occupations in support of therapy and the goals of therapy or as adjuncts to therapy (Barrera & Vella, 1987; Case-Smith & Nastro, 1993; Dunlea, 1996; Hinojosa, 1990; Hinojosa & Anderson, 1991). A smaller number of studies have focused more specifically on mothering itself, and it is these studies that are of particular relevance to our research.

Burke, Clark, Hamilton-Dodd, and Kawamoto (1987) developed the Maternal Role Preparation program to help first-time mothers prepare for the birth of their child. This occupational therapy program directly addressed the maternal skills and habit patterns of women who would be doing the occupations of mothering for the first time. A subsequent article (Hamilton-Dodd, Kawamoto, Clark, Burke, & Fanchiang, 1989), reported the results of this pilot study. The authors did not find the maternal preparation program
to be associated with greater observed maternal competence. Dyck (1992) studied the normal occupational behavior of 25 women from a mixed-income suburb of the Greater Victoria area in British Columbia, Canada, exploring the nature of mothering occupations as they result from a complex dynamic between the person and the environment. Dyck found that the occupations of mothering were derived from daily routines that intermeshed home provisioning, practical child care, paid employment, transporting children, and providing children with recreational and extracurricular activities. Hermann's (1990) study of adolescent mothers emphasized the facet of mothering that relates to the developmental level of the person who is mothering and its potential to affect such activities as physical caregiving. She found that the participants engaged in a greater percentage of adolescent activities than mothering activities, though they were mothering young children. Hermann's study supports the developmental nature of occupational performance in general.

Using a feminist approach to the analysis of one mother's construction of her definition of mothering, Pierce and Frank (1992) described the mothering of an infant with multiple disabilities from care in the neonatal intensive care unit through care at home. This story highlighted the need for occupational therapy practitioners to understand a woman's conceptualization of her mothering occupations because these shape the type of involvement she will have with her child. In a mother–child life history that demonstrated the effect of the dynamic process of adaptation on the life of one mother of a child with serious disabilities, Larson (1996) illustrated the power of maternal values to direct the occupations of the woman's life as she aimed for the maximal development of her child. In a study of time use by mothers of children who were typically developing and mothers of children with either multiple disabilities or Down syndrome, Crowe (1993) outlined eight descriptive categories of the activities comprising the daily lives of mothers: homemaking, child care, recreation, personal care, participation and socialization, employment, education, and rest and sleep. If we use the Yerxa, Clark, Jackson, Pierce, and Zemke (1990) definition of occupations as chunks of meaningful activity that can be named in the lexicon of the culture, these activities can be viewed as comprising mothers' daily occupations.

More recently Crowe, VanLeit, Berghmans, and Mann (1997) explored the caregiving occupations of mothers of young children as they investigated mothers' perceived occupational roles. They reported that mothers of children with Down syndrome had fewer roles than mothers of children who were typically developing. This finding supports the commonly held view that the occupations of mothering children with disabilities are even more time-consuming and energy-intensive than caring for children who do not. This issue was raised by Esdaile (1994) in a discussion of the mothering occupations of women caring for children with disabilities. Esdaile also highlighted the lack of space and time for mothers' social participation and interest development.

The studies cited have contributed to a growing body of knowledge on the occupations of mothering per se. Our own interest was in exploring, in particular, the occupations of mothers of children with severe disabilities while living in a challenging urban environment. Such knowledge can assist occupational therapy practitioners to be better informed about the occupations of mothers of children with severe disabilities and enhance their therapeutic intervention.

**Method**

We chose the qualitative method of phenomenology (Barritt, Bleeker, Beekman, & Mulderij, 1985) to study the occupations of mothering because it allows an examination of the complex everyday world of individual experience and how the person constructs meaning from that experience. In phenomenological studies, data are always processed through the subjectivity of the researcher (Dickie, 1997). The researchers' assumptions or "preunderstandings" for this study were as follows:

1. Mothering is an occupation in relation; that is, an occupation that requires a minimum of two persons engaged in joint activities or tasks—the mothering person and one being mothered.
2. The occupations of mothering would be prominent in mothers' descriptions of their lives with young children.
3. Our personal views of research frame our research method.

Our first assumption proceeds from the first author's background as an infant mental health specialist (Olson & Baltman, 1994) and the second author's mother–child interaction research (Esdaile & Greenwood, 1995a, 1995b) that support our strong belief in the importance of relationship. Because mothering occurs within the space between the mothering person and the one being mothered, we chose a definition of mothering that incorporates the work of Glenn (1994) and Barnard and Martell (1995). Mothering is defined as a variable relationship constructed within different historical and cultural contexts in which one person, usually an adult female, nurtures and cares for another.

The second assumption is derived from our personal histories as White, middle-class, professional women of middle-European background brought up in heterosexual, Roman Catholic families (Ruddick, 1983). We have studied developmental psychology, taught child development, and practiced as occupational therapy practitioners in the community within a social–educational model focusing on mother–child interactions and co-occupations (Dunlea, 1996). We are mothers ourselves.

Regarding our third assumption, we believe that the phenomenological research method supports a listening to
the experiences of women in their occupational engagement, as opposed to observing or measuring it further. We believe that we can gain an understanding of their lives through this listening and that this understanding will ultimately contribute to better service delivery for our clients.

Participants

This pilot study involved two mothers of young children who had received infant mental health services (Olson & Baltman, 1994) through a home-visiting program. These two mothers volunteered to be interviewed about their daily lives with their infants. They were also interviewed about the infant mental health services that they were provided, which were designed to strengthen the social, emotional, cognitive, and physical well-being of infants within the context of secure, stable, caregiving relationships.

Pseudonyms have been provided for both participants and their children. One mother, Sandra, was a 26-year-old single, Black woman with a 2-year-old daughter, Debbie. Her daughter had been a healthy, developing child until she was diagnosed early in her first year with shaken baby syndrome. Subsequently she was described as having cerebral palsy, blindness, and severe cognitive and language delays.

The second mother, 27-year-old Merion, was also single and Black. Her 4-month-old son, Scott, born with a seizure disorder of unknown origin, was severely and multiply handicapped. He died at 1 year of age. Home visits began shortly after his birth and continued with Merion for 3 months after his death.

Data Collection and Analysis

The first author interviewed each mother twice between 1 and 2 years after the completion of the home visits. The home visits were done by an infant mental health specialist. The interviews were semistructured (see Appendix) and lasted about 1 to 1.5 hr. Open-ended questions encouraged the mothers to describe their daily life with their children and what it was like to experience therapeutic home visits. Interviews were audiotaped and resulted in 58 pages of transcription. The mothers were invited to read the transcriptions and discuss them with the interviewer. One mother elected to do so, and her additional comments were incorporated into the interview data. Thematic analysis of the interview data and the determination of essential themes were done using the selective highlighting approach in which statements or phrases that seemed essential to the experience being described were identified (Van Manen, 1990). Both authors separately and independently determined essential themes, but through negotiation and repeated readings, joint agreement was reached regarding the overarching and supporting themes.

Results

Essential Themes

During the home visits, the mothers reported that most of their discussions centered on the occupations of mothering. From the mothers’ stories, we identified one overarching theme—doing “what I got to do.” Supporting this overarching theme are the subthemes of (a) mothering as caring, with the separate components of mothering as nurturing and mothering as advocacy, and (b) the impact of support systems (or lack thereof) on the occupations of mothering.

Overarching Theme: Doing “What I Got To Do”

Merion believed that Scott had defined mothering for her: “Before Scott was born, I had two other children. I was a very wild person. Hung out, partied, and everything like that.” After Scott was born: “It’s like, you know, take care of family, just go to work, come home, take care of the family, and then go back to work.” Mothering meant paying total attention to the needs of a dependent other. Her mothering was only in relation to Scott and his needs. Merion described herself after Scott died:

> Very insecure. When Scott was there, I didn’t need nobody...When Scott was living, I did mostly everything myself. Whatever I had to do. But when Scott died, it look like, I just, I didn’t know how to do nuthin’ no more; I just didn’t know.”

As she adjusted to Scott’s death, Merion extended her notion of mothering on the basis of her experience with Scott to her two older children, though the exact activities within the occupations of mothering were changed. But Merion does not expect that kind of mothering behavior from all mothers: “Like I say, every mother is not going to be like me. Every mother is not going to take on the responsibility....It’s not that they are a bad person, they just don’t handle it.”

Sandra repeatedly acknowledged that mothering is “what I got to do,” such as diapering, bathing, and feeding. But she spoke equally often of shared family activities—going out to dinner, sending her daughter to camp, spending a day at the amusement park. For her, mothering was what she had to do daily but doing it in a way that was as normal as possible for herself, for her child, and eventually for her husband. She saw the occupations of mothering as normalizing the experience of caring for a child with severe disabilities.

Mothering as Caring: Nurturing and Advocacy

The mothers described performing different activities in the name of caring. These included routine physical care activities, such as those that Sandra described. Because Debbie had to be fed through a gastrostomy tube, Sandra acquired skills used by professionals, including the ability to handle and care for the feeding pump. Debbie’s survival
Feeding was the single most important occupation of Sandra's day, yet she described the tasks of feeding as not at all out of the ordinary, saying that this is "what I must do." This comment was made without regret or hint of burden. These feeding tasks were part of the occupations that were deeply embedded in her daily round of meaningful activities.

Merion also kept to additional daily routines related to her son's survival, such as giving seizure medicine at carefully prescribed times:

I knew that Scott had to have that first med at 6:00 in the morning, and I knew that if he didn't have that med by 12, he would be having a seizure....So, I had to get up; I had to do what I had to do. If I had to be up till 2:00 in the morning...till 4:00, 5:00 in the morning, that's what I had to do.

Other life-preserving routines had to be followed: "If I had to suction him every hour on the hour, that's what I had to do....I know that if I didn't do it, Scott would not survive." There was no anger or burden in Merion's words. Nor did either of these mothers understand these routines to be motivated by guilt. Rather, Sandra and Merion described these occupations of mothering in a matter-of-fact manner.

Besides nurturing, caring took another form for both mothers. Both found and organized agency services to meet their children's educational needs, acting both as advocates for their children and case managers (Bazyk, 1989; Kolobe, 1991). Sandra described the tasks that were involved. These included telephoning agencies that might have appropriate services for Debbie, writing for information about possible services, and attending meetings, even university-related training sessions, in order to help her child. For Merion, the case management activities included mobilizing early intervention services for Scott's returns from multiple hospitalizations. Both mothers were proud of their competence in completing these tasks without the assistance of outsiders, such as professional case managers. Both mothers identified these activities of case management and advocacy as components of caring.

These mothers were responsible for scheduling appointments, maintaining medication schedules, and planning a round of activities that included the transportation and personal safety of their children. Providing these linkage services (Broday & Schoonover, 1986) is not unique to mothers of children with disabilities. Mothers of children who are typically developing also describe expending their time and energy on carpooling; arranging play dates; and, often, taking total responsibility for scheduling the child's daily activities.

For mothers of children with disabilities, advocacy tasks are part of mothering (Bazyk, 1989; Traustadottir, 1991). All mothers need to advocate, but this becomes much more difficult in a challenging environment. Sandra must speak out for Debbie's needs to become visible and taken care of by society. Sandra must attend meetings, though she finds it hard to make her needs understood by far-distant politicians. She must read literature, although she does not feel capable of reading and comprehending long text. Sandra ascribed her willingness to participate in this study as a way to become seen and heard. She told us her story with the expectation that what her everyday life has been like. The knowledge that her story might help another mother, or a professional working with mothers, provided some support for her to continue mothering.

For both Sandra and Merion, caring expanded to include obtaining, maintaining, and using a variety of rehabilitation equipment, such as wheelchairs, braces, prone standers, and bathtub chairs. In conjunction with their occupational therapists and physical therapists, these mothers became knowledgeable equipment consumers. Consumer occupations included collaboration with a professional on possible equipment choices, financial planning to be able to purchase equipment when necessary, and environmental adaptation and negotiation. The simplest physical activity—getting out of the house to reach transportation to a scheduled appointment—required preplanning for Sandra to negotiate a growing child in braces and a wheelchair down a flight of stairs; there was no elevator in her building.

Merion, without readily available transportation, relied on her problem-solving abilities to assure transportation for the many occasions that Scott required unscheduled trips to the hospital. She described one incident in which Scott suddenly stopped breathing and she had no telephone to call for help. She reported that she heard shooting in the street outside her home, which she knew from experience would be followed by police sirens and the imminent arrival of police vehicles. She went into the street and stopped a police car and begged for transportation to the hospital. This anecdote illustrates Merion's motivation to ensure the survival of her child and the problem-solving skills that are essential when mothering a child with serious medical problems. It also illustrates the impact of context on mothering solutions.

Merion reported another incident in which Scott missed a scheduled ophthalmology outpatient appointment because of an emergency hospitalization. Understanding the medical system in which she and her son were located, she knew that rescheduling the missed appointment might mean months on the clinic waiting list. Serendipitously, she met the ophthalmologist in a hospital elevator and convinced him that Scott needed to see him that day, as scheduled, right there in the hospital. Caring solutions that meet a child's special needs often must be made without benefit of preparation.

Mothering as caring extends beyond the life of the one child being mothered into that of the broader community.
For both mothers, caring activities extended into this realm. Sandra became the president of the Parent–Teacher Association at her daughter’s school, and as such, she attends community-wide meetings that have state and federal government implications not just for her daughter, but for other children in the community who have disabilities. She mentors other mothers as they enter the school world with concerns, similar to her own, for the immediate care and future of their children. After Scott’s death, Merion became a parent advocate with two community agencies. She credited Scott as the source of her strength, and she understood her current positions as directly connected to her caring for Scott.

**Impact of Support Systems on the Occupations of Mothering**

The context of mothering for both of these women was deficient in support systems for the occupations of mothering. Both mothers had other family—sisters, brothers, and a mother in Merion’s case—but they were not supportive to them in their mothering. Sandra’s new spouse, Ralph, though not Debbie’s biological father, has been willing to help in the everyday tasks of caregiving, but only since he was laid off from his job. Sandra could not count on her extended family members for support of any kind, even though her brother lived in the same house. In fact, her relatives were afraid of Debbie, and this fear prevented them from being a source of support. Sandra facetiously commented, “What are they afraid of? Catching something?”

Sandra repeatedly referred to her maternal obligation to find appropriate godmothers for Debbie, an important task that she was finding hard to complete. The first woman Sandra had selected for a godmother changed her mind when Debbie’s course of normal development was permanently altered. Her next two choices were unacceptable; one was “strung out on crack,” and another had just had a stroke.

The notion of godmother was familiar to the interviewer but her understanding of it was different from Sandra’s. In Sandra’s culture, the tradition of othermothering exists. The othermother concept describes an esteemed relationship between an older woman and a younger girl. Collins (1990) has written that African and African-American communities have acknowledged the problems related to investing one person, the mother, with total responsibility for mothering. Consequently, othermothers “assist blood mothers by sharing mothering responsibilities” (Collins, 1990, p. 119). Behar (1993) described a similar relationship in certain Hispanic cultures called *comadre*. It is our speculation that Sandra’s concern about a godmother for Debbie was connected to this tradition of othermothering. Given the lack of social and financial support in Sandra’s life, the need for an othermother is particularly relevant.

**Discussion**

**Context**

It is a tenet of occupational therapy that context influences a person’s occupations (Dunn, Brown, & McGuigan, 1994; Kielhofner, 1995; Nelson, 1988). Both levels of context—the microsystem level, which includes the physical location and the interpersonal relationships therein, and the macrosystem level, which includes those generalized “patterns of ideology and organization of the social institutions common to a particular culture or subculture” (Bronfenbrenner, 1979, p. 8)—affect mothering occupations. The caregiving activities that comprise the occupations of mothering are not often seen because the context in which they are performed is the home, considered a private domain. It becomes easy for society not to consider these caregiving occupations as valuable because they are not easily translatable into the language of the macrosystem that deals with such concepts as paid work. If the microsystem caregiving activities could be seen, however, this invisibility and consequent lack of valuation of caregiving occupations might change. This sentiment was echoed by Sandra who wanted the mental health therapists to come to her home at “any time. Sometimes she [the infant mental health worker] would call and say, ‘Is this a bad time?’ And I would answer, ‘This was the time.’” Sandra wanted the therapist to see her struggles with hair combing, for example, as well as share her child’s laughter during bathing. She wanted to be seen in her everyday caregiving occupations and be acknowledged by society for what she was doing.

In this study, mothering occupations were also affected by macrosystem factors, which for these mothers included poverty, violence, and abuse. Both were living in an inner city in the poorest neighborhoods where there was a proliferation of intervention agencies but little money and other resources. Merion reported:

> I really didn’t have the money to stay at the hospital, and there would be days and days that I would stay. There would be days when I would go without eating....I really didn’t have the money, but had to stay. I had to borrow money.

Eventually, Sandra married Ralph, who supported their family while she continued her maternal occupations. However, when Ralph was laid off, they were forced to reorganize their lives. Ralph took on certain occupations of mothering while Sandra worked outside the home. For this family, economics influenced the distribution of maternal occupations between the parenting partners.

When Merion was growing up, violence was not just outside her door but inside her own home. Her mother had been in an abusive relationship when Merion was young. In fleeing this abusive situation, Merion’s mother had abandoned her children. Merion, who admits to resentment toward her mother for this abandonment, now feels that she understands the circumstance that forced her mother to such extreme behavior.
At the time of this study, several years after the diagnosis of shaken baby syndrome was made, Sandra was able, without guilt or self-recrimination, to discuss the fact that her daughter had been a victim of violence at her then-boyfriend’s hands. However, she had sought mental health intervention when, in her daughter’s third year, she found herself frequently crying, feeling bad, and hoping that Debbie would somehow become normal again. She worried that these feelings would interfere with her “doing for Debbie.” Sandra felt guilty for having left her child with her boyfriend only to return home and learn that the child was in the hospital in very serious condition. She needed help to grieve for her child’s lost normalcy while simultaneously caring for Debbie who was severely handicapped.

Mothering and the Practice of Occupational Therapy

We believe that the occupations of mothering per se deserve the attention of occupational therapy practitioners. These occupations contribute to maternal health that is essential to child development. Although this was a pilot study and included only two participants, we heard in the mothers’ stories the potential for connecting the occupations of mothering children with severe physical disabilities to the practice of occupational therapy in these areas: co-created mothering occupations centered on a child’s demand for preservation, the influence of the macrosystem (environment) on the occupation of mothering (Bronfenbrenner, 1979), and practice dilemmas (Lawlor & Mattingly, 1998) created, in part, by the macrosystem.

In identifying mothering as “doing what I got to do” in relation to their particular child, participants’ occupations of mothering were co-created with another (their child) as a specific network of activities comprising the mother’s everyday life. Ruddick (1983) has written that a child has three demands: preservation, growth, and acceptability. Our two participants told us that when mothering a child with severe disabilities, preservation determines mothering occupations. The fabric of a mother’s life, that is, the round of activities that comprise her day, are determined by a particular relationship with an individual child. However, mothering occupations are not formed exclusively by the complex interactions that comprise our personal histories. There is the additional influence of environmental forces, such as the isolation described by Rossiter (1986) and echoed by the two mothers in our pilot study.

Rossiter (1986), though not specifically studying mothers of children with disabilities, explored the influence of support systems on the occupations of mothering young children. She argued that the condition of feeling isolated that mothers experience when caring alone for their children inside their homes, outside of the view of society, strongly influences the occupations of mothering. We support this notion and propose further that mothering young children without disabilities is not antithetical to mothering young children with severe developmental disabilities. In fact, there may be more similarities than differences.

Sandra’s need to be seen in her occupations of mothering is a reaction to the invisibility she believes surrounds both herself and her child. Rossiter (1986) described this same invisibility with mothers of very young children without disabilities. She presented the factors that isolate mothers: ceasing to leave home to go to a workplace; eliminating previous participation in social events outside of the home; and, primarily, being confined to their own household. The macrosystem, that is, society, supports and even constructs this isolation, to some degree, if it values paid work over caring for young children or if it does not provide adequate transportation or other services to facilitate mothers leaving their households. Rossiter concluded that the separation and invisibility of the occupations of mothering cut mothers off from social supports and relegated their problems to their individual struggles.

In the clinical practice of occupational therapy in pediatrics, we meet persons like Sandra and Merion daily. Sandra told us that it was important for her to be seen. She stated that the occupational therapists who had treated her daughter before the study saw her daughter’s physical limitations and her needs for therapy and equipment but did not see Sandra as a mother having needs as well.

Lawlor and Mattingly (1998), who identified the “who’s the client” practitioner dilemma within the family-centered intervention approach, explained that within a clinic culture–medical model of service delivery, the client is easily defined as that person actually receiving hands-on treatment. What, then, becomes of the occupational needs of other family members, particularly the mother?

Pawl (1995) speculated that a parallel process to the development of object permanence exists for young children. That is, young children must believe that they exist in the minds of their caregivers, even when out of their mother’s sight. This knowledge, that they exist for the other, provides young children with feelings of safety and security. We believe that occupational therapy practitioners offer mothers a comparable opportunity to be seen and held in the mind of another, namely the therapist’s mind, as mothers do their occupations of mothering. However, this requires a broadening of our understanding of the term client to include associated clients (Fearing, Clark, & Stanton, 1997).

Finally, our tacit knowledge (Mattingly & Fleming, 1994) of the nature of the real work of occupational therapy as practiced within our current health care system, that is, the macrosystem, is another connection raised by these pilot data (Lawlor & Mattingly, 1998). If narrowly defined real work is only that work that can be reported in meetings or for reimbursement purposes, then Sandra’s issues might remain unrecognized as legitimate occupational therapy work. It is our contention that the occupations of mothering are also the real work of occupational therapy.
Limitations

Data were collected with only two participants, both from the same geographical location. This location—an inner city context—contributed greatly to the shaping of the participants’ lives and occupations. Mothers from other locations would describe different contextual factors, and these, too, require study in order to increase our understanding of how context influences the occupations and experiences of mothering. Additionally, although our data consist of detailed descriptions of the experiences of two mothers, the themes that emerged may not generalize to others in their peer group and beyond.

Some may see a limitation in our relying on what these participants told us based on their recall after a period of time has passed. Though memory does degrade over time, we accept a mother’s own reconstruction of her story as valid for her and do not believe that a need exists for corroborating evidence from other sources, such as medical charts (Brown, Lumley, Small, & Astbury, 1994).

Conclusion

In this study, the preliminary overarching theme that we identified was that the occupations of mothering young children with severe developmental disabilities in a challenging urban environment involved an acceptance of doing what had to be done. However, what had to be done was created by the mother’s relationship with one particular child at one specific historical period of that child’s life. These factors intersected with the woman’s own beliefs about what she must do in the context in which she and her child lived. Therefore, the context of these women’s lives and the caring occupations that took multiple forms were the interrelated subthemes. Further research is needed to increase our understanding of mothering occupations per se and, in particular, mothering children with disabilities in challenging environments. ▲

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Appendix

Interview Questions

1. Thinking back on how the infant mental health visits began, tell me about how they started.
2. Tell me about that first visit.
3. What was your daily life like with ____________ before the visits started?
4. What kinds of things did you do during your visits?
5. What was it like having this person come?
6. What was it about this worker, or these visits, that made you want them to continue?
7. Tell me about your daily life with ____________ during the time of the visits.
8. Tell me about your life with ____________ now.
9. Looking back on all the visits and thinking about them now, how do you remember them?
10. How has this experience—of being interviewed about your infant-parent visits—been for you?

References


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