Learning to Live With Ambiguity:
Rethinking Ambiguous Loss for Mothers
of Children With Disabilities

Yoon Joo Lee1, Hye Jun Park2, and Seung Yeon Lee3

Abstract
The purpose of this study was to explore the mothering experiences of children with disabilities. The theory of ambiguous loss was applied to interpret the meanings that mothers give to the process of caregiving and the ways they stay proactive in the midst of challenges. Eleven mothers of children ages 6 to 35 with various disabilities participated in in-depth interviews to talk about their child’s educational history, their family’s routine, and the rewards and challenges of raising a child with disabilities. Findings illustrate that the mothers faced different experiences of ambiguity depending on the visible or invisible nature of their child’s disabilities. However, regardless of the nature of the disabilities, the mothers had learned to live with ambiguity in the face of new and continuous challenges. They did this by redefining their lives through maintaining valued identities as mothers and redefining the meaning of family. Findings also imply that the scope of ambiguous loss needs to be expanded.

Keywords
parenting, children with disabilities, ambiguous loss

Introduction
The parenting experience is often portrayed as a journey. When parents embark on this journey, it is natural for them to face unexpected events, regardless of how well they planned beforehand. When a child is born with significant disabilities, the journey takes a very different form. Yoder and DiVenere (2004) described the family’s experiences of caring for children with disabilities as “working through the maze” (p. 52), highlighting the complex nature of disability and its impact on families. Some parents are able to cope with these unexpected situations, but others experience more challenges, feeling lost in the middle of nowhere, or immobilized and unable to move on with their lives. Thus, the differences in how mothers of children with disabilities make meaning out of adversity are in need of further exploration.

While many studies (i.e., Bristol et al., 1988; Gray, 2002; Hauser-Cram et al., 2001) address family stress, caregiver burden, and coping among parents of children with disabilities, only a few studies elaborate on the complex nature of disability and changing family dynamics over time. Though professionals’ perspectives on disability and families of children with disabilities are often based on a medical model that equates disability with impairment and limitation (Lalvani, 2015), these studies, instead of portraying the children as a “burden” and the focus of dysfunction in families, draw attention to their dynamic and complex family life. For example, Robinson et al. (2015) described the experience of parents of children with disabilities as “a balancing act” between developing the positive qualities in their children and managing the challenges of their conditions. The current study is based on the similar assumption that children with disabilities are not a burden on their family members.

To understand the multifaceted aspects of parenting children with disabilities, it is important to consider the interplay among types of disabilities and degrees of severity, changes in disability conditions over time, social support available to families, and parents’ subjective appraisals of their children (Lee et al., 2015; Park & Chung, 2015; Patrick-Ott & Ladd, 2010; Whittingham et al., 2013). One of the most complex aspects of understanding children with disabilities is the extensive range of individuality and variation within a diagnosis (Haugaard, 2008). The wide spectrum of disability conditions can leave parents feeling overwhelmed or at a loss, with little explanation for their own child’s experiences.

1Brooklyn College, City University of New York, Brooklyn, New York, USA
2Seoul National University, Seoul, Republic of Korea
3Ewha Womans University, Seoul, Republic of Korea

Corresponding Author:
Hye Jun Park, Department of Child Development & Family Studies/Research Institute of Human Ecology, College of Human Ecology, Seoul National University, 1 Gwanak-ro, Gwanak-gu, Seoul 08826, Republic of Korea.
Email: hyejun@snu.ac.kr

Creative Commons CC BY: This article is distributed under the terms of the Creative Commons Attribution 4.0 License (https://creativecommons.org/licenses/by/4.0/) which permits any use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage).
How parents come to understand and respond to their children also reflects a range of diversity and individual difference. For a more complete picture of the experiences of families of children with various disabilities, the puzzle pieces that are the lived experiences of the parents, across their life spans, need to be assembled (Bengtson, 2009). The current study attempts to illuminate these multifaceted and nonlinear aspects of parenting through in-depth interviews with mothers at different points in their life courses. This study particularly examines similarities and differences between their experiences of raising children with various disabilities.

Conceptual Framework

The theory of ambiguous loss (Boss, 1999, 2002, 2006, 2007, 2016) provides a useful framework for deepening understanding of the changing nature of parenting children with disabilities. The ambiguous loss theory was originally developed to explain the physically present but psychologically absent condition of family members with chronic illnesses, such as Alzheimer’s disease, or the physically absent but psychologically present situation of families with missing members or immigrant families (Boss, 1999, 2002). The stress- and resiliency-focused theory has since expanded to include linkages to meaning, mastery, ambivalence, identity, and hope (Boss, 2006). Furthermore, family boundaries have been conceptualized in broader and more symbolic ways, with the assumption that families can be both physical and psychological entities (Boss, 1999, 2002). Boss (2016) described a “psychological family” as people who we lean on physically or symbolically in times of adversity or celebration.

Over the past 10 years, studies applying ambiguous loss have increasingly included a wider range of populations, including families of children with disabilities (Boss, 2016). O’Brien (2007) highlighted conflicting and contradictory emotions in the mothers of children with autism spectrum disorder (ASD). The concept of ambiguous loss was used to explain the mothers’ ongoing struggle to make meaning out of their ambivalence toward adjusting their expectations for their children as they grew. Drawing on Boss (1999, 2006) and Patrick-Ott and Ladd (2010) vividly illustrated the lifelong experience of caring for a child with multiple disabilities through one mother’s narratives and the lens of ambiguous loss. Scorgie and Wigans (2011) applied the theory in their longitudinal study, describing parents’ expressions of ambiguity and frustration as they dealt with the ongoing needs and demands of their children with disabilities during their transition to adulthood.

Despite these attempts to extend the theory of ambiguous loss to families of children with disabilities, more research is needed to better understand how parents live with ambiguity and feelings of ambivalence as their children grow. Although the notion of ambiguity carries a pathological connotation of caregiver burden as seen in previous research, this study looks at both the positive and challenging aspects of caregiving for children with disabilities. We apply the theory of ambiguous loss to describe multidimensional and nonlinear aspects of mothers’ experiences as they raise children with disabilities. To capture a wide range of ambiguity, we do not focus on one specific disability but ongoing and specific issues at different points in the mothers’ life courses by interviewing mothers of children of different ages.

Method

Participants

Purposive and snowball sampling techniques were used to invite participants. The selection criteria for the mothers were the following: (1) their child had to have been diagnosed with a specific disability or had to be receiving or have received special education services in the New York metropolitan area and (2) the children had to be different ages. These criteria were set to establish a diversity in the nature of disability and ages of the children for the purpose of capturing multifaceted and nonlinear aspects of parenting in the mothers’ life courses. Eleven mothers of children with various disabilities, ages 6 to 35, were invited. Characteristics of the participants are summarized in Table 1. Their names have been changed, and they have been otherwise suitably de-identified.

The first author is a person with disabilities and a former special education teacher and current teacher educator working in the city where the study took place. She was a board member in a nonprofit organization that served immigrant parents of children with disabilities. Through informal and formal professional networks, she contacted local parent support groups to invite participants. Thus, some of the participants were active members of either parent support groups or parent-to-parent groups. All procedures for participant selection and data collection received IRB approval.

Procedures

Through incorporating interviews, this study took a phenomenological approach that focused on the lived experiences of participants and the meanings they make from those experiences (Seidman, 2019). The first and second authors, who have many years of experience conducting interviews as qualitative researchers, conducted most of the interviews together. The first author, as a person with a disability, helped contextualize, humanize, and interpret the findings (Kuczynski & Daly, 2003).

The interviews took place in locations and times that were convenient for the mothers. During the interviews, the mothers were presented with a series of questions, asking for a brief introduction of their child, summary of the child’s educational history, and description of the family’s daily routine,
as well as questions pertaining to the challenges and rewards of raising a child with disabilities and their own personal growth. As the mothers responded, informal conversations related to the questions often evolved, allowing them to freely discuss among themselves and share their personal experiences. Each interview session lasted an average of 2 hours. Two individual interviews were conducted with Mrs. J and Mrs. K because of their schedules. Three group interviews were conducted with the rest of the participants. The interviews were digitally recorded and transcribed upon participant consent.

**Data Analysis**

As a process of meaning making, data analysis for this study was complex, inductive, emergent, and interpretive (Marshall & Rossman, 2011). To analyze the data, we individually read the transcripts numerous times, identifying sections of the interview narratives that were most descriptive of particular experiences. We started by exploring the mothers’ comments about their own perspectives on their children with disabilities, their other children, and their relationships outside of their immediate family. We engaged in initial inductive and heuristic coding processes, identifying important narratives from the interviews through analytic memoing (Miles et al., 2020). We looked for similarities and differences in the narratives of mothers whose children had similar disabilities. We also looked at how the mothers responded to challenges and described success in their mothering experiences. Finally, the narratives were grouped together according to elements of the ambiguous loss theory (i.e., physical loss, psychological loss, and psychological family). All interview content was coded separately by the authors, and any discrepancies were adjusted together. The third author had the important role of identifying and addressing any bias that the other two researchers who conducted the interviews might have brought to the analysis, thus supporting the credibility of the process.

**Table 1. Characteristics of Participants.**

| Child (age) | Mother | Child’s characteristics (diagnosis, special needs, school etc.) | Family context |
|------------|--------|---------------------------------------------------------------|----------------|
| Ben (6)    | Mrs. B | - Down syndrome; mild cognitive developmental delay          | - Only child   |
|            |        | - Inclusion class in public school (1st grade)               |                |
| Carey (15) | Mrs. C | - Down syndrome; mild cognitive developmental delay          | - Has older brother |
|            |        | - Special education class in public school (10th grade)      | - Recently immigrated from South Korea |
| Danny (10) | Mrs. D | - Cerebral palsy; epilepsy; microcephaly; significant physical disabilities; cognitively high functioning; communicates with computer-generated device | - Has older sister and younger brother |
|            |        | - Special school for students with orthopedic impairments (5th grade) | - Both parents designed his computer for communication |
| Eddie (19) | Mrs. E | - Congenital brain anomaly; significant physical disabilities; cognitively high functioning; communicates with computer-generated device | - Only child |
|            |        | - Special school for students with orthopedic impairments (11th grade) | - Family immigrated from South Korea |
| Frank (13) | Mrs. F | - Asperger syndrome; challenging behaviors                    | - Twin sister, typically developing, attends different school |
|            |        | - Special school for ASD (8th grade); difficulties with school attendance/constant phone calls from school | |
| Gail (13)  | Mrs. G | - Dyslexia; gifted; long search for diagnosis                | - Has two brothers |
|            |        | - Inclusion class in public school (8th grade); difficulties with school attendance/constant notes from the school | |
| Harry (15) | Mrs. H | - No specific diagnosis; difficulties in getting diagnosis; language delays; challenging behaviors and emotional issues | - Has two sisters |
|            |        | - Special education class in public school (10th grade); history of transferring between several schools | - Little support from his father, father is still in denial |
| Isaac (17) | Mrs. I | - Autism spectrum disorder; challenging behaviors; delayed in language development; cognitively high functioning | - Family immigrated from Egypt |
|            |        | - Special school for ASD (11th grade)                        | - Has younger brother |
| Jamie (19) | Mrs. J | - Asperger syndrome; cognitively high functioning           | - Mother finished doctoral study in special education |
|            |        | - High school graduate; taking two college courses in art at community college; difficulty finding jobs | - Has older sister and younger brother |
| Kevin (35) | Mrs. K | - Hearing impairment; communicates with American Sign Language | - Has two younger brothers |
|            |        | - Attended general education public school for K–12; college graduate | - Married; both he and his wife work full time; wife has hearing impairment |
Two overarching themes emerged from our analysis of the mothers’ narratives: (1) differences in the experience of ambiguity in mothers of children with visible disabilities and mothers of children with invisible disabilities and (2) redefinition of the role of mother and the meaning of family as ways of living with ambiguity.

Results

Different Experiences of Ambiguity

Ambiguous loss associated with invisible disabilities. Oftentimes, a child with invisible disabilities, such as ASD, is physically present as a family member but has challenges communicating and relating to others, even to their closest family members such as parents or siblings. This issue of physical presence but psychological absence emerged in the narrative of a mother who had a grown son with significant hearing impairment. Mrs. K shared the feelings of ambiguity she had when her son, Kevin, was physically present but socially distant. She recollected a moment when Kevin was sitting on the couch with his two younger brothers, but they were engaged in their own activities without any interaction, like in parallel play among toddlers. Because of the communication challenges, there was not much intimacy or closeness between them as siblings. Mrs. J, the mother of 19-year-old Jamie, a child with Asperger’s syndrome, shared her challenges in communicating with her son:

When I try to talk with him about something as simple as “How was your day?” it’s constantly thrown in my face that he has a disability. I can forget it when I look at him. But when I interact with him, it brings up all my own issues and my fears and my insecurities for his future all in that exact same moment.

The challenges of invisible disabilities, such as hearing impairment or learning disabilities, are harder for outsiders to understand because children with these disabilities appear totally “normal” from a distance or even in casual interactions (Davis, 2005). Mrs. J clearly articulated the ambiguity she felt because her son was physically able but had difficulties socially connecting with others. Mrs. J further expressed the irony in the normal appearance of her son, who had recently graduated from high school:

I’ve had other mothers from support group say, “Oh, you’re so lucky, he’s so handsome. He looks so normal.” It’s in some ways a disservice because he doesn’t present typically disabled. It’s much, much harder to prove.

It usually takes much longer for parents to receive a diagnosis of ASD or behavioral issues because these disabilities are not readily discernible, even to the parents or the children themselves. Even after diagnosis, many parents remain confused, especially when their child’s disabilities do not have visible physical manifestations. Mrs. I shared her family’s struggle to accept her son, Isaac, as having autism:

The time of Isaac’s official diagnosis was when he was almost 8 years old. Official means that my husband accepted the diagnosis. I couldn’t help but admit he had autism due to the severe behavior problems he’d had since he was about 5. But my husband, a medical doctor, had refused to accept it. He [the doctor who diagnosed my son] was one of the big names in the field of autism. He was a neurologist. He told my husband that Isaac is autistic from his front to his back and his side. My husband had no choice. Yet we still believed that he would be better someday.

Mrs. H, the mother of Harry, a 15-year-old boy with several behavior issues, was still looking for an appropriate diagnosis after a history of numerous medications and school placement transfers. She shared her challenges in dealing with Harry, his various behavior issues, and the lack of a specific diagnosis:

He denies it himself. He’s not aware that he has any kind of disability. “I am okay,” “I don’t have a disability,” “Why do people treat me like this?” “Why do you put me in special ed?” “I want to get out of special ed,” “I want to be like others.” He feels like he’s a normal child, typical child, like the others. So this is a problem I’m facing with my child.

Davis (2005) described how the invisibility of a disability does not necessarily lessen its impact or make the disability less serious. The mothers’ narratives illustrate the unique challenges they experienced when their children were not “seen” as disabled.

Ambiguous loss associated with visible disabilities. It is harder to escape stigmatization for individuals whose disabilities are more visible (Lee & Bursztyn, 2011). Often, the cognitive and intellectual abilities of people with physical disabilities are underestimated. Unlike the ambiguous nature of invisible disabilities, the visibility of physical disabilities may present different types of experiences and challenges. For example, physical disabilities or disabilities such as Down syndrome are clearly visible at birth or known to parents even before birth. Mrs. B shared about a different beginning, when she was informed about her son’s Down syndrome before his birth. She had been overwhelmed but had wanted to be prepared and on top of the situation.

Seriously. So, I have to be honest, my first year was, like, you know, really stressful, and I mean, even though I’m kind of glad that I knew he had Down syndrome, because I started kind of doing the research about early intervention and the contact for services and saying, “Oh, I want to set up the schedule.” When I called, they were like, “Ma’am, he has to be born first. Ma’am, we have to have a person.” But that was because I was so overwhelmed, and I really wanted to be on top of it. Well, the hospital found an agency which would work with us. So he got early intervention services immediately after birth.
Learning to Live With Ambiguity as a Mother

Redefining the role of mother: “I am the mother.” To a certain degree, all the mothers had to deal with ambiguous loss—loss that occurs without closure. Even though they had gone through the initial process of understanding their child’s diagnosis, they had to deal with the loss of their “ideal” child again as the child grew up. The mothers constantly mentioned the nonlinearity of their lives. Despite all the hard work required to keep moving through the maze, there were times when the mothers had to step back or retrace their steps to look for alternative routes. As the mother of a grown son who had successfully graduated high school and was taking courses at a community college, Mrs. J talked about her son’s new challenge of transitioning to adulthood with limited social skills:

He has graduated high school now and now we’re in a transitional situation where I’m learning about all the services. Unfortunately, as in most cases with New York schools, there is no preparation for after they graduate. You’re back at pre-K, basically. So that’s where we’re at right now.

Mrs. D described her journey as a caregiver to a child with significant disabilities including cerebral palsy, epilepsy, and microcephaly with partial agenesis of the corpus callosum:

It’s a marathon. It’s not about going fast today, but it’s about picking it all up and trying again tomorrow. Taking care of a child with special needs is all about endurance because you’re never going to get it right the first day. And so having the mind-set of not expecting everything to go perfectly today, but being able to pick it up again tomorrow.

The excerpts from these two mothers’ interviews illustrate that, regardless of the visibility or invisibility of their children’s disabilities, the unending nature of their journeys remained the same. In the midst of living with ambiguity at different stages of their lives, the mothers stayed proactive and showed a sense of determination.

Since disability conditions are unique to each individual and their family context, parents learn how to live with their children and eventually become experts at meeting their children’s needs. Through the accumulation of daily interactions and transitional tasks, such as going through medical treatments, entering new programs or schools, and helping their children reach developmental milestones, parents become the most knowledgeable about their children (Grant et al., 2007). Mrs. E faced a pessimistic prognosis from doctors regarding her son, who had significant physical disabilities due to a congenital brain anomaly. She remembered, “The doctor told me that Eddie would only open and close his eyes,” but she was able to overturn the doctors’ dismal projection. At the time of the interview, 19-year-old Eddie was attending a high school for students with orthopedic disabilities and was preparing for entrance to college, even though he was able to use only one index finger to manipulate a computer keyboard. As Mrs. E recollected her earlier memories, her voice rose:

I try and I try not to do too much of that because I realized that he has a really great pediatrician and I came with notes [on Down syndrome] and stuff, and finally, he said to me, “Put that down, have fun with your son.” And I really heard him. And, you know, as parents of special needs, you are consciously anxious. I mean, I am anxious about, you know, this and that, and you know what? I just need to have fun with him. This is it. That’s my story.

Ironically, severe physical disability more easily catches others’ attention and support, but discrepancies between physical limitations and cognitive abilities present different levels of challenge for both mothers and children. In addition, disability conditions change as children grow. Some children’s abilities improve while others’ worsen over time. In many cases, children need more physical or medical care as they become older, while their cognitive development shows no limitations. Mrs. D shared the struggle she experienced in an impartial hearing to obtain related services that her son, Danny, needed to address his multiple disabilities including cerebral palsy, epilepsy, and microcephaly:

Last year and the year before, they said, “Yes.” It’s hard to get it in the beginning, but it’s not just that. It’s that he’s compelling. He’s an odd case because he is so physically disabled and so intellectually gifted that they tend to give him more. I think because people are compelled by his potential.

It was heartbreaking for some mothers to see the mismatch between their child’s level of cognitive development and their physical limitations, as seen in Mrs. E’s comments on the changes in their daily lives. She showed mixed feelings toward her son Eddie’s growing awareness and wish for independence:

Eddie used to like to go out and to eat at the restaurants. But for the last 2 to 3 years, we have not eaten out. When he was young, he was not aware of being fed. But now, he does not like to be looked at. He also knows that it is not easy for us to take him out, so he tries not to. Even when we are out, he insists on staying in the car. Eddie said to me, “I want to live my own life. When I go to college, you live your own life.” It’s sad.

The excerpts from the mothers’ interviews show how they experienced moments of ambiguity because of discrepancies in their children’s physical and cognitive competencies. With visible disabilities, mothers had to be more actively involved as strong advocates for their children, while mothers of children with invisible disabilities had to deal with the discrepancies by becoming spokespeople for their children.
I told the doctor, “I am his mother.” You have medical knowledge, but I am Eddie’s mother. You only see Eddie in your office and make judgment. But I can feel that he can do something. You think that I don’t understand, but I just know he can. I will do my very best.

To a certain extent, these mothers can be seen as overprotective in their relationships with their children. For example, Mrs. E’s and Mrs. H’s remarks reflect how their sense of identity was completely defined by their roles as caregivers for their children.

Whenever I got call from school for any reason, I ran there like a bullet. (Mrs. E)

So, every activity, every thought, every day, I’m thinking about him. Most times, “What is he doing? What shall I give him? What is he doing with homework? How can I make him improve?” So it affects everybody at home. (Mrs. H)

As explained by O’Brien (2007), identity ambiguity means parents are unable to view their own lives as independent from the difficulties of their children’s experiences. Thus, they fail to maintain clear boundaries between themselves and their children. Implicit in the construct of identity ambiguity is a negative connotation that these individuals need help maintaining clear boundaries between themselves and their children. Yet, the findings of this study bring a different interpretation to this traditional notion. Because these mothers were deeply involved in all aspects of their children’s lives, their children were able to make significant progress. More important to consider is how the mothers perceived their situations and how they prioritized their caregiving for their children and for themselves. Mrs. B shared her changing perspectives about herself as a mother and as an individual:

Last November, I was diagnosed with Parkinson’s disease. As a result of this, I have also become an advocate for myself. I never took care of myself the way I should have before the diagnosis. I suspect most moms don’t. I realized that if I don’t “re-fuel” or don’t help myself, i.e., eat better, exercise, be creative and be positive, it will have a negative impact on the way I care for my family and especially Ben.

The mothers focused on the rewards they gained as their children slowly reached milestones of development. Eddie’s mother was keenly aware of the physical burden of caring for a young man with a severe physical disability and the emotional drain of dealing with paperwork, phone calls, and meetings required to provide the best education and care services for her son. At the same time, she wanted to share her knowledge and experience of caring for Eddie with other mothers of children with severe physical disabilities. Mrs. D also expressed clear signs of resilience, rising above challenges while finding strength. She explained how the parents of children with disabilities need to be more proactive getting resources for their child.

I think that my life has changed completely. And I’ve become more powerful because I have to be. Because when you have children who have nothing wrong, when you send them to school, they go to school, they learn, they’re fine. When you have a child with a disability, you have to get him/her what he/she wants. And so, you have to find a way to make everybody [teachers and professionals] do what you say. Because otherwise he/she [your child] won’t get what he/she needs.

Redefining the meaning of family: Who is in and who is out. The mothers constantly mentioned the nonlinearity of their lives. During their lifelong journey of facing uncertainty and ambiguity, the mothers often drew support from relationships beyond immediate family, as caregiving for a child with disabilities often changes the nature of relationships with family members and friends. Mrs. D shared her thoughts about some of her extended family members:

I am very close with my parents. Even though they are older, they did the very best they can for my kids. It’s hard sometimes, because Danny is heavy. But the rest of my family, it’s like they have no clue. So it changed my relationships to be less family-centered and more, like, your friends you choose. Like, I have people buy Danny Lego. How ridiculous is it to give him Lego? He can’t use his hands. I mean these are his aunts and uncles. It’s like they don’t see him and they don’t know him. It’s more about how do you see my very severely disabled child and how do you see our family in that context and decide whether you are in or not.

Additionally, Mrs. B discussed the importance of relationship-building with other mothers of children with disabilities:

I develop a network of people. If someone needs something, I say, “Okay, you call this one” or “You call that one.” Even though it’s hard, it feels good to be able to provide for my child and help other people. It feels like you help all your friends who don’t know what to do. It feels empowering. You don’t feel like a victim. You feel like you’re in charge.

Several mothers were actively involved in parent support/advocacy groups. Mrs. J was an active PTA member in her son’s special education school. Mrs. F and Mrs. K were working as regional coordinators of a parent-to-parent group. Other mothers had an informal support network of parents of children with disabilities. As the mothers went through different life experiences, their definition of family broadened to include those who were able to accept their child with disabilities. Often, the mothers redefined family boundaries based on who was more involved or understanding and who was not.
Discussion

The mothers in this study vividly showed the complex and changing nature of disability conditions by sharing about their emotionally charged memories of pregnancy; first meetings with doctors, teachers, and other professionals; difficult questions raised by their children about their differences; conversations with other children; numerous meetings for school placements; and the people they felt connected to. To describe the mothers’ experiences, we incorporated the notion of invisible disability (Davis, 2005), which is a physical or mental condition that is not visible from the outside, such as a psychiatric disability, traumatic brain injury, and epilepsy. As Davis (2005) explained, an invisible disability such as ASD is not readily discernable and children who have this condition may even appear “normal.” Thus, they constantly provoke questions and contradictory feelings of hope and despair in their caregivers (Larson, 1998; O’Brien, 2007). This study explores the contrast between physical limitations and social/cognitive challenges, or visible and invisible disabilities, with the aim of deepening understanding of the complex and changing nature of raising children with various disabilities. Depending on the nature of their children’s disabilities, the mothers went through different experiences of ambiguity. For example, they dealt with unique challenges when their children were not seen as disabled. This experience illustrates ambiguity arising as a result of psychological loss (Boss, 2007).

To understand the experience of families of children with disabilities in a meaningful way, it is important to look at multiple aspects of their situation within a life course context. In particular, we highlight how mothers were able to face new and continuous challenges through maintaining a valued identity as a mother and developing a support network beyond family members. The mothers’ interviews showed how it was possible to find meaning in their experience even when a loss was unclear and ambiguous (Boss, 2016). To adapt to life with ambiguity, the mothers remained active by performing many tasks as primary caregivers while relinquishing the need for complete control over the situation. They showed competence in knowing what was best for their child and held higher expectations even though their opinions might not have been fully supported by professionals. At the same time, they understood their child’s disabilities were ongoing, complicated, and without closure.

The mothers’ stories revealed that they had redefined their lives and become more resilient in the face of new and continuous feelings of ambiguous loss. Their ability to embrace these paradoxes in daily interactions and in life transitions is critical to understanding the uniqueness of parenting all children with special needs, not just with ASD (O’Brien, 2007). Their stories are consistent with and build upon the research of Park and Chung (2015), who used the figurative illustration of the child as an extension of the mother’s body to describe how mothers of children with disabilities have strong identities as 24-hour care providers. Nicholas et al. (2016) also reported that mothers of children with ASD described their roles as “all encompassing,” as the mothering demands of their children vastly exceeded those associated with typically developing children. Therefore, it is natural for these mothers to become deeply involved in all aspects of their children’s lives, so that their children can make significant progress.

Several mothers made strong statements about their relationships with others who were not immediate family members. Relationships with people who contributed to their children’s lives were meaningful and significant to the mothers, affecting how they defined family boundaries. Gottleib (2002) called for “responsive communities” in which support for people with disabilities and their families is woven into the moral and ethical framework of society—a commitment that requires a massive and likely unrealistic, alteration of social priorities. The mothers’ stories illustrate the importance of support beyond family and the process of redefining “family.” Their relationships with other parents of children with disabilities developed into a form of supportive and intimate extended family with whom the parents shared similar challenges in parenting (Nicholas et al., 2016; Park & Chung, 2015). These findings confirm the urgent need for formal and informal networks of support within cultural and local communities.

The mothers’ narratives further suggest that traditional ways of thinking about family boundaries may not be completely applicable when discussing relational dynamics in families of children with disabilities. The mothers experienced a reorganization of their psychological family as they established who was in it and reconstructed family roles (Boss, 2006). Although psychological family is core to the theory of ambiguous loss (Boss, 2016), the concept has not been articulated in previous studies that discussed the application of ambiguous loss to families of children with disabilities (i.e., Patrick-Ott & Ladd, 2010; Scorgie & Wilgosh, 2011). Therefore, the current study extends the scope of ambiguous loss beyond that which is dependent on disabilities. However, the extent of discussion on psychological family is limited in this study because only the mothers’ narratives were analyzed. The findings suggest a need for more research that can reconstruct boundaries in families of children with disabilities. Future research may look into psychological family by exploring differences between individual perceptions of family membership and roles. Boss (2016) explained that ambiguous loss leads to boundary ambiguity, that is, not knowing who is in or out of one’s family system. Boundary ambiguity can be used to examine how parents of children with disabilities manage challenges by clarifying family membership and roles.

This study sheds further light on the meaning of loss. Typically, loss of the ideal child has been associated with parents’ initial experience of their child’s disability, occurring immediately after diagnosis, and a common assumption
is that these parents go through five stages of grief during the course of their child’s development (Ellis, 1989). However, this study shows that the mothers’ life journeys have not been a linear movement ending in total acceptance of the disabilities of their children. They did not master coping skills at specific points in their lives, and feelings of ambiguous loss resurfaced during different life transitions. It was clear the mothers had to come to terms with the discrepancies between their initial expectations for their children and their actual life experiences multiple times. Mrs. J’s comment, “You’re back at pre-K basically,” appropriately captures the never-ending aspect of the caregiving experience of children with disabilities.

Moreover, the theory of ambiguous loss is applied in this study differently than in previous studies. The mothers had to contend with ambiguous loss that was recurring, but they had learned to live with the ambiguity without becoming lost in their parenting journeys. In Van Vugt and Versteegh (2020), vulnerable mothers who had experienced child abuse expressed difficulty in depending on others for support and needed to cope with previous ambiguous loss through meaning-making of the past (their own broken childhood). In contrast, the mothers in this study were undergoing a continual process of finding meaning as their children grew up. This study started with an examination of how ambiguous loss might be used as a framework to understand the experiences of mothers of children with disabilities, similar to other studies (O’Brien, 2007; Patrick-Ott & Ladd, 2010). However, after an in-depth analysis of the mothers’ narratives, this study expands the notion of ambiguous loss to include that which exists in the past and continues in the present and future.

**Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Funding**

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The author(s) received financial support for the publication of this article from Seoul National University.

**ORCID iDs**

Yoon Joo Lee [1](https://orcid.org/0000-0003-0300-072X)

Seung Yoon Lee [2](https://orcid.org/0000-0001-7914-4899)

**References**

Bengtson, V. L. (2009). The life course perspective applied to families over time. In P. G. Boss, A. J. Doherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.), *Sourcebook of family theories and methods: A contextual approach* (pp. 469–499). Springer.

Boss, P. (1999). *Ambiguous loss*. Harvard University Press.

Boss, P. (2002). *Family stress management: A contextual approach* (2nd ed.). SAGE.

Boss, P. (2006). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss*. W. W. Norton & Co.

Boss, P. (2007). Ambiguous loss theory: Challenges for scholars and practitioners. *Family Relations*, 56, 105–111.

Boss, P. (2016). The context and process of theory development: The story of ambiguous loss. *Journal of Family Theory & Review, 8*, 269–286. https://doi.org/10.1111/jfrt.12152

Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology, 24*(3), 441–451. https://doi.org/10.1037/0012-1649.24.3.441

Davis, N. A. (2005). Invisible disability. *Ethics, 116*, 153–213.

Ellis, J. B. (1989). Grieving for the loss of the perfect child: Parents of children with handicaps. *Child and Adolescent Social Work, 6*(4), 259–270.

Gottlieb, R. S. (2002). The tasks of embodied love: Moral problems in caring for children with disabilities. *Hypatia, 17*(3), 225–236.

Grant, G., Ramcharan, P., & Flynn, M. (2007). Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psycho-social model. *Journal of Applied Research in Intellectual Disabilities, 20*, 563–575.

Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability, 27*(3), 215–222.

Haugaard, J. J. (2008). *Child psychopathology*. McGraw-Hill.

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Krauss, M. W. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development, 66*(3), 1–131. https://doi.org/10.1111/1540-5834.00151

Kuczynski, L., & Daly, K. (2003). Qualitative methods for inductive (theory-generating) research: Psychological and sociological approaches. In L. Kuczynski (Ed.), *Handbook of dynamics in parent–child relations* (pp. 373–392). SAGE.

Lalvani, P. (2015). Disability, stigma and otherness: Perspectives of parents and teachers. *International Journal of Disability, Development and Education, 62*(4), 379–393. https://doi.org/10.1080/1034912X.2015.1029877

Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science and Medicine, 47*(7), 865–875.

Lee, Y. J., & Bursztyn, A. (2011). Understanding childhood disabilities through culturally diverse families’ perspectives. In A. Bursztyn (Ed.), *Childhood psychological disorders: Current controversies* (pp. 15–35). Praeger.

Lee, Y. J., Park, H. J., & Recchia, S. L. (2015). Embracing each and growing together: Redefining the meaning of caregiving/parenting a child with disabilities. *Journal of Child and Family Studies, 24*(12), 3662–3675. https://doi.org/10.1007/s10826-015-0175-x

Marshall, C., & Rossman, G. B. (2011). *Designing qualitative research* (5th ed.). SAGE.

Miles, M. B., Huberman, A. M., & Saldana, J. (2020). *Qualitative data analysis: A methods sourcebook*. SAGE.

Nicholas, D. B., Zwaigenbaum, L., Muskat, B., Craig, W. R., Newton, A. S., Kilmer, C., Greenblatt, A., Roberts, W., & Cohen-Silver, J. (2016). Experiences of emergency department care from the perspective of families in which a child has autism spectrum disorder. *Social Work in Health Care, 55*(6), 409–426. https://doi.org/10.1080/00981389.2016.1178679
O’Brien, M. (2007). Ambiguous loss in families of children with autism spectrum disorders. *Family Relations, 56*, 135–146.

Park, H. J., & Chung, G. H. (2015). A multifaceted model of changes and adaptation among Korean mothers of children with disabilities. *Journal of Child and Family Studies, 24*, 915–929. https://doi.org/10.1007/s10826-014-9902-y

Patrick-Ott, A., & Ladd, L. D. (2010). The blending of Boss’s concept of ambiguous loss and Olshansky’s concept of chronic sorrow: A case study of a family with a child who has significant disabilities. *Journal of Creativity in Mental Health, 5*, 74–86.

Robinson, C., York, K., Rothenberg, A., & Bissell, L. (2015). Parenting a child with Asperger’s syndrome: A balancing act. *Journal of Child Family Studies, 24*(8), 2310–2321. https://doi.org/10.1007/s10826-014-0034-1

Scorgie, K., & Wilgosh, L. (2011). Parents’ experiences, reflections, and hopes as their children with disabilities transition to adulthood. *International Journal of Family Studies, 16*(2), 55–72.

Seidman, I. (2019). *Interviewing as qualitative research: A guide for researchers in education and the social sciences* (5th ed.). Teachers College Press.

Van Vugt, E., & Versteegh, P. (2020). “She gave me hope and lighted my heart”: The transition to motherhood among vulnerable (young) mothers. *Children and Youth Services Review, 118*, 105318. https://doi.org/10.1016/j.childyouth.2020.105318

Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013). Predictors of psychological adjustment, experienced parenting burden and chronic sorrow symptoms in parents of children with cerebral palsy. *Child Care Health Development, 39*(3), 366–373. https://doi.org/10.1111/j.1365-2214.2012.01396.x

Yoder, J., & DiVenere, N. (2004). Family-centered care and the family’s perspective: Traumatic brain injury, cancer, and comorbid learning challenges. In C. M. Vargas & P. A. Prelock (Eds.), *Caring for children with neurodevelopmental disabilities and their families: An innovative approach to interdisciplinary practice* (pp. 35–66). Lawrence Erlbaum.