The Ambiguities of Out-of-Home Care:
Children With Severe or Profound Disabilities*

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Abstract: Ambiguous loss and boundary ambiguity experienced by families during the process of placing their child in out-of-home care was described by parents in 20 families raising a child with severe or profound developmental disabilities. In retrospective interviews, parents discussed their experiences before and after placing their child and how they experienced ambiguous loss as they raised a child that was psychologically absent but physically present. Parents faced ambiguities related to the nature and diagnosis of the disability, support services, and placement. A second situation of ambiguous loss was created when the child was placed. Parents experienced two forms of boundary ambiguity (role and membership ambiguity) and ambivalence regarding placement decisions. Research and clinical implications for working with families are presented.

Key Words: ambiguous loss, boundary ambiguity, developmental disabilities, placement.

Approximately 4.5 million individuals in the United States have some type of developmental disability, defined as “severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22” (Administration on Developmental Disabilities, n.d.). Developmental disabilities may be the result of genetic makeup, environmental factors, such as illness or pregnancy complications (The Arc of the United States, n.d.), or involve both genetic and environmental components. Lenhart (2000) divided developmental disabilities into four categories that are not necessarily mutually exclusive: (a) cognitive impairments, (b) sensory and other physical impairments, (c) genetic disorders, and (d) neurological disorders.

Depending on the type and severity of the impairments, families raising a child with severe or profound developmental disabilities (SPDD) may encounter multiple stressors that can disrupt family functioning (Dyson, 1993; Hodapp, 2002). Family stressors may be related to the initial diagnosis, parental roles, additional caregiving demands, the level of disability, availability of and access to services, financial resources, decisions about guardianship, and family functioning and relationships (Jackson, 2004).

Background

Although the extant literature has examined many of these stressors (Jackson, 2004), family stress theory posits that not all stressor events occurring in families are clear-cut, which may result in situations of ambiguity. Consequently, families raising a child with SPDD may experience situations of ambiguous loss (Boss, 1999) which involve “[a]n unclear loss resulting from not knowing whether a loved one is . . . absent or present” (Boss, 2004b, p. 554). When families experience an ambiguous loss, they cannot obtain definitive facts about a situation, making it difficult to correct or manage (Berge & Holm, 2007; Boss, 1999, 2002).

Boundary ambiguity refers to the family members’ perceptions of the ambiguous loss and may exist in any situation of loss—expected or unexpected,
normative or nonnormative (Boss et al., 1990). Boundary ambiguity can range from high to low, and situations of ambiguous loss often are high in boundary ambiguity. Moreover, high boundary ambiguity can be a barrier to a family’s stress management, as well as a risk factor for both personal and relational well-being (Boss, 2004b).

Sensitizing Concepts and Purpose of the Study

Chronic illness and disability are both conditions where the potential exists for ambiguous loss and boundary ambiguity (Boss, 1993, 1999, 2002, 2004a); however, much past research has focused on other situations of ambiguous loss, such as when a family member is diagnosed with Alzheimer’s disease. Only recently have studies (Berge & Holm, 2007; Boss & Couden, 2002; Garwick, 2005) examined boundary ambiguity in families who have members with chronic illnesses or medically fragile conditions. The purpose of this research was to extend recent work (Berge & Holm; Garwick) by describing ambiguous loss and boundary ambiguity experienced by families raising a child with SPDD prior to and after placing their child in out-of-home care. Boss’s (2002, 2004a, 2004b, 2006) theoretical work pertaining to ambiguous loss, boundary ambiguity, and ambivalence served as the sensitizing concepts (Gilgun, 2004) of the study in that they provided a framework for both the review of literature and text analysis. These sensitizing concepts guided the development of our research question, “How do families of a child with SPDD describe ambiguous loss, boundary ambiguity, and ambivalence experienced before and after placing their child in out-of-home care?”

Ambiguous Loss

Boss identified two situations of ambiguous loss that have the potential to contribute to a high degree of boundary ambiguity and, consequently, negative outcomes—when a family member is perceived as being physically present but psychologically absent, or psychologically present but physically absent. Families who have placed a child with SPDD in out-of-home care could experience both situations of ambiguous loss, perhaps even concurrently. Prior to placement, the child is physically present but, because of cognitive impairments or inability to communicate, may be perceived by family members as being psychologically absent. When the child is placed in out-of-home care, the child becomes physically absent but still might be psychologically present in the minds of family members who have cared for her or him. In fact, Boss (2006) suggested that both types of ambiguous loss can occur simultaneously.

Boundary Ambiguity

Although boundaries generally describe family membership, subsystem configuration, role reorganization, and the flow of information, boundary ambiguity focuses on family member perceptions of the situation. Boundary ambiguity is more about the psychological structure of the family (e.g., perceptions) than it is about the physical structure (see Boss, 2006). Boss indicated, “The higher the incongruence between the psychological family and the physical family, the higher the boundary ambiguity in the family system” (Boss, 2006, p. 12). Thus, the structure of the family matters, but only as it impacts family process. Consequently, “perceptions, even more than structure, determine family boundaries” (Carroll, Olson, & Buckmiller, 2007, this issue, p. 211).

Berge and Holm (2007) identified reasons for boundary ambiguity in families who have a child with a chronic illness that can also be applied to families raising a child with SPDD. According to Berge and Holm, key characteristics of the condition or disability can contribute to boundary ambiguity. For instance, when a disability is ambiguous in both its treatment and its progression, greater likelihood for boundary ambiguity exists (Boss et al., 1990). Because families raising a child with SPDD may face ambiguous situations in not knowing how long their child may live or the course of their child’s illness, they may be unsure about how to interact with the child or could wonder if they should develop an attachment to the child because of a short life expectancy (Berge & Holm).

Boss and Greenberg (1984) described two sources of boundary ambiguity. Boundary ambiguity from sources outside the family may result if the family “cannot get the facts surrounding the event of loss” (p. 536). Raising a child with SPDD is an exemplar of this type of boundary ambiguity when the condition, progression, and status of the loss “is and continues to be uncertain” (pp. 536 – 537). The lack of information regarding an event of loss
precipitates the ambiguity. A second source of ambiguity could emerge from within the family when family members are able to obtain information regarding an event of loss, but they either deny or ignore this information. In this case, they may cut themselves off emotionally from a family member who is still present or exclude a family member when he or she is, in fact, still present (Boss & Greenberg).

These sources of boundary ambiguity can contribute to two different forms of boundary ambiguity. Role ambiguity focuses on who performs what tasks and roles (Boss et al., 1990; Burr, Leigh, Day, & Constantine, 1979; Kahn, Wolfe, Quinn, Snoek, & Rosenthal, 1964) and is associated with internal family boundaries, including a lack of clarity regarding expectations about who does what within the family (Berge & Holm, 2007). Membership ambiguity addresses the boundaries between the family and the outside world or the external family boundary (Berge & Holm) or the family's perception of “who is in and who is out” of the family (Boss & Greenberg, 1984; Boss et al.).

Families who place a child with SPDD in out-of-home care may face both role and membership ambiguity. Greater role ambiguity might exist if the disability requires more demands for treatment and care. In addition, membership ambiguity would be more likely if the child received many treatments outside the home for long periods of time, and the condition was terminal, especially if the condition was diagnosed at birth (Berge & Holm, 2007). After placement of the child with SPDD, membership ambiguity could increase as family members grapple with making sense of whether the child with SPDD is in or outside of the family.

Theory regarding normative family transitions indicates that when a normative family developmental loss occurs, changes occur in the composition of the psychological family. If the family is to cope successfully with this developmental change, a psychological reorganization is necessary. Such a reorganization would apply in the case of a child with SPDD who is placed in out-of-home care. When the child enters out-of-home care, the physical organization of the family changes, whereas the psychological family may not if parents or other family members continue to keep the child present in their minds (Boss, 2006).

Ambivalence

High boundary ambiguity contributes to ambivalent feelings during situations of ambiguous loss and is considered a normal response, although not everyone who experiences an ambiguous loss will have ambivalent feelings. The family member’s personality, socialization, the setting, and religious and cultural beliefs may influence their responses and ability to tolerate ambiguity (Boss, 2002). Nevertheless, the most resilient families may become vulnerable and immobilized when faced with long-term ambiguity. Even when the loss cannot be changed, the family’s perception of the loss can be changed, which can result in better family adaptation (Boss, 2004a).

In sum, raising a child with SPDD and placing her or him in out-of-home care has the potential to create a situation of ambiguous loss and boundary ambiguity in families. Throughout the process, ambiguous loss and boundary ambiguity may contribute to feelings of ambivalence on the part of family members. The purpose of this research was to investigate these phenomena as families described the process of raising a child with SPDD and eventually placing him or her in out-of-home care.

Method

A confirmatory study was conducted that utilized secondary analysis of previously collected qualitative texts and included elements of both retrospective interpretation (Radina & Downs, 2005) and deductive qualitative analysis (Gilgun, 2005). In the present study, researchers sought to find answers to questions that emerged from an initial study (Jackson, 2004; Jackson & Olsen, 2005) that were not exhaustively investigated at that time (Radina & Downs) and used “a loose set of ideas and concepts” that came from theory and previous research to guide the analysis (Gilgun, 2005, p. 42). Specifically, the sensitizing concepts of ambiguous loss, boundary ambiguity, and ambivalence (Boss, 2006) were used in examining situations when families have children with SPDD and place them in out-of-home care.

Participants

Theoretical sampling, a form of purposive sampling used in grounded theory qualitative research to foster sample homogeneity (Creswell, 1998; Strauss & Corbin, 1998), was employed in the initial study. In accordance with grounded theory (the theoretical framework in the initial study), data were collected until categories became saturated (i.e., interviews no
longer provided additional understanding of the category), which typically requires a sample size of 20 – 30 individuals (Creswell). Sample homogeneity is considered necessary to focus the data and generate results (Miles & Huberman, 1994). In accordance with theoretical sampling, selection criteria were established to increase the likelihood that participants’ experiences would be similar enough for saturation and convergence, yet unique enough to allow for depth and variability within themes.

All participants met the following inclusion criteria: (a) were a parent of at least one child with developmental disabilities; (b) placed at least one child who had developmental disabilities in some form of out-of-home care in the state of Utah; (c) were married at the time of the initial placement (the participant did not need to be married at the time of the interview); (d) had a child whose disability level was determined as severe or profound at the time of initial placement, as defined and measured by the Division of Services for People With Disabilities (DSPD) in the state of Utah (the authors assessed if the child was below age-appropriate levels in areas of self-care, expressive and/or receptive language, learning ability [IQ], mobility, capacity for independent living, self-direction, and economic self-sufficiency); (e) made the initial placement decision when the child was between 2 and 30 years of age; and (f) made the decision to place the child at least 1 year prior to the interview. Participants were excluded from the study if (a) the placement of the child was obligatory (e.g., court ordered) or (b) the interviewer and a potential participant knew each other. In cases where two parents of the same child agreed to be interviewed, both parents were interviewed conjointly. However, if one spouse chose to participate and the other did not, the willing partner was not excluded from the sample. In addition, participants did not have to be a biological parent of the child with SPDD to participate.

State and private agencies in Utah provided a pool of potential participants from which 20 families with children with SPDD were recruited. At the time of data collection, the second author, who recruited the participants and conducted all of the interviews, was a student in a family studies program and had previously worked with children with SPDD. Of the 20 interviews, 16 were couples, 3 were individual mothers, and 1 was an individual father (i.e., 17 fathers and 19 mothers). Of the 36 participants, 3 were not biological parents (i.e., one couple had adopted their child with disabilities and the other nonbiological parent was a step-father). Of the four participating parents interviewed individually, the father and one of the mothers had spouses who had died after the placement decision was made (the father had remarried at the time of the interview), whereas the other two mothers were divorced from the biological fathers of their child after the placement had occurred and had since remarried (one biological father was unreachable; the other biological father declined to participate). No participants received remuneration.

All children of the participating parents had multiple disabilities (e.g., mental retardation, autism, epilepsy, and communication disorders). Almost two thirds (65%) of the children were determined to have profound disabilities through the Utah DSPD six-point system; the other 35% were categorized as severe. Of the children with SPDD, 55% were male and 45% were female. Children had been placed in group home care (45%), residential care (35%), and professional parenting care (20%). Professional parenting is similar to specialized foster care where the child with SPDD lives with and receives care from paid trained volunteers; the natural parents maintain custody and are encouraged to remain involved. Various agencies in Utah coordinate professional parenting care, which can be secured through both private and government funding.

Approximately 75% of the children were placed before the age of 18. The average age of the child with SPDD at time of initial placement was 11 years. The average time in out-of-home care was 13 years, and the average age of the child with SPDD at the time of the interview was 24 years. All 36 parents interviewed reported continued contact with their child after placement, which may be a function of the volunteer sample. Most parents (91%) reported satisfaction with their child’s placement, and 89% indicated that their decision was permanent. At placement, all fathers reported full-time employment, 32% of the mothers were employed full time, and 52% of the mothers were full-time homemakers, which may be because of high care demands for children with SPDD. Most of the participating parents had four or more children, which is unusual for parents living in the United States; however, 86% were Latter-Day Saint (Mormon), who, on average, tend to have larger families (see Jackson, 2004).
Procedures
The initial study was approved by the institutional review boards of two universities and the Utah Department of Human Services. All participants except one requested to meet in their homes; the other interview was conducted at the participant’s business office. In cases where both spouses chose to participate in the study (16 interviews), the parents were interviewed conjointly. Each participant provided written informed consent prior to being interviewed. In addition, participants were told they could choose not to respond to any given question but were encouraged to share their stories and describe their child with special needs. This was followed by several broad and open “grand tour questions” (Hill, Thompson, & Williams, 1997) (e.g., “Tell me about how having a child with SPDD affected your lives, both benefits and limitations”). When asked to describe their experiences, the participants gave responses to many of the interview questions without them ever being asked by the interviewer. The researcher then asked specific questions regarding information that was not provided as a result of the initial questions. At the close of the interview, parents completed written questionnaires. In interviews where two parents were present, questionnaires were completed independently. Interviews lasted from 2 – 4.5 hr and were recorded on audiocassette tapes.

The Interview
A review of literature was conducted to generate the semistructured interview questions administered in the initial study. Individuals who had knowledge regarding children with disabilities then reviewed and revised the interview questions, which centered around (a) stressful factors associated with home life, (b) reasons parents considered placement, (c) the steps parents employed in reaching a placement decision, (d) forms of support, (e) information regarding placement(s), (f) noticeable changes in the family after initial placement, (g) the family’s use of therapeutic services, and (h) less retrospective effectiveness of the decision-making processes. Both parents also completed the written demographic questionnaire regarding characteristics of the child with SPDD at placement, parental perceptions of placement, and demographic information.

Data Analysis and Coding
For the initial study (Jackson, 2004; Jackson & Olsen, 2005), retrospective, self-report interviews of parents who had placed a child with SPDD in an out-of-home setting were collected, recorded on audiotapes, transcribed verbatim, verified, and analyzed using grounded theory to identify parental coping strategies for managing stresses experienced following out-of-home placement (Jackson; Jackson & Olsen). Although the initial measures did not specifically focus on ambiguous loss, the open-ended nature of the interview resulted in the spontaneous emergence of ambiguous loss and boundary ambiguity themes from the transcript during the first round of text analyses. Consequently, the authors decided that this evidence of ambiguous loss merited a secondary analysis that would specifically consider ambiguity that centered around the process of raising a child with SPDD and placing the child in out-of-home care. The thick, rich, and holistic descriptions of the participants’ experiences from the study interviews were closely reexamined using the sensitizing concepts of ambiguous loss, boundary ambiguity, and ambivalence as guidelines (Gilgun, 2005).

Qualitative research methods were utilized to categorize prevalent themes. NUD*IST Vivo (Non-numerical Unstructured Data Indexing, Searching, and Theorizing), or NVivo, computer software (version 1.3; QSR International Proprietary Limited, 2000) was used to reduce data. Texts were analyzed for this study using a process of qualitative data analysis described by Neuman (2006) and LaRossa (2005). Using the sensitizing concepts from the literature, the researcher (the first author) initially coded the texts in the transcripts for the major themes of ambiguous loss, boundary ambiguity, and ambivalence through a process of open coding. The major themes were then adjusted and refined through discussion with the coinvestigator. After a second reading of the participants’ responses, in the axial coding phase, modifications were made to the categories, including the collapsing of some categories and the identification of subcategories. Selective coding identified the best exemplars of cases that illustrated each theme and was the basis for the “storyline” (LaRossa; Neuman).

Although fathers’ and mothers’ responses were differentiated in the transcriptions of the interviews, often parents alternated in telling of their experiences. Consequently, mothers’ and fathers’ responses were not analyzed separately; however, the “family interview” was coded. In addition, some interview text was “double coded” or assigned a code from more than one category. Throughout the process,
analytic memos describing the emerging themes were written as the coding categories were developed.

The trustworthiness of the data (Lincoln & Guba, 1985) was assessed through *credibility*, which included sustained engagement by the researcher in the field, diligent observation, and negative case analysis. *Comparability* and *translatability* was facilitated by the use of rich and thick descriptions, which resulted in over 1,000 pages of interview transcriptions. *Dependability* (reliability) and *confirmability* (objectivity) were made possible through audits performed on the results (Creswell, 1998). Consequently, the first author developed audit trails to document the conceptualizations of categories in the data and the second author reread the responses in each category and subcategory to verify that passages fit the category definitions. In addition, a child life specialist who had experience with children with disabilities reviewed the theoretical codes and verified that they fit her experience.

**Results**

The qualitative analysis revealed themes of ambiguous loss, boundary ambiguity, and ambivalence. Themes and the percentage of interviews that included each theme are presented in Table 1.

**Ambiguity From Outside the Family**

For many families, numerous layers of ambiguity were associated with raising the child with SPDD both before and after placing the child in out-of-home care. These ambiguities contributed to the situation of ambiguous loss and came from sources outside the family. They centered around parents’ perceptions regarding the nature and diagnosis of the disability, the life expectancy of the child, support services, and placement.

Ambiguity often commenced with the birth of the child with SPDD because families and medical professionals sensed that something was wrong, but there was no definitive diagnosis or clear description of the exact nature of the disability. For example, one mother of three children who had a 22-year-old son with profound disabilities who had been placed for 11 years said,

> They think he probably has a form of muscular dystrophy, but they don’t know what kind . . .

They don’t think he particularly fits into autism—he looks like he has Cerebral Palsy, but we really don’t think that he actually has Cerebral Palsy . . . So they really don’t understand what the nature of his disability is.

For many families, only after a period of time did the parents have an idea of exactly what the diagnosis was. The parents of six children who had a 19-year-old daughter with profound disabilities who had been placed for 8 years explained,

Father: We felt there was something different and abnormal about her right when she was born. . . . Mother: And I go to the doctor and I say, “This child, she’s not right. She’s not doing this and she’s not doing that.” And I’d get this, “Oh, she’s just slower. You’re used to having four real intelligent children and this one just isn’t as intelligent.” . . . When she was 18 months old, a neighbor who had an autistic child said, “Well, I think your child’s autistic” . . . and she told me to contact [two hospitals and doctors]. Father: . . . and our first diagnosis of autism came from [them].

In addition, parents sometimes experienced the added ambiguity of not knowing whether the SPDD was genetic in nature and whether or not subsequent children born into the family would also have a disability. One mother of four children who had a 49-year-old daughter with profound disabilities who had been placed for 42 years stated, “I’ve often wondered . . . was it genetic? But we don’t know. We haven’t pursued it . . . but I worried each time I was pregnant whether or not my child was going to be okay.”

Some parents also felt the ambiguity of not knowing how long the child would live. One mother of four children who had a 9-year-old daughter with profound disabilities who had been placed for 2 years explained,

> They could tell us nothing. And really, they did tell us, “This child might never live to see her second birthday. She’s got a lot of brain abnormality, and she will not live to two.” But here she is—she’s almost ten and she’s thriving like any other child.
Table 1. Study Sensitizing Concepts and Related Themes of Ambiguous Loss, Boundary Ambiguity, and Ambivalence (N = 20)

<table>
<thead>
<tr>
<th>Sensitizing Concepts and Coding Categories</th>
<th>Thematic Content</th>
<th>n</th>
<th>%</th>
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<tbody>
<tr>
<td><strong>Ambiguity from outside the family</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Ambiguous diagnosis</td>
<td>Type, severity, or prognosis of disability was unknown</td>
<td>19</td>
<td>95</td>
</tr>
<tr>
<td>b) Ambiguous life expectancy</td>
<td>Unknown how long child with SPDD would live</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>c) Ambiguity regarding caseworkers/support services</td>
<td>Family was unsure of the services available or how to obtain them, or interacted with multiple caseworkers, service providers, or coordinated many types of services</td>
<td>18</td>
<td>90</td>
</tr>
<tr>
<td>d) Ambiguity about placement</td>
<td>Parents did not know exactly what to do about placement or had to make an immediate decision about placement or getting their child on the list, whether they felt good about it or not; child experienced multiple placements</td>
<td>20</td>
<td>100</td>
</tr>
<tr>
<td><strong>Ambiguous loss</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Physically present, psychologically absent</td>
<td>The “death of dreams” of raising a normal child</td>
<td>15</td>
<td>75</td>
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<tr>
<td>b) Physically absent, psychologically present</td>
<td>Child is always in the parents’ mind after being placed</td>
<td>13</td>
<td>65</td>
</tr>
<tr>
<td>c) Experienced both</td>
<td>Both types of ambiguous loss described</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td><strong>Boundary ambiguity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Role ambiguity</td>
<td>Ambiguity concerning who does what</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1) Spouse</td>
<td>Less time spent with spouse or less quality “couple time” because of the child with SPDD</td>
<td>17</td>
<td>85</td>
</tr>
<tr>
<td>2) Sibling</td>
<td>Siblings’ relationship and role with child with SPDD is different than might be expected; siblings do not know how to react or relate to child; or how things are better for siblings now that child is placed</td>
<td>19</td>
<td>95</td>
</tr>
<tr>
<td>3) Parent</td>
<td>Parents feel guilty that they are not performing their role as a parent and are neglecting their “well” children</td>
<td>17</td>
<td>85</td>
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</table>
Ambiguities were also apparent in the professional support services received by families caring for the child with SPDD before and after placement. Parents sometimes were unsure of available services or how to access them and dealt with numerous caseworkers, services, or hospice situations prior to placement, and multiple placement locations afterward. One father said,

 But the[y] . . . really never did sit down and explain the program. You knew there were group homes out there, you knew a little about what group homes were for and what they did. You didn’t know how they were funded, how they work, or what your role is going to be once a child was placed in that group home, what rights you would still have or wouldn’t have, what it’s going to cost you, all those kinds of considerations were never explained to you.

A mother of four children with a 20-year-old son with profound disabilities who had been placed for 8 years said this regarding her child’s caseworkers, “Oh, our child with special needs has been through 3,000. I mean, he’s just got a change in social workers . . . two weeks ago. We’ve gone through so dang many social workers.” In addition, there were also sometimes ambiguities associated with the quality of services the child received.

Parents were often uncertain about when their child would advance to the top of the list of individuals waiting to receive full-time services. Parents spoke of not really knowing when the child would be placed, then receiving a telephone call and having to decide in a short period of time whether to place the child permanently. The mother of the 20-year-old son with profound disabilities who had had numerous caseworkers also stated:

 You have to decide within . . . two hours whether to put him in . . . “You’ve got to decide now because there’s this one placement, and if you don’t take it, there’s ten others that would take it.” So we had to decide right then.

Table 1.  Continued

<table>
<thead>
<tr>
<th>Sensitizing Concepts(^a) and Coding Categories</th>
<th>Thematic Content</th>
<th>(n)</th>
<th>%</th>
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<tbody>
<tr>
<td>b) Membership ambiguity</td>
<td>Ambiguity regarding who is “in” and “out” of family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1) Child in and out of family</td>
<td>Child is in and out of the family (alternates between placement and home)</td>
<td>18</td>
<td>90</td>
</tr>
<tr>
<td>2) Possibility of losing placement</td>
<td>Fear that child will lose placement and come back into the home</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Ambivalence</td>
<td>Parents have mixed feelings after placement regarding their placement decision, guilt about abdicating role as a parent of the child with SPDD; not able to make decisions for child because a social service agency took over</td>
<td>20</td>
<td>100</td>
</tr>
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SPDD = severe or profound developmental disabilities.

Note. The \(n\) and % represent the number of families whose interview responses included the theme (mother and father interviews were conjoint).

\(^a\)Sensitizing concepts in bold font.
experience both situations of ambiguous loss: the child with SPDD being perceived as physically present and psychologically absent prior to and following placement, as well as psychologically present but physically absent when the child was placed in out-of-home care. Parents spoke about their sense of loss regarding the opportunities and experiences that their child would probably not have because of the nature of their disabilities. In this case, they were raising a child who was physically present, but the child without SPDD they had expected to raise was psychologically absent. Parents reflected on the loss of their child’s future life, whom their child might not be able to become, and missed opportunities. More than one parent used a “death” metaphor in describing this. A father of four children who had an 8-year-old son with a profound disability who had been placed for 2 years stated, “. . . it’s actually very devastating when you first find out that your child [with profound disabilities] . . . is born, because it’s like the child that you had imagined in your mind has been killed or died, and suddenly you’ve got this other child.” A mother of three children with a 10-year-old son with profound disabilities who had been placed for 4 years said, “Yeah, it was kind of a death of dreams.” Her husband added,

Yeah, it was like a death. . . . Somebody who is severely retarded is never going to go to college . . . they’re never going to get married, they’re never going to have kids. . . . When it comes to your expectations . . . your dreams . . . , there is very little difference in a death and being labeled severely retarded—except that it’s a slow lingering death that you have to look at every single day. So, it’s like having a death and keeping the corpse in your home. It’s not that morbid, but emotionally it’s pretty tough.

The father of a 25-year-old son with autism and mental retardation described his loss in terms of the relationship with his son: “Well, I think the hardest thing is, because he’s not very communicative, you don’t know what he is feeling.” Even though his son was physically present (and his father could visit him when he wanted), the inability to communicate because of the nature of his son’s developmental disabilities created a psychological distance or absence in the relationship.

During the interviews, parents also addressed the other situation of ambiguous loss where the family member was physically absent but psychologically present. Parents spoke of the sense of loss that placement created in their lives. Although placement resulted in the physical absence of the child with SPDD, the child remained psychologically present in the minds of family members. The father of a 10-year-old son with profound disabilities who had been placed for 4 years stated, “The only disadvantage [to placement] is your emotional feelings about losing him, his presence, and your guilt of placing him.” The father of a daughter with profound disabilities who was placed at age 7 and had been in placement for 2 years added: “Well, I think the only adverse effect [of placement] is that it never leaves your mind that she’s your own flesh and blood that can’t stay in your home.”

Once again, several parents used metaphors of death to explain the loss associated with placement. The father of a daughter who had been in various placements for over 11 years illustrated,

Because in some ways when you put a child in a placement, it’s like dealing with a death. The child is suddenly not there anymore; even though you can see them on the weekend, the child is not there 24 hours a day, 7 days a week. And there’s that void that you have—like when you get somebody that dies.

The ambiguity associated with the loss appeared to enter the equation in part because placement did not have the element of finality that death has; their child was neither with them nor permanently gone. Parents continued to worry about their children, as well as see them, making the loss less clear-cut than death. Consider the ambiguous loss created for a mother of a son placed 19 years ago (at age 8) as she described: “[I]n some ways, it was kind of like having a funeral every week, to go down there [to his placement] and be with him.”

The ambiguous nature of the loss because of out-of-home placement was further complicated and intensified because the parents chose the very event that created their loss. The mother of four with a daughter with profound developmental disabilities who was placed 11 years prior to the interview shared, “And there’s the guilt—you’re the one that placed them. And with death, you didn’t cause the
death; but here, you caused it. And it’s hard to go through.” Knowing that they made the decision to place, and fearing to reverse it because of potential consequences, parents reported feeling caught between the proverbial “rock and a hard place,” which further generated guilt on top of the already difficult ambiguous loss. Furthermore, the data indicated that many parents who placed a child with SPDD experienced both situations of ambiguous loss—where their child is perceived as being physically absent and psychologically present (because of placement) and physically present but psychologically absent (because of the nature of the disabilities).

**Boundary Ambiguity**

Parents also described the boundary ambiguity they felt before and after placing the child with SPDD in not knowing who was in and outside of the family. Before placement, often boundary ambiguity was felt because families needed to be separated because of care of the child. For example, one mother lamented, “We had a lot of family activities [and] sometimes one of us would go with the other kids, and it was like our family was always broken in two.” After placement, boundary ambiguity was also felt by parents. A father of a son with mental retardation, autism, and behavior disorders described placement as “... kind of like the empty nest syndrome—it was kind of like a big void in our lives. And there was really nothing that really took up that void.”

A mother described her experience in placing her child in full-time care this way:

“... the hardest day in my life, I cried so hard [sniffs]. Taking and leaving him there, with all his stuff and all his toys . . . I was just so upset . . . it was just awful [sniffs]. Of course, I knew he was in good hands, but it was very difficult . . . I knew I could go visit him and . . . call him . . . [but] that was the hardest day of my life [sniffs].”

Two specific sources of boundary ambiguity also emerged from participants’ responses. Parents described experiences with role ambiguity before and after placing the child with SPDD and membership ambiguity after placement.

**Role ambiguity.** Parents described experiences with role ambiguity that resulted from the excessive time demands, stress, and responsibility placed on the parents, and sometimes even the siblings, in trying to meet the needs and manage the behaviors of the child with SPDD. Parents told of their inability to perform their roles as spouses and as parents to the other children in their family because caretaking was taking over their lives. Consequently, before placement, the heavy responsibility of caring for the child with SPDD contributed to role ambiguity between being a parent and a spouse and not being able to be a parent to both the child with SPDD and to other children simultaneously, which frequently contributed to out-of-home placement.

The parents, especially the mothers, often spent inordinate amounts of time in caretaking or coordinating caretaking prior to placement. Participants perceived that this resulted in the inability to spend time with their spouse or work on their marriage relationship because of caregiving. Consequently, many couples described ambiguity between their roles as parents to the child with SPDD and as spouses. One mother of four children who had a 28-year-old daughter with severe disabilities who had been placed for 6 years said, “In the very beginning it put us in a mind set that we were parents first and married secondly.” And, her husband added, “And that the family came before our relationship.” A father of three children with a 10-year-old son with profound disabilities who had been placed for 4 years noted,

> Your entire existence is focused around one human being, and any other human being in your life suffers . . . we weren’t growing as a couple . . . it was “our child with special needs-centric.” It’s not that we would be talking about divorce . . . we never talked about our relationship—it was always, “Well, how is our child with special needs? What do we need to do?”

Marriages that were already strained suffered even more. A divorced mother of two children who had a 13-year-old son with severe disabilities who had been placed for 5 years described her situation in the following way:

> . . . [I]t’s hard on a good marriage, but on a bad marriage it’s a death sentence. I’ve known people with autistic kids who have a good marriage, and it still strains them. They have to fight for their time together.
Parents also recognized that they sometimes expected their children to perform caretaking roles that were beyond what would be required of siblings of children without SPDD because of the complicated needs of the child with SPDD. Thus, role ambiguity may have also existed for siblings of children with SPDD who became parentified in order to assist with caregiving. One mother stated, “. . . our oldest boys . . . babysat . . . so much that we felt that they were getting really bitter . . . we could see that . . . they needed to have a life also—this was not their burden.”

Because of the unpredictable behavior and level of care needed by the child with SPDD, parents reported that the need to care for the child with SPDD was often at the expense of caring for their other children. This form of role ambiguity appeared to challenge the parenting roles of simultaneously being a parent to the child with SPDD as well as his or her siblings. Caring for the child with SPDD encroached on time with other children and parents had to make difficult decisions regarding the distribution of time and attention. A father of three children who had a 10-year-old son with profound disabilities who had been placed for 4 years related why he and his wife had decided to place their child with SPDD in out-of-home care:

I don’t think [our other children] ever got any one-on-one [care] before—except to feed them and bathe them . . . you’re talking about a seven-year-old who had never been to a movie . . . with Mom and Dad . . . I mean, they were living like Anne Frank: they were just cooped up in a house, couldn’t go anywhere, and couldn’t do anything.

Furthermore, often parents indicated that they finalized their placement decision because they felt obligated to not neglect their role as parent to their other children in order to care for the child with SPDD. The mother of four children who had a 9-year-old boy with profound disabilities who had been placed for 4 years explained,

And we’re very, very fortunate to not have some juvenile delinquents because for three or four years, we were just completely engrossed in caring for one soul (becomes emotional). And I said to my husband, “Do you sacrifice one to save three, or do you sacrifice three to save one?”

When placing their children, parents frequently experienced role ambiguity and guilt in feeling like they had abdicated their role as a parent. One father of eight children who had a 25-year-old son with severe disabilities who had been placed for 8 years explained,

That was probably part of the hard part for me . . . I was saying . . . “How can I give up my child when it’s my responsibility?” . . . Even though I may not have what it takes facility-wise, supervision-wise, and training-wise . . . it was still there in my mind . . . “I am the dad; I have responsibility to . . . take care of them, and provide for their needs. . .” I almost felt some guilt and feelings that way about, “He’s going to the state.” And his wife added, “And I’m admitting I can’t do it.”

Even though parents were relieved after placement, some parents discussed how difficult it was to turn over their role as caretaker. One mother of a son with mental retardation, autism, and behavior disorders said, “You miss being in the middle of the battle—it’s like, ‘Wait, this really gave me purpose in life,’ . . . and it was like, ‘Oh, gee. What am I going to do now?’”

Membership ambiguity. After placement, family members experienced membership ambiguity that was manifest in the frustrations of feeling like the child was in their life but out of their life. A mother of a daughter with behavior disorders, epilepsy, and mental retardation who had been placed for 2 years noted,

. . . it’s empty (becomes emotional) it’s an absolute empty feeling to go back in her bedroom and know that she’s not there. Your family’s not complete . . . because there’s an empty bedroom and there’s an empty spot at the table . . . We still have a missing link . . . there’s a part of us that’s still missing, and we’re ever, ever aware of that—it never goes away—there’s always something missing.

Other parents used a “death” metaphor in describing placement. One father whose son with behavior disorders, epilepsy, and mental retardation had been placed for 8 years said,
When you’ve had somebody . . . for so many years, it’s hard to go on . . . [and] there’s still some times you still feel like, “I would like to have all the kids together,” . . . and it’s like a death in the family . . . [there is] a grieving process . . . because of the loss of that child out of your home . . . even though you know you’re going to get him back, there’s still that loss.

After placement, some families also experienced membership ambiguity that centered around the fear that the child with a SPDD would lose his or her placement and possibly end up coming back home. A father whose child was being cared for by professional parents explained,

“We really felt that he would wear out any other family, and to some degree that’s already been borne out. He wore out . . . his first placement within a year . . . basically she called us up and said, “I need you to pick up your child with special needs . . . tomorrow—I can’t care for him anymore.” And that was our fear.

Ambivalence

After placement, many parents experienced ambivalence and feelings of guilt about their decision. Although they felt it was a good decision for the sake of the family, they struggled to reconcile giving up their child. One parent of a daughter who had been placed for 42 years questioned, “Are we just passing the buck to somebody so that we can have this freedom?” A father of a son who had been placed for 19 years said, “I don’t think it was a hard decision to be honest with you.” His wife then added, becoming emotional, “Making it wasn’t hard; it was living with it—that was so hard.”

A single mother discussed pressures she felt from others regarding placement that heightened her ambivalence:

One woman . . . said, “We just don’t think your child with special needs [is] that bad.” And I thought, “You don’t know. You don’t know what I’ve been through.” . . . I called my friend . . . [who] said, . . . “I know you’re a good mom.” . . . [T]hings like that helped me, because I thought, “Maybe I am a bad mom. Maybe he’s not that bad. And I put him in there and I shouldn’t have.” So, it’s almost like I needed reinforcement from my friends to say, . . . “You’re a good mom. Your child with special needs [has] got problems.” But there is that guilt.

In addition, parents reported that siblings in the family also felt ambivalent about placement. One mother of a son who had been placed for 8 years described her child’s response prior to placement, “. . . [Our children] would come to us . . . and say, “Well, I don’t want my sibling with special needs to go,” or say, ‘I’m so glad he’s going!’” Another father described his son’s ambivalent reactions when they talked of placement, “. . . [O]ur middle son said, ‘No way. No way. NO WAY! What kind of a parent would do that?’ . . . [but finally] . . . he said, ‘We’ve got to. Dad, we’ve got to do something about her.’”

In sum, evident throughout the interviews were themes of ambiguity, ambiguous loss, and ambivalence. These themes emerged from the texts, even though the interview questions for the initial study were not designed to tap ambiguous loss.

Discussion

Although previous theorizing has suggested that chronic illness and disability are situations of ambiguous loss (Boss, 1993, 2004a), few studies have addressed this issue. The purpose of this research was to extend previous work by describing ambiguous loss and boundary ambiguity in families who are raising a child with SPDD and who have placed their child in out-of-home care. Themes of ambiguous loss, role and membership boundary ambiguity, and ambivalence emerged from the data. The contribution of this study is in examining the phenomenon of raising a child with SPDD using the lens of ambiguous loss and boundary ambiguity. The current research found that the raising of a child with SPDD created a situation of ambiguous loss as parents faced the "death of dreams" in raising a child that was physically present but psychologically absent. In addition, parents experienced a "deluge" of ambiguities (Boss & Couden, 2002) related to the nature and diagnosis of the disability, the life span of the child, professional support services, and placement. Role ambiguity was created by the excessive demands placed on parents and family members to care for the child with SPDD to the exclusion of
time for working on couple and parent-child relationships. Sometimes siblings were asked to perform caretaking roles that were beyond what would be normally expected. After placement, parents felt role ambiguity in turning over their roles as caretakers to someone else. Membership ambiguity was manifest in family members feeling that the child was both in and out of their life and through fears that the child with SPDD would lose his or her placement. Although the child with SPDD was physically absent, the child continued to be psychologically present in parents’ minds (Boss, 2006). Finally, parents experienced mixed feelings of ambivalence as they struggled to reconcile placing their child.

Limitations

Although this study provides a starting point for future research, some limitations must be acknowledged. The current sample was small, predominantly Caucasian, and included mostly two-parent families where the mother stayed at home to care for the child with SPDD. Consequently, more can be learned in future studies about ambiguous loss in families from other ethnic backgrounds and families where mothers are employed or parents are raising children by themselves. Indeed, Creswell (1998) suggested that subsequent studies with more diverse samples can serve the purpose of confirming or disconfirming the results of an initial study.

This study was a secondary data analysis and interview questions did not specifically target the constructs of ambiguous loss and boundary ambiguity. Nevertheless, themes of ambiguous loss and evidence that the child was present in family members’ minds (Boss, 2006) were found throughout the interview transcripts. It seems that much more could be learned regarding the nuances of both types of ambiguous loss in families where mothers are employed or parents are raising children by themselves. Indeed, Creswell (1998) suggested that subsequent studies with more diverse samples can serve the purpose of confirming or disconfirming the results of an initial study.

Clinical Implications

Situations of ambiguous loss related to symptoms of anxiety and depression, family conflict, denial, and grief and tend to immobilize and to impede both understanding and coping (Boss, 2006). The goal of effective clinical treatment is not to eliminate ambiguity or obtain closure but to increase resilience—to learn to successfully manage and live with the ambiguity (Boss, 1993, 1999, 2006). Resilience is more than recovery or “bouncing back;” “it means rising above traumatic and ambiguous losses by not letting them immobilize and living well despite them” (Boss, 2006, p. 27).

To enhance resilience, Boss (2006) identified the following clinical objectives for professionals working with families struggling with ambiguous loss: (a) finding meaning, (b) tempering mastery, (c) reconstructing identity, (d) normalizing ambivalence, and (e) revising attachment. These objectives were utilized as a conceptual framework for interpreting and presenting the clinical implications of this study, and if achieved, may lead to the discovery of hope for individuals experiencing ambiguous loss.

Finding meaning. Boss (2006) indicated that in situations such as ambiguous loss where there are no solutions, it is helpful for people to make sense of what has happened, allowing them to better cope
with the related stressors, as well as engage in grieving. In finding meaning in having a child with SPDD, common rationales reached by parents in this study to deal with the death of dreams included that having a child with disabilities: taught the parents about themselves, helped siblings learn how to be more caring, brought the family closer together, and made them stronger as both individuals and as a family. The initial study found that parents adopted positive attributions about their child’s placement that helped them make sense of their situation and better cope with the emotional stresses of placement, particularly feelings of guilt, abandonment, fear, worry, and powerlessness (Jackson, 2004; Jackson & Olsen, 2005). When attempting to make sense out of placement, parents often spoke about how it was advantageous for their child (e.g., our child receives better care; our child has had increased potential, growth, and development; our child is more independent; should something happen to us, we know our child will be taken care of), their other children (e.g., our other children are happier and receive better care and attention from us), as well as themselves (e.g., it freed us to just love her, now we’re happy to see him—now it’s quality time together, our family life has improved) (Jackson; Jackson & Olsen).

**Tempering mastery.** Boss (2006) used the term mastery to denote the sense of perceived control a person has over his or her life. A critical aspect of adapting to life with ambiguity is relinquishing the need for complete control over the ambiguous situation without becoming passive. Boss refers to this process as tempering mastery. Boss (1999, 2006) recommended that people with ambiguous losses stop looking for the perfect solution. Tempered mastery can be attained by revising perceptions, reducing blame, actively making decisions, augmenting successful experiences, transforming and reassembling family rules and roles, adapting current rituals, and creating new meaningful rituals (Berge & Holm, 2007; Boss, 2006). Accepting their child’s disabilities or out-of-home placement as less than ideal gives parents permission to divert their energy from focusing on unrealistic expectations to coping with and healing from their losses. Recognizing the ways in which disability and/or placement has made family life incongruent with expectations of how it could have been, identifying what can and cannot be changed, accepting the things that cannot be changed, and changing the things that can be changed to better approximate “normalcy” can also help temper mastery. Creating new rituals centered around visitation can also help create a sense of control over placement and associated boundary ambiguities.

**Reconstructing identity.** According to Boss, “Knowing who we are in relation to partially absent or present family members [membership ambiguity] requires cognitive and emotional reconstructions of roles, status, boundaries, and rituals” (2006, p. 115). The process of reconstructing identity looks at the reorganization of the psychological family by establishing who is in the psychological family and reconstructing family roles. For families with children in placement, part of this process is dealing with the interspersed physical absence and presence of their child created by family visits to the placement and child visits home from the placement; as such, role flexibility improves resiliency (Boss, 2006). The following questions can help parents as they establish new identities and roles: “How am I still the parent of my child with SPDD now that someone else takes care of her?” “What do I need to do to remain a parent to my child in out-of-home care?” “How and when will we have contact with our child?” “What will we do when we are together?”

**Normalizing ambivalence.** Boss (2006) has explained that normalizing ambivalence is achieved by identifying the conflicted emotions that result from ambiguity (e.g., feelings of love and anger toward the person creating the ambiguous loss) and realizing that they are both normal and manageable. Because ambivalence may be a larger source of stress than the actual disability (Boss, 1993) or placement, helping people label the ambivalence they are experiencing increases their ability to cope and may also help reduce the anxiety, blame, guilt, and immobilization that might result from ambiguity (Berge & Holm, 2007; Boss, 1993, 1999). Because parents of children with SPDD in placement report ambivalent feelings of sadness, guilt, and relief about placing their child, identifying the ambivalence and then normalizing it can increase resilience. A normalizing effect may also occur as parents discover that their ambivalences from having a child with SPDD (the joy and despair) and then placing that child in out-of-home care (sadness, guilt, and relief) are phenomena shared by other people in similar situations. Reinterpreting stressful reactions as “normal” can have a comforting and reassuring effect, which further provides a sense of relief to parents who may feel their lives lack normalcy.

**Revising attachment.** According to Boss (2006), “This is a gradual process of learning to live with
The prospect of recovering the lost person while simultaneously recognizing that the loss may become permanent” (p. 162). Boss recommends the implementation of dialectical thinking—holding two seemingly contradictory beliefs simultaneously (Linehan, 1993)—as one of the primary interventions for revising attachments because it helps create tolerance for stress and ambiguity. The following are possible hypothetical dialectics derived from the results of this study that may help family members struggling with boundary ambiguities from disability and placement: “Many of the dreams I had for my child may be gone; I am lucky that my child is still in my life,” “I feel guilty about placing my child; I know that placement is best thing for my child and the rest of the family,” “Maybe my child will learn and improve enough at his placement to come home; I realize that he may live the rest of his life—however long that may be—in out-of-home care.”

In sum, ambiguous loss and boundary ambiguity are useful constructs to help us better understand the experiences of families of children with SPDD who have placed their child in out-of-home care. In addition, the substantive area of families raising a child with developmental disabilities is a fruitful domain for research regarding ambiguous loss. Use of therapeutic practices such as finding meaning, tempering mastery, reconstructing identity, normalizing ambivalence, and revising attachment can assist families of children with SPDD in better managing ambiguous loss.


Gilgun, J. F. (2004, March). Some guidelines for the design of qualitative research with emphasis on dissertation research. First Brazilian International Conference on Qualitative Research, Minneapolis, MN.


