Ambiguous Loss in Families of Children With Autism Spectrum Disorders*

Marion O’Brien**

Abstract: Learning that a child has a lifelong developmental disorder is stressful and challenging to any family, yet it is clear that some families adapt and adjust more readily than others. In this article, it is proposed that a diagnosis of an autism spectrum disorder (ASD) is especially likely to be experienced as ambiguous loss. Interviews with mothers of children with ASDs are used to identify whether mothers express feelings of ambiguous loss when talking about their child. Then, a specific hypothesis derived from ambiguous loss theory—that higher levels of identity ambiguity in mothers are linked to higher levels of depressive symptoms and perceived stress independent of the severity of the child’s diagnosis—is tested and found to be supported. Recognition of ambiguous loss in families of children with ASDs would help professionals provide more effective support and assistance to families.

Key Words: ambiguous loss, autism, developmental disability, family adjustment.

An extensive literature exists on the outcomes for parents when children have developmental disabilities. It has been commonly reported that parents, especially mothers, of children with disabilities experience more depressive symptoms (Noh, Dumas, Wolf, & Fisman, 1989; Sloper & Turner, 1993) and higher levels of stress (Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Kazak & Marvin, 1984; Pelchat et al., 1999) as compared with parents of children who are typically developing. However, in contrast to this bleak picture, some researchers have noted that many families of children with disabilities adapt successfully to their child’s needs and manage to function well (e.g., Hastings & Taunt, 2002; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001).

Efforts to understand why some families accommodate more readily to a child’s disability than others have focused largely on two factors: child characteristics, especially type and degree of severity of the child’s disability, and social support available to the family. For the most part, the severity of a child’s disability has not been consistently linked to family functioning (Baker, Blacher, Crnic, & Edelbrock, 2002; Wallander & Varni, 1998): although social support has been found to be helpful in reducing psychological distress of parents (Dunst, Trivette, & Cross, 1986; Minnes, 1998), it does not provide an explanation for the initial variation in distress.

In this article, it is proposed that ambiguous loss theory (Boss, 1999, 2004) can be used to help understand differences in parental responses to learning that their child has a lifelong and pervasive disability. The specific situation examined here is the diagnosis of an autism spectrum disorder (ASD) in a child. In brief, it is suggested that many parents of children with ASDs experience a sense of ambiguous loss. The child they thought they had is not the child they must learn to live with. Thus, parental expectations must change. Further, parents’ ability to tolerate and manage the ambiguity of their child’s disability is proposed as a key factor in their experience of ambiguous loss and the related confusion over family members’ identities, both of which contribute to emotional distress.

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Ambiguous Loss in Autism

The theory of ambiguous loss (Boss, 1999, 2006) arose out of family stress theory, which posits that stress results whenever there is change within a family. According to Boss, the most severe stressors are those changes that are not clear-cut but are ambiguous. In these cases, resolution of the situation is not possible and the outcome not predictable. In examining family response to chronic illness and to Alzheimer’s disease, Boss and colleagues (Boss & Couden, 2002; Caron, Boss, & Mortimer, 1999) have identified several areas of ambiguity that contribute to family distress: (a) a lack of clarity in diagnosis, (b) difficulty in predicting outcomes, (c) day-to-day changes in functioning of the ill person that affect family relationships, (d) the fact that the ill individual may give an outward appearance of health thus raising expectations for his or her behavior and functioning within the family, and (e) fear that important emotional relationships will be affected by the illness. All of these areas of ambiguity apply directly to the situation of parents whose children are diagnosed with ASDs.

Lack of clarity in diagnosis. ASDs are considered to have a neurological basis, but there are no known biological markers. Therefore, diagnosis must rely on clusters of behavioral symptoms, primarily in the areas of communication, social interaction, and repetitive and restricted interests (American Psychiatric Association, 2000). As a result, the diagnosis of an ASD is never straightforward, and the process of identifying the child’s disorder is often prolonged. In addition, the etiology of ASDs remains unclear. Genetic links that are evident to researchers who examine the big picture (Shastry, 2005) are not always discussed fully with parents. Many parents continue to believe earlier or more skilled medical intervention at the time of birth or an avoidance of childhood immunizations might have altered their child’s course.

It does appear that autism results from an interaction between a genetic propensity and some environmental trigger occurring either pre- or postnatally (Rutter, 2000). The identification of candidate genes for the disorder will be only the first step in what may be a long process of understanding what causes autism. In the meantime, many parents remain confused and uncertain about their child’s ASD diagnosis.

Difficulty in predicting outcomes. ASDs take as many forms as there are children with the disorder (Coplan, 2003). No two children show the same pattern of symptoms or strengths, and the specific events that challenge one child appear to be handled easily by another. Similarly, the long-term outcome for individuals with ASDs is highly variable (Howlin, Goode, Hutton, & Rutter, 2004). Some adults who appeared to be rather severely impaired as children are able to hold jobs and live with minimal support, whereas others require intense support and intervention throughout their lives. Parents truly do not know what their child with an ASD will be like as an adult.

Ambiguity can be amplified when parents read or hear about children whose autism has been “cured” through intensive intervention or a new dietary or medical therapeutic approach. The challenge for parents whose children have ASDs is to accept the reality of the permanent nature of their child’s condition while maintaining optimism about potential gains that can be made through effective intervention (Boss, 2006; O’Brien & Daggett, 2006).

Day-to-day variability in functioning. Children with ASDs have good days and bad days. What is easy for them to do at one time may create chaos and conflict later that day or the next time the situation arises. This variability in behavior makes it difficult for parents to plan activities or respond effectively to their children’s behavior. Another aspect of ASDs that contributes to ambiguity is the fact that many children, even those who are relatively severely impaired in some domains, show considerable abilities in other domains (Gillberg, 2002; Ozonoff & Rogers, 2003). The inconsistency in children’s performance levels can keep family members feeling off-balance, never quite certain whether the child is truly unable—or just unwilling—to learn certain basic skills.

Appearance of health. Children with ASDs do not look obviously different from healthy children in their early years. Many parents whose children are diagnosed with ASDs believed for a number of years that their children were developing typically or at least that their children were basically healthy if a bit odd or especially difficult (O’Brien & Daggett, 2006). Thus, at the time they receive a definitive diagnosis, most parents must alter their image of their child and of their own relationship with the child. Furthermore, the fact that children with ASDs look just like typical children often encourages extended family members and friends to discount...
the child’s diagnosis and convey messages to parents that they are overreacting or being alarmist in pursuing a diagnosis (O’Brien & Daggett). Such messages undermine parents’ self-confidence and increase their sense of ambiguity.

Loss of relationships. The nature of autism itself, especially the difficulties of individuals with ASDs to perceive others’ feelings and share meaningful experiences with others, creates a situation of considerable ambiguity within the family. The child with an ASD is clearly still present in the household; in fact, the child with an ASD is likely to require an increased amount of parental attention and family resources over those devoted to a child who is developing typically. Yet, psychologically, the child is not entirely present, at least not according to traditional views of the ways a child participates as part of a family. Accordingly, the nature of the parent-child relationship must change—in this sense, ASDs represent a situation of ambiguous loss to parents.

Identity Ambiguity in Families of Children With ASDs

A key aspect of ambiguous loss that has been identified in a number of situations is boundary ambiguity (Boss, 1988, 1999, 2004; Caron et al., 1999; Kaplan & Boss, 1999). Although most commonly described as confusion over who is inside the family and who is not, boundary ambiguity can also be experienced as ambiguity regarding separation between family members’ identities (Boss & Greenberg, 1984). It is this latter component of boundary ambiguity, here labeled identity ambiguity, which is applied in this study to families of children with ASDs. When a child is diagnosed with autism, the identities of the child and parent can become unclear, and the parent-child relationship changes. Some parents respond to this identity ambiguity by taking on responsibility for all aspects of their child’s life, blurring the boundaries between themselves and their child. If parents of children with ASDs are unable to separate their own life situation from their child’s disability, they can be described as experiencing identity ambiguity. Similar responses have been identified in other populations. For example, Ireys and Silver (1996) found that mothers who perceived their child’s chronic illness to have a greater impact on the family were more likely to experience mental health problems than those who viewed the illness as having less impact, regardless of the actual medical severity of the child’s illness. Similarly, Trute and Hiebert-Murphy (2002) developed a measure of positive and negative appraisals of disability and found that mothers who reported relatively more negative than positive appraisals showed higher levels of parenting stress 7 years later.

The Present Study

The research reported here included two components. In the first, semistructured interviews with 63 mothers of children with ASDs were examined to explore whether issues related to the theory of ambiguous loss come up spontaneously when parents talk about their experiences. The goal of this qualitative portion of the study was to determine whether the
application of the theory of ambiguous loss to the situation of families of children with ASDs appears to have face validity. Such evidence is needed prior to addressing specific research questions arising from the theory of ambiguous loss to these families.

In the second, quantitative part of the study, a hypothesis derived specifically from ambiguous loss theory was tested in these same 63 mothers: whether high levels of identity ambiguity are directly related to high levels of perceived stress and to depressive symptoms in mothers of children with ASDs. Analyses also controlled for the level of severity of the child’s ASD symptoms because stress and depressive symptoms might be expected to be higher in mothers of children with more severe disabilities and/or more difficult behavior. It was predicted that identity ambiguity would account for significant variance in stress and depressive symptoms of mothers of children with ASDs and that symptom severity would not moderate this relation.

Method

Participants

The 63 participating mothers (including 2 adoptive grandmothers and 6 other adoptive mothers) ranged from 23 to 54 years ($M = 35.8$). The majority of mothers (81%) were White, and about half the mothers (54%) were college graduates. As is common for mothers of children with special needs (Booth & Kelly, 1999), most of the mothers (58%) were not employed outside the home. All but 11 of the mothers were married or partnered (83%). The children’s fathers (or grandfathers in two cases) ranged from 25 to 57 years; half of them had college degrees and all but two were employed. Family incomes ranged from less than $1,000/month to more than $10,000/month, whereas the median family income was between $2,500 and $3,000/month.

The children of participating mothers ranged from 2 to 13 years ($M = 70.8$ months), although half were 5 years or younger. The vast majority of the children (87.3%) were boys. The children were largely in good physical health; relatively few had been born prematurely or had serious perinatal problems, and their mothers reported the current health status of 90% of the children to be good or excellent.

Just about half the children ($n = 32$) were diagnosed with autistic disorder (AD), the ASD subtype that includes significant deficits in all three of the core areas: communication, social interaction, and restricted/repetitive interests (American Psychiatric Association, 2000). The other half ($n = 31$) were diagnosed with other ASD subtypes that are defined primarily by the presence of fewer symptoms or less severe symptoms than required for a diagnosis of AD. Within this group, 16 children were diagnosed with pervasive-developmental disorder not otherwise specified (PDD-NOS), 7 with Asperger syndrome, 2 with high-functioning autism, 3 with atypical autism, and 3 with mild autism. For the quantitative analyses, the families were divided into these two groups, which differed by the number and severity of children’s ASD symptoms.

Procedure

Families were contacted through several diagnostic clinics at a major Midwestern medical center. Letters describing the study were sent to families by clinic staff after parents had scheduled or completed a developmental evaluation for their child. Parents interested in participating returned contact information to the research team, who then sent them survey packets. Two waves of data were collected; in the first wave, letters were sent to 50 families and in the second wave, letters were sent to 268 families. Postcards indicating interest in participating were returned from 149 families (47%). Informed consent forms and questionnaire packets were then sent to all of these families; a total of 122 complete packets were returned (82%). After receipt of their survey packets, mothers were interviewed by telephone about their experiences with their child prior to and during the period surrounding their evaluation and diagnosis. Of the 122 mothers who participated in the larger study, 63 had children who were diagnosed with ASDs; these are the mothers included in this report. All procedures were approved by the Institutional Review Boards of both the medical center and the affiliated university.

Interviews

Mothers were interviewed over the telephone by female graduate students in child clinical psychology, developmental and child psychology, and counseling psychology, all of whom had experience working with children with developmental disabilities and their families. The interview protocol was semistructured, intended to capture the nature of
the mothers’ experiences with their child before a diagnosis was received, during the evaluation and diagnostic process, and in the time (approximately 6 – 12 months) since receiving a firm diagnosis at the medical center. All interviews were recorded and transcribed verbatim.

The interview questions were not designed specifically to identify elements of ambiguous loss theory but to provide insight into family issues that would help professionals gain a more complete understanding of the concerns and needs of parents of children with ASDs (see O’Brien & Daggett, 2006). In reading and analyzing the transcripts, individual differences in mothers’ responses to autism became apparent. Efforts to place these differences in theoretical context led the author to consider the theory of ambiguous loss. The transcripts were then reexamined to determine whether mothers referred to their experiences and feelings in terms that suggested they were struggling with issues of ambiguity. Thus, the analytic approach used was deductive qualitative analysis (Gilgun, 2005) in which the interviews were studied with a specific question in mind. This question concerned whether aspects of ambiguous loss theory could be identified in any of the mothers’ conversations about their children and their experiences dealing with their children’s ASDs. In other words, the transcripts were analyzed for spontaneous expressions of mothers’ feelings of ambiguous loss in their experiences surrounding their child’s diagnosis. Such expressions would indicate that the theory of ambiguous loss appeared to have meaning to these mothers.

Two readers knowledgeable about the theory of ambiguous loss independently identified interview segments as expressing ambiguity, defined (Boss, 1999, 2006) to include expressions of conflicting thoughts and feelings (ambivalence); hopelessness or helplessness (loss of mastery) alternating with hope or being in control; doubt about one’s identity, role, or relationship with the child; self-blame or incompetence; anxiety about the future; and uncertainty or confusion about the child’s diagnosis. Only those excerpts that both readers identified as indicators of ambiguity were used as examples in the present report.

The goal of this deductive qualitative analysis was to provide evidence regarding the meaningfulness of the concept of ambiguous loss in mothers’ reports of their own and their family’s response to a child’s diagnosis of an ASD. In short, this analysis was an important first step prior to testing specific hypotheses derived from ambiguous loss theory in mothers of children with ASDs.

**Questionnaire Measures**

**Demographics.** Demographic characteristics of the families, including family composition, income, education and employment status, and child characteristics, were obtained via maternal report.

**Identity ambiguity.** Subscales from two questionnaires were combined to create an index of identity ambiguity: the Impact on Parent subscale of the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris, & Horne, 1996) and the six-item Parent Control subscale of the Health-Specific Locus of Control measure (Rau & Ware, 1981). The Impact on Parent subscale includes six items assessing the extent to which mothers report themselves to be preoccupied with their child’s ASD and its impact on themselves. The Parent Control subscale includes six items measuring mothers’ beliefs in their own responsibility for and ability to control the outcome for their child. Both scales were modified so that items referred to the child’s disability rather than the respondent’s own illness. Each item used a 5-point scale ranging from 1 = strongly disagree to 5 = strongly agree; higher scores indicated greater identity ambiguity. One item from the Parent Control subscale (“What I did when my child was a baby has little or no relation to his or her problem”) was found not to be correlated with the other items and was therefore dropped. The alpha for the remaining 11 items was an acceptable 0.69. The 11 items summed to create the identity ambiguity score listed in Table 1.

**Depressive symptoms.** Mothers reported on their symptoms of depression within the last week using the Center for Epidemiological Studies-Depression scale (Radloff, 1977). This widely used scale lists 20 symptoms of depression, with the frequency of experiencing each rated on a 4-point scale ranging from 0 = less than once to 3 = 5 or more days per week. Cronbach’s α was 0.89 for this sample.

**Child-related parenting stress.** The parent-child dysfunctional interaction and difficult child subscales of the short version of the Parenting Stress Index (Abidin, 1990) were used to assess mothers’ perceptions of stress linked directly to their child. This 24-item measure consists of statements describing mothers’ feelings about their child (e.g., “My child doesn’t seem to smile as much as other...
Table 1. *Items Making up the Measure of Identity Ambiguity*

<table>
<thead>
<tr>
<th>Consequences for parent subscale of the modified Illness Perception Questionnaire (Weinman et al., 1996)</th>
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<tbody>
<tr>
<td>My child’s condition strongly affects the way I see myself as a person</td>
<td></td>
</tr>
<tr>
<td>My child’s problem strongly affects the way others see me</td>
<td></td>
</tr>
<tr>
<td>My child’s problem has serious economic and financial consequences for me and my family</td>
<td></td>
</tr>
<tr>
<td>My child’s condition is difficult for me to live with</td>
<td></td>
</tr>
<tr>
<td>My child’s problem does not have much effect on my life (reverse scored)</td>
<td></td>
</tr>
<tr>
<td>My child’s problem will have major consequences on my life</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent Control subscale of the modified Health-Specific Locus of Control scale (Rau &amp; Ware, 1981)</th>
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<tbody>
<tr>
<td>There is a lot I can do to control my child’s problem</td>
<td></td>
</tr>
<tr>
<td>My child’s problem is my own fault</td>
<td></td>
</tr>
<tr>
<td>I have a lot of confidence in my ability to help my child overcome his or her problem</td>
<td></td>
</tr>
<tr>
<td>There is little I could have done to prevent my child from having his or her condition (reverse scored)</td>
<td></td>
</tr>
<tr>
<td>What I do can determine whether my child’s problem gets better or worse</td>
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</tbody>
</table>

Indications of Ambiguity in Mothers’ Descriptions of Their Experiences

The deductive qualitative analysis used to identify statements suggesting that mothers were experiencing feelings associated with ambiguous loss revealed frequent expressions of conflicting or contradictory emotions and ideas about the child and about ASDs, confusion about the child’s and their own future, and alternations between hope and hopelessness, feeling in control and feeling helpless. More than half the mothers interviewed made statements that were coded by both readers as representing ambiguity. Only a few illustrative examples of the mothers’ descriptions of their feelings of ambiguous loss are reported herein.

Ambivalence, or the expression of contradictory feelings in situations of ambiguous loss, was common among respondents. One mother of a 7-year-old child recently diagnosed with Asperger syndrome and sensory integration disorder said, “I’m a little more hopeful now that there’s something that we can do about it . . . [but] some days I get pretty depressed because I know he’s always going to have it.” Another mother of a preschool-age son with AD accompanied by language delays and high levels of aggressive behavior expressed her ambiguity this way: “I still feel sorrow for my son, and I still am hopeful.” Quite a few mothers expressed a wide range of emotions, similar to those described by this mother of a 5-year-old boy with AD:

[My feelings] kind of go back and forth depending on the situation. I mean, sometimes I’m very frustrated when he’s not doing what he’s supposed to do. Sometimes I feel sad because he doesn’t have the social skills that other kids his age have. And sometimes [I feel] just thrilled because he’s made wonderful progress in the last year.

This mother was typical of many who clearly recognized a loss but were uncertain exactly what that loss meant for them and for their child.
Another aspect of ambiguous loss that was identified in these mothers’ narratives had to do with the uncomfortable feeling of being on a roller coaster, not knowing on any given day whether things would go well or be difficult. “Some days are good, and some days are bad” was the summary of one mother of a 3-year-old child with significant delays and a diagnosis of PDD-NOS. The ambiguity that surrounds the diagnosis of ASDs was reflected by the mother of a relatively severely affected 3-year-old child who was adopted shortly after birth; she said, “Autism is just such a Pandora’s box. There are just a million different variables every single day.”

When children displayed widely varying skills in different domains, mothers found themselves constantly off-balance, not knowing what level of functioning to expect from their child. One mother of a second grader diagnosed with atypical autism described her son’s inconsistency this way: “You know, autism’s weird. He’s doing math, really advanced math, he’s doing algebra, he’s reading two years ahead of his grade, and then he’ll say, ‘Which way’s left?’ I don’t understand.” The difficulty and ambivalence involved in adjusting expectations to the child’s abilities were at the heart of the concerns of a mother of an 8-year-old child with Asperger syndrome:

I’ve got real mixed feelings. Part of me may be expecting too much of him, but then there’s part of me that says he’s very, very bright and he should be expected to do what is expected of his age. I don’t want him thinking he can get by in life with less, but if this is all that we can expect from him, then maybe I am expecting too much.

The lack of clarity regarding outcomes for children with ASDs was also reflected in the mothers’ reports of their concerns. Some found themselves contrasting the likely future for their child against what their expectations had been for their child prior to receiving the diagnosis of an ASD. One mother whose preschool-age son had only recently been diagnosed with severe autism said that

We were driving the other day and it dawned on me that, you know, he may never drive. You realize things, like what his life may be like. And yet you have hope, and you want to make his life as good as it can be.

Other mothers focused on the realization that things would never be the same for anyone in the family. An adoptive mother of a 4-year-old son shared her feelings of dismay and fear when she said, “I went through the stage of ‘I can’t believe this is happening, I don’t want to spend my whole life doing this.’” Another mother, whose kindergarten-age son was in the midst of receiving a diagnosis of an ASD, was articulate in describing the ambiguous nature of her family’s situation:

The frustrating part of it is that I know that there isn’t anything that I can do about it, and I feel bad, but then I feel better because I know there is nothing that can be done about it.

Finally, the ambiguity led many mothers to feel they were somehow to blame for the presence of an ASD in the family. A typical feeling was expressed by this mother whose son had been diagnosed with AD: “When I got the diagnosis of autism, I took it personally, thinking, did I do something wrong when I was pregnant?” Another mother clearly felt responsible for making things better for her 11-year-old son but saw no clear path to follow: “You feel like it’s the parents’ job and you’re supposed to know what to do. You’re supposed to be able to help this and you can’t.” One mother seemed to sum up what many were feeling when she said, “I wonder . . . what things would be like if he were different or something.”

Relation of Identity Ambiguity to Stress and Depressive Symptoms

The qualitative portion of the study indicated that mothers of children diagnosed with ASDs have feelings that fit constructs arising from the theory of ambiguous loss. The next step involved testing a specific question derived from ambiguous loss theory. Therefore, quantitative analyses were conducted to determine whether identity ambiguity, or the blurring of roles and responsibilities between mother and child, was related to mothers’ perceptions of stress related to parenting their child with an ASD and to their reports of depressive symptoms. For these analyses, families were divided into two groups on the basis of the number and severity of ASD
symptoms displayed by the child. Children diagnosed with AD had significant impairments in all three core areas of autism; the children in the “other” group had fewer symptoms and their symptoms were less severe.

Descriptive data. Demographic factors were not consistently related to the constructs of interest. The only significant correlations between demographic factors and study variables were for depressive symptoms; mothers of older children \(r = -0.25, p = .048\), older mothers \(r = -0.27, p = .034\), and mothers with higher levels of education \(r = -0.41, p = .001\) reported fewer symptoms of depression. Child gender, family income, and partner status were not related to any of the study variables.

Descriptive data on measures of identity ambiguity, depressive symptoms, and stress by diagnostic group are shown in Table 2. Comparisons of the means using \(t\) tests indicated no statistically significant differences, but a marginal difference in depressive symptoms, with the mothers of more severely affected children (the “AD” group) showing somewhat higher depressive symptoms. The mean score for this group was higher than the score of 16 defined as the cutoff for further clinical evaluation (Radloff, 1977). However, the lack of significant differences between the groups indicated that symptom severity was not a major factor in mothers’ experience of identity ambiguity.

Tests of the study hypothesis. Results of the tests of the study hypotheses are shown in Table 3. The analysis for depressive symptoms included child age and maternal education as control variables because preliminary analyses indicated these factors to be correlated with reports of depressive symptoms (maternal age was correlated with both child age and education level and so was not included). In both models, diagnostic group was entered first, then identity ambiguity, and finally, the interaction between diagnostic group and identity ambiguity. The hypotheses tested were that identity ambiguity would be linked to depressive symptoms and stress, and that child symptom severity, defined by diagnostic group, would not moderate the effect. That is, the prediction was that identity ambiguity would be related to negative outcomes equally in both groups.

The analysis for depressive symptoms indicated that identity ambiguity contributed significantly to depressive symptoms, and this effect was the same for both diagnostic groups. Identity ambiguity accounted for 14% of unique variance in the model. Results of the analysis for child-related stress were similar; identity ambiguity again was a significant predictor of stress across both groups of mothers, accounting for 23% of the variance. The finding that the severity of the child’s ASD was not related to stress or depressive symptoms and did not moderate the relation between identity ambiguity and these outcomes, strongly suggests that maternal distress is linked directly to identity ambiguity arising from the situation of ambiguous loss.

Discussion

In this study, mothers’ narrative reports and their survey responses were used to examine the utility of the application of the theory of ambiguous loss to families of children diagnosed with ASDs. Both qualitative and quantitative results indicated that the theory of ambiguous loss has direct relevance to the experiences of these families. The inherent ambiguity of autism, related to the lack of knowledge surrounding its etiology, symptoms, treatment, and outcome, suggests that parents whose children are diagnosed with ASDs experience conflicting realities and emotions. Coming to terms with the discrepancies between their initial expectations for their child and family and the altered outlook that is required

Table 2. Mean Scores for Measures of Identity Ambiguity, Depressive Symptoms, and Child-Related Stress by Diagnostic Group

<table>
<thead>
<tr>
<th></th>
<th>Autistic Disorder (n = 32)</th>
<th>Other ASD Diagnosis (n = 31)</th>
<th>(t) (63)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity ambiguity</td>
<td>M 35.15, SD 6.49</td>
<td>M 32.52, SD 6.12</td>
<td>1.66, (p = .103)</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>M 16.89, SD 11.06</td>
<td>M 11.73, SD 10.98</td>
<td>1.86, (p = .068)</td>
</tr>
<tr>
<td>Child-related stress</td>
<td>M 64.13, SD 15.42</td>
<td>M 62.21, SD 15.07</td>
<td>0.50, (p = .620)</td>
</tr>
</tbody>
</table>

Note. ASD = autism spectrum disorder.
for a family to continue to function well after a child receives an ASD diagnosis is a process that few families can be expected to negotiate easily.

According to ambiguous loss theory, when people experience ambiguous loss, they have difficulty making decisions, are unable to alter family roles and routines even when these old ways of doing things do not fit their new situation, question their beliefs and competence, and become exhausted (Boss, 1999, 2004, 2006). It is the ambiguity of the situation, not the psychological characteristics of the individual that contributes to perceptions of stress and inadequate functioning (Boss, 1999, 2006). In the narratives of mothers of children with ASDs, expressions of stress arising from ambiguity were common. Many mothers, when asked about their feelings at different points after receiving their child’s diagnosis, reported conflicting and contradictory emotions: fear and hope, helplessness and determination, frustration and joy. When looking to the future, mothers tended to cling as well to their images and expectations from the past. Although not all the mothers interviewed expressed feelings that could be described as arising from ambiguous loss, more than half did so. Thus, it seems evident that the theory of ambiguous loss has direct relevance to many families of children with ASDs.

The second component of this study tested hypotheses derived from ambiguous loss theory: Identity ambiguity would be related to mothers’ depressive symptoms and perceptions of stress connected to her child with an ASD, and this relation would not vary with the severity of the child’s disorder. For this analysis, identity ambiguity was defined as the extent of overlap mothers perceived between their own identities and those of their children with ASDs. As predicted by ambiguous loss theory, mothers with high identity ambiguity also reported more symptoms of depression and perceptions of higher stress related to their child with an ASD than those who were less personally identified with their child’s condition.

Table 3. 

<table>
<thead>
<tr>
<th>Depressive Symptoms</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>ΔR²</th>
</tr>
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<tbody>
<tr>
<td>Controls</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child age</td>
<td>-0.09</td>
<td>0.04</td>
<td>-0.23*</td>
<td></td>
</tr>
<tr>
<td>Maternal education</td>
<td>-3.00</td>
<td>0.86</td>
<td>-0.40**</td>
<td>0.222**</td>
</tr>
<tr>
<td>Diagnostic groupa</td>
<td>-3.10</td>
<td>2.62</td>
<td>-0.14</td>
<td>0.018</td>
</tr>
<tr>
<td>Identity ambiguity</td>
<td>0.68</td>
<td>0.19</td>
<td>0.39***</td>
<td>0.143***</td>
</tr>
<tr>
<td>Diagnostic group ×</td>
<td>0.04</td>
<td>0.39</td>
<td>0.03</td>
<td>0.000</td>
</tr>
</tbody>
</table>

Adjusted ΔR² = 0.33, F(5, 57) = 7.07, p < .001.

<table>
<thead>
<tr>
<th>Perception of Child-Related Stress</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic groupa</td>
<td>-1.92</td>
<td>3.84</td>
<td>-0.06</td>
<td>0.004</td>
</tr>
<tr>
<td>Identity ambiguity</td>
<td>1.16</td>
<td>0.27</td>
<td>0.49***</td>
<td>0.230***</td>
</tr>
<tr>
<td>Diagnostic group ×</td>
<td>-0.56</td>
<td>0.60</td>
<td>-0.37</td>
<td>0.013</td>
</tr>
</tbody>
</table>

Adjusted ΔR² = 0.21, F(3, 59) = 6.45, p < .001.

Note. ASD = autism spectrum disorder. Betas reported at point of entry.
aDiagnostic group: 1 = autistic disorder, 2 = other ASD diagnosis.
*p < .05, **p < .01, ***p < .001.
another family member. Although the scales used here to index identity ambiguity were not originally developed to measure this construct, the items are descriptive of a situation in which a mother is not clear where her identity ends and her child's begins. Some of the items used, especially those from the locus of control measure, may involve issues of mastery (Boss, 2006) rather than identity ambiguity. Further development of measures to examine constructs that are described by the theory of ambiguous loss, including boundary ambiguity, identity ambiguity, and mastery in families of children with ASDs, would be helpful.

The reality of ASDs is that they are lifelong and pervasive; nevertheless, with effective intervention and appropriate supports, many individuals with ASDs are able to function at home, in school, and in the community (Howlin et al., 2004). It is very clear that ASDs do not result from poor or inadequate parenting but instead are genetic disorders, possibly triggered by pre- or postnatal environmental events that are out of the control of parents (Rutter, 2000). Mothers are therefore not the cause of their children's ASDs nor can they alone affect the outcomes for their children. Thus, a mother is expressing identity ambiguity when she feels her own life is so entwined with that of her child that she is somehow responsible for his or her ASD or should be able to determine the outcome for her child.

Given the limitations of this study, including its cross-sectional nature, the fact that all of the measures were collected from mothers, and the lack of a measure developed specifically to index identity ambiguity, the findings reported here can only begin to suggest the potential value of a continuing program of research on ambiguous loss in family adjustment to the diagnosis of ASDs. It is clear that longitudinal work, with independent and multiple measures of both identity ambiguity and psychological well-being, is needed to examine change in mothers' perceptions of their role as related to changes in stress and depressive symptoms and also to parents' decision making regarding intervention services for their child. Research must also be extended beyond mothers to include fathers, siblings, and extended family members, all of whom can be expected to experience ambiguous loss to some degree and to influence the responses of one another. In addition, the measure used in this study, although it addresses important aspects of the construct, was not originally intended to assess identity ambiguity. The development and testing of measures of identity ambiguity and other aspects of boundary ambiguity that address issues specific to parents of children with ASD would be an important step toward clarifying the experience of ambiguous loss in this population.

**Limitations**

The theory of ambiguous loss has generally been applied to families in which an adult member is missing from the family, either physically or psychologically (Boss, 1977, 1980; Boss & Couden, 2002; Boss et al., 1990; Caron et al., 1999), and less often to circumstances in which a child is the focus. In one child-focused interview study, DeYoung and Buzzi (2003) examined differences in emotional and coping responses between parents of children who had been murdered and parents of children who had been abducted and were still missing 6 – 16 years later. Parents of murdered children reported themselves to feel “better off” than those of missing children because they could resolve their loss and share their grief with other parents in similar situations. Parents of missing children reported the need to remain hopeful while at the same time moving forward with their own lives. In another study focusing on parents, Golish and Powell (2003) used the construct of ambiguous loss to describe the emotional responses and communication patterns of parents whose infants were born prematurely. Premature birth is typically accompanied by a period of time when parents are unsure about the child's eventual health, and even survival; thus, the time surrounding early birth is clearly one of ambiguity for parents and other family members.

The diagnosis of an ASD in a child is similar in some ways to each of these situations but has unique elements as well. When a child has an ASD, the child is not physically absent but psychologically different from the child the parents expected, and the parents are called upon to adapt to those differences on a day-to-day basis. By comparison with prematurity, an autism diagnosis is not a time-constrained situation but one in which parents must live with the contradiction inherent in recognizing the irreversible nature of their child's condition while maintaining a long-term commitment to the child's upbringing. Thus, families of children with ASDs
can be expected to experience ambiguity and loss over many years and to need support in their efforts to live with the emotions that often emerge at each new phase of their child’s development.

**Implications for Practice**

Labeling the experience of ambiguous loss for parents of children with ASDs is important, because, in most cases, parents are not aware that their distress, confusion, and immobility are located in the inherently ambiguous situation and not in themselves. As has been often noted by Boss (1999, 2004, 2006; Boss & Couden, 2002), identifying the source of the difficulty in the loss that people have experienced can be a major step toward helping individuals reorganize their thinking and thus begin to employ their usual coping mechanisms rather than remaining “stuck” in a pattern that is no longer appropriate to their changed family circumstances. The theory of ambiguous loss predicts that parents’ ability to make decisions with regard to gaining access to services for their child could be impaired as long as they are unable to come to terms with the ambiguity of ASDs. In such cases, helping parents increase their tolerance for living with ambiguous loss so that children can receive appropriate services may have long-term implications for children’s outcomes.

An understanding of ambiguous loss could help professionals who work with families of children with ASDs to be more supportive and empathetic. Even today, despite considerable empirical work showing that “grief work” is not effective in helping people cope with traumatic loss (see review in Bonanno, 2004), many professionals who work with families of children with disabilities expect parents to progress through grief stages (Shuchter & Zisook, 1993). Another common belief among practitioners is that psychologically healthy parents will eventually achieve resolution following a child’s diagnosis (Pianta, Marvin, Britner, & Borowitz, 1996). Both of these models assume linear movement from psychological distress to a form of closure accompanied by a return to stability and positive functioning. Many professionals also assume that all families will follow a similar path, and, when a family does not meet this expectation, the family is often labeled dysfunctional or “in denial” (Stroebe, 2001).

As noted by Boss (2004, 2006), however, there is no closure or resolution in cases of ambiguous loss. Although parents may accept and cope with the presence of an ASD in their lives, they will never entirely let go of their image of their child before they learned the diagnosis. To make the best choices among educational and intervention services for their child, parents must be aware that autism is a severe and lifelong condition while at the same time holding out hope for improvement in their child’s symptoms. These beliefs are paradoxical but can energize parents to seek ways to move toward new goals for their child rather than becoming immobilized and isolated.

The diagnosis of an ASD in a child presents families with difficult to resolve loss issues. Using the theory of ambiguous loss as a framework for the study of families of children with disabilities holds great promise for advancing our understanding of the challenges these families face and their resilience in learning to live with ambiguity.

**References**


