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Understanding Ambiguous Loss in Parents of Children with Autism Spectrum Disorder

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Abstract

A diagnosis of autism spectrum disorder (ASD) can be challenging in many ways. Often, research focuses on financial and other developmental challenges. In this study, we aimed to learn about the complex experiences of parents when they receive a diagnosis of ASD for their children. This research can aid in parents' process of understanding their own feelings and what their child's diagnosis means for the family.

We sought to understand parents' views on:

1. Signs of ambiguous loss (AL) in families with children diagnosed with ASD.
2. Other challenges families face.
3. Helpful resources and support for families dealing with AL.

We did a qualitative study using semi-structured interviews with eight parents. Through an explication process, we developed themes and subthemes from the transcribed interviews. The results showed that parents face issues like emotional highs and lows, uncertain outcomes, and challenging relationships. Many participants shared positive experiences with supportive services. Parents need more support, and children with ASD need extra resources.

Keywords: Autism Spectrum Disorder, Ambiguous loss, Families of autistic children, Educational Partners, Support Services.

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Authors' Note:

The researchers of this article are not part of the Autism Spectrum (AS) community. For this paper's purpose, we will alternate using person-first and identity-first language to empower individuals based on the work of Robison, a researcher, advocate, and person diagnosed with AS (Robison, 2019). We realize that each autistic person has a right to choose the language that best serves them, and we aim to honor their unique lived experiences when talking about AS and disability.

1. Introduction

The prevalence of developmental disabilities in children has increased in the last decade; approximately one in six children have at least one developmental disability, including autism spectrum disorder (ASD) (Zablotsky et al., 2019). Families with children diagnosed with developmental disorders have higher levels of chronic stress (Bluth et al., 2013). For example, the additional lifetime cost of living with ASD into adulthood was $3.2 million per person, including hospital, dental, prescription, home health, emergency, and special education services (Ganz, 2007; Tathgur & Kang, 2021). While factors such as financial strains have been considered, emotional factors like ambiguous loss (AL) are often overlooked (Boss, 2016; Lavelle et al., 2014). To better understand their experiences and identify beneficial support and resources for mitigating AL, this study aims to explore AL in parents of children with ASD.

The researchers sought to learn about their experiences prior to, during, and after the diagnosis process to understand how to increase support. Through qualitative analysis, three research questions were targeted: (1) What indicators are there to suggest AL in families whose children receive an ASD diagnosis? (2) What other challenges do families experience? (3) What resources and supports are most beneficial to families in mitigating AL?

1.1 Autism Spectrum Disorder

The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5) defines ASD as a group of neurodevelopmental conditions that can lead to issues with communication and social skills. ASD can cause restricted and repetitive behaviors and challenges in other areas of functionality (American Psychiatric Association, 2022). In 2018, researchers published a report on the prevalence of ASD in the United States. The study revealed that 23 out of 1000 eight-year-old children have ASD (Maenner et al., 2021).

When an ASD diagnosis is received, families often move through a cycle of acceptance and anguish (Bravo-Benítez et al., 2019) and their reactions range from relief and hope to guilt, shock, anger, and powerlessness. Ambiguity and fear can bring desperation (Bendixen et al., 2011). Parents often alter professional and social lives to seek connections with their autistic children. This shift can lead to self-neglect, burnout, and resentment (Bravo-Benítez et al., 2019). Early diagnosis facilitates resource access (Centers for Disease Control, 2022), but a significant lag exists between concern and evaluation (e.g., 20-month waits).

Caring for children with ASD impacts family social life, finances, and mental health (Sansosti et al., 2012; Tathgur & Kang, 2021). Parents worry about their child's social support, friendships, autonomy, psychological well-being, school environment, and physical well-being (Biggs & Carter, 2015). Families often face delays in accessing sufficient career, social, and educational transition services post-high school, leading to concerns about their child's future (Cheak-Zamora et al., 2015). This results in a heavy burden of lifelong care, with approximately 80% of children with ASD living with parents into adulthood (Shattuck et al., 2012).

1.2 Ambiguous Loss and Autism Spectrum Disorder

Loss and grief are complex inescapable phenomena of life. Ambiguous Loss (AL), a term coined by Pauline Boss in the 1970s, describes grief associated with psychological absence and physical presence. AL is often unclear, confusing, incomprehensible, and sometimes traumatic when a loved one is physically present, but psychologically and emotionally distant. Families often experience AL when members have neurological or neurodevelopmental differences including autism spectrum disorder (ASD) (Boss, 2009). AL theory allowed people to effectively cope with a newfound understanding of their feelings.

Ambiguous loss theory implies that caregivers of children with ASD must decide what is true regarding their loved one's status so that they can engage in the grieving process. Symptoms of AL can include complicated grief, depression, anxiety, and ambivalence but more specifically, Boss (2007) claims that ambiguity lies in the experiences of the family as a unit and the ability to understand their child's lived experience. Subsequent research has supported this claim (O'Brien, 2007) with others finding evidence of uncertainties in community acceptance (Celik Ahbab & Eksi, 2018). When a child is diagnosed, parents or caregivers start to accept that life will never be the same (Patrick-Ott et al., 2010), and may experience chronic sorrow, or the lingering feelings of sadness for the loss of hopes, dreams, and expectations for what they thought their child's life would be. Feelings of guilt, self-blame, resentment, and deep sadness can occur in non-death grievers (Gitterman & Knight, 2019).

Normalizing AL can mitigate the long-term effects of grief. If not intervened, disenfranchised grief, or grief that is not publicly acknowledged, socially validated, or publicly mourned (Doka, 2008) can cause emotional harm and dysfunction in caregivers and families (Canitz & Haberstroh, 2022). Moreover, avoidant behaviors in carers, home life, and denial may increase if the grief is unaddressed. Confronting and accepting ambiguous loss may prevent maladaptive coping (Bravo-Benítez et al., 2019). Recognizing the trace of AL can be an opportunity for counselors to intervene and better support clients (Knight & Gitterman, 2019).

1.3 Current Study

This current study aims to give voice to the experiences of family members who have been affected by a child's ASD diagnosis. Participants were parents or legal caregivers of preschool to twelfth grade children diagnosed with ASD. The purpose of this current study is threefold: (1) expand on the work of O'Brien (2007) to gain additional insight into families of children with ASD navigating AL; (2) fill the literature gap by exploring the depth of the connection between ASD and AL; and (3) examine the role of counselors in helping families manage with AL associated with ASD diagnosis. The research questions for this study are: (1) What indicators are there to suggest AL in families whose children receive an ASD diagnosis? (2) What other challenges do families experience? (3) What resources and supports are most beneficial to families in mitigating AL?

2. Method

The researchers used a phenomenological approach and applied purposeful sampling to recruit participants. We distributed advertisement flyers via directors of three Autism Centers in the Northeastern U.S. Inclusion criteria included parents or legal caregivers of PreK–12 children with ASD living in the U.S. Out of 12 potential participants, eight agreed to an interview.

Phenomenological inquiries are completed until data saturation is achieved (Moustakas, 1994). We reached saturation after eight participants ages 25-55. All participants were married and employed; each had an ASD-diagnosed child aged 4-17 (See Table 1 for additional information). Their children exhibited varied challenges associated with ASD, including isolating, repetitive, or destructive behaviors. All but one child had communication challenges. Four children received early diagnoses (2-3 years), and four received late diagnoses (4-8 years). For confidentiality purposes, pseudonyms (P1-P8) are used to identify the participants. To understand the essence of their experiences (Moustakas, 1994), we asked 11 open-ended semi-structured interview questions, to allow for great exploration of their emotions. Our questions asked about the diagnosis process, a typical day, and support systems. The first researcher conducted the interviews, and the second researcher transcribed the interviews. To reach consensus on themes, we used an abbreviated explication process, adapted from Groenewald (2004). This five-step process involved bracketing and phenomenological reduction, delineating units of meaning, clustering units into themes, summarizing interviews, and validating/modifying themes to create a composite summary. To delineate meaning, we extracted relevant statements then eliminated redundancies. We clustered units of meaning into themes by grouping quotes under codes. Each interview was summarized, validated, and modified through discussions. An external qualitative researcher reviewed transcriptions and themes, leading to further modifications for accurate participant voice capture. Finally, we formed general and unique themes for all interviews and composite summaries.

3. Results

Data analysis revealed three themes and eight subthemes. Theme one, "Ambiguous Loss and Autism Spectrum Diagnosis," included emotional instability, unpredictable outcomes, and disrupted relationships. Theme two, "Additional Challenges," encompassed apathy and lack of societal awareness, family isolation, and inadequate training. Theme three, "Beneficial Resources and Supports," covered professional and social support.

3.1 Ambiguous Loss and Autism Spectrum Diagnosis

This theme explored indicators of AL. The subthemes that emerged were emotional instability, unpredictable outcomes, and disrupted relationships.

3.1.1 Emotional Instability

Emotional instability was prevalent in all interviews. Some of the parents' emotional instability surfaced from not knowing how to meet their children's needs. Families expressed frustration, hopelessness, curiosity, and defeat.

> *I still… remember what the room looked like, I remember where my daughter was sitting, I remember where my husband was… I remember when we left, I called my parents right away… to say [ASD was] confirmed... It's a very vivid memory … even though we knew… it just stung! All the frustration now turned to relief and defeat* (P2)

This theme also demonstrates the disconnect between family members' emotional struggles to relate to their children; families felt lost.

> *I feel like I've hit it [acceptance] but then there's other stuff that show me I haven't gotten to that point…I don't know if that'll be in a month, I don't know if that'll be in ten years from now. I think it's just as she gets older and we see maybe where she is like with her…level…of autism, maybe that's when I'll accept life a little bit better... because I have to think of perspective. She's six.... a lot of six-year-olds can pick out their own clothes... we still have to do everything for her. So, at times I still feel like I have a baby.* (P2)

3.1.2 Unpredictable Outcomes

All parents expressed uncertainties when describing the outcomes for their children. The anticipation of seeing their children reach goals or regress was an ongoing concern. **"***You see him gaining, and then you see a regression…with all the ups and downs that's a lot too"* (P5). One parent felt overwhelmed and described their child as "*totally dependent on them*." Parents were concerned about their child's futures regarding social relationships, long-term care, careers, and life skills. "*What's he gonna be like when he's 16? I will not be here forever and that worries me"* (P1). One parent described their uncertainty when they received their daughter's diagnosis:

> *[Her] diagnosis changed my wife forever. Our daughter is eight years older than our second child because my wife had this crippling fear that all our other kids would be the same… As a Pastor, that was very difficult for me. I preach about faith constantly as my household struggles with our own test of faith. I have come to accept it.* (P8)

3.1.3 Disrupted Relationships

Disrupted relationships are a key indicator of AL (Boss, 2016), and participants described dissonance in their other relationships. These disruptions caused stress which was evident as P5 described how she recognized her inability to give the same attention to her other children. She states "*I feel them fighting for the attention because I'll have to stop the conversation to address something with him [autistic child]. And I can tell they're getting upset."*

Family strain was evident because families saw no end to their stressful circumstances. Some expressed physical and emotional disconnectedness as they managed the pressure to keep up with financial and other obligations. Work life balance as well as healthy intimacy was hard to achieve. Participant P1 stated, "It's *a full-time job…managing his care. We've talked about working less…but then we cannot afford to, so we keep doing the same thing."*

3.2 Additional Challenges

The second research question explored other challenges that families experience. Families shared stories of barriers presented by professionals and members of their communities. Additional subthemes such as apathetic society, family isolation, and lack of or inadequate training emerged.

3.2.1 Apathy and Lack of Awareness in Society

This theme acknowledges the perceptions about autism that families encounter within society. Participants shared experiences. P2 stated, "As *a parent I feel like you're judged*." Parents shared the lack of effort by others to understand their children's differences. Other parents expressed disappointment when they were met with judgement from others. "*If we had a kid that was physically disabled or… it was really clear that they had a disability, and they were acting a certain way in public… you'd have more empathy. But…we don't get that feeling…we get like all of the dirty looks"* (P1). Some participants avoided social interactions because of the reception from others. In an extreme case, P1, stated, "*My kids have aunts and uncles that literally live right down the street, and they haven't seen them in like a year... They kind of just stay away from us."* Other parents tried to understand that some work has been done to educate the public and acknowledged that there is still more work to be done. As P4 stated, **"***You hear all this autism awareness…but there's not really like what that means, like, the breakdown of the language and behavior. Every kid is so different. There's one saying that I've heard several times, 'if you've ever met someone with autism, you've never met someone with autism.'"*

3.2.2 Family Isolation

Isolation emerged as an experience of daily life. Many parents felt misunderstood. Some shared their children's challenges prevented them from engaging in social activities. P5, provided a detailed explanation stating:

> *"Before… we would go places...It didn't matter if we had to wait... But…he had allergies, and his attention span is limited. And [the family] is like, 'well how come we can't take you out for Mother's Day dinner?' and I'm like, because we can't sit in the restaurant, and I don't know what they're making, I don't know how long it's gonna take."*

In such instances, isolation becomes easier to manage. Some of the participants shared that most attempts to socialize are with parents in similar circumstances who can show consideration.

3.2.3 Lack of or Inadequate Training

Participants expressed feelings of frustration when facing systemic barriers such as lack of inadequate training in health care, school systems, and childcare. They shared that some professionals do not have competence and may be ill-equipped or underinformed about ASD. A parent, P3, described frustration with a physician who was unaware of their lived experiences:

> *'why was it so hard for me to convince you that there was something going on with [my child] and that I needed your guidance in what to do?'. And [the doctor] said, 'I'm not trained for that. I know nothing about this field'. And I thought, here we are, living…where everyone wants to live, and our doctor didn't know how to guide me.*

Parents also thought the school system was difficult to navigate. Some participants stated that their children do receive the necessary support. However, some expressed that schools have inadequate support, especially at the administrative level. P1 shared:

> "*When you get past the teachers and… therapists… it's not a lot of support from the school... And a lot of the parents that I'm with have similar feelings. A lot of them have had to hire attorneys or advocates just to get their kid what they need. It's unfortunate."*

3.3 Beneficial Resources and Supports

The third research question explored resources that are beneficial to families with autistic children. Researchers sought to understand which services are beneficial in mitigating AL. Psychoeducation and groupwork were successful interventions reported by participants. Therefore, the following themes of social and professional support emerged.

3.3.1 Social Support

Social support often began informally in conversations with other parents of children with ASD. Parents found deep connections in support groups. Some parents, such as P1 and P8 started a support group. P1 shared, "*I felt like there was a necessity for it, so I just kind of like grass roots started a parents' group…We have a group of 40 parents now."* Those who joined organized groups found the groups by word of mouth or via online platforms. P4 shared an experience where she had a glimmer of hope after being part of a self-help group organized by an organization that provided social skills for her daughter. She indicated that, "*I got to meet with the parents of the other kids…we all chatted in a room while we watched the class. When I left, I was like, 'oh my gosh this is like therapy for me.'"*

3.3.2 Professional Support

Participants shared the value of professional support when it was effective and informed care. This theme varied in codes including experiences with educators, counselors, and medical professionals. This contrasted to the negative experiences with providers who lacked ASD awareness and training. The appreciation for informed professionals who advocate on behalf of the participants was evident in a statement P6 made, "*She's [school counselor] helping to talk to all the different teachers right now to kind of ease their way in getting to know my son. And I really appreciate that too because I can't do that with every teacher, so I really am very appreciative of their support."* Another participant, P8, shared hopes and aspirations about his daughter's career, and the obvious challenge he had of not knowing how to help her. He stated, "*She is so passionate about cooking. In her* *own words, she says "I will become a chef…*[but]*where do I begin to find support for her*?" However, this participant described how a school counselor took interest in his daughter's passion and provided resources.

Table 1. *Participants demographics*

Interviewee Classification	Interviewee Identification	Gender	Number of Children	Age of Child with ASD
				At data collection
Mother	P1	Female	2	4
	P2	Female	1	6
	P3	Female	1	10
	P4	Female	2	5
	P5	Female	3	6
	P6	Female	2	10
	P7	Female	3	17
Father	P8	Male	3	14

4. Discussion

The results from this study indicate that families of children with ASD shared key experiences of AL. Consistent with the findings of O'Brien (2007) the current study shows families with autistic children experience AL. Participants described mixed feelings upon receiving their child's diagnosis. Celebrating the wins of progress then feeling the pain of their barriers was a common thread. Similar to Bravo-Benítez's (2019) findings, families in this study held feelings of acceptance and emotional anguish as they grieved the ASD diagnosis. Participants reported ambivalence, acceptance, and disbelief which is like Lee et al., (2022) who found that this is because families are confused about their children's condition.

Indicators of AL include short-term and long-term unpredictability. Families talked about how difficult it is to adapt to their children's daily needs. At the same time, they frequently had worries about the future (Lee et al., 2022). Our findings also support the AL indicator of disrupted relationships within the family system. As family members navigate the cycle of care for autistic children, others within the family such as siblings' experience changes to identity– their self-image, personality, and social relationships are impacted (Healer & Reader, 2020).

Several challenges for families emerged in this current study such as apathy and lack of awareness in society, family isolation, and lack of or inadequate training. Isolation was also a theme, and participants shared accounts of feeling excluded or unwelcome. Moreover, the lack of empathy from relatives was congruent with literature. Participants reported feeling judged and misunderstood by their communities (Cheak-Zamora et al., 2015). Families admitted surrendering familiar routines and traditions when others did not understand their child's diagnosis and needs (Bravo-Benìtez, 2019). Further evidence of strain on the family is associated with full-time care and financial burden (Bluth et al., 2013).

Inadequate training is another theme of this research. Several participants shared the lack of support in schools, unavailable qualified child-care, and uninformed clinical professionals as barriers. Participants shared frustrations when people invalidated their children's lived experiences. Families remarked about the assumptions of ASD and how it often yields misinformation and distance– and this is why practicing humility and self-education can be a way to create meaningful relationships across disciplines (Robison, 2019).

5. Implications

Clients rarely seek care for AL because many do not know of the theory (Boss, 2016). This research can aid in parents' process of understanding their own feelings and what their child's diagnosis means for the family. Providing parents with an identifier of their feelings may help them cope with their child's diagnosis sooner. Studies have indicated children who received diagnosis and intervention services earlier than age five exhibited stronger development progression (Okoye et al., 2023). It is important that professionals guide these families by processing their emotions during and after diagnosis. By labeling their experiences of AL, parents can come to terms with their feelings and be emotionally available to seek out early intervention services.

Clearly, professionals need more psychoeducational training on ASD and AL theory (Knight & Gitterman, 2019). If professionals do not do their part families may experience the effects of disenfranchised grief (Weiss et al, 2023). Clinicians and counselors have the ethical responsibility to inform families and provide resources on AL by pursuing ongoing education and developing new skills (American Counseling Association, 2014). Meanwhile, as indicated in this study and in other literature, mitigating AL through social support is just as crucial (Boss, 2016). One participant mentioned that finding appropriate outside services for their child felt like a glimmer of hope. Similarly, participants of this study and in other literature shared the value of therapy, support groups, collaboration with the counselors and outside services (Jackson et al., 2018). Support groups with families of children with ASD provide connection, universality, and understanding (Krishnan et al., 2017).

This research shows that clinicians can teach clients resiliency skills to effectively bolster their tolerance of AL (Boss, 2016). Parents in this study shared that misinformation and disbelief of their children's ASD was common in delaying diagnoses (Lee et al., 2022). Therefore, the research shows that to better inform and prepare families– caregivers need to be included in the treatment plans of their children both pre and post diagnosis. Overall valuing AL psychoeducation can be life changing for families, because it provides space to process and put a name to complex feelings (Boss, 2016).

6. Limitations and Future Research

Qualitative studies oftentimes come with limitations simply based on the structure of the research. Limitations of this study include generalizability and only parent feedback. Voices from the children with ASD, their siblings and surrounding community members are missing in this research. As with any study that involves interviewing a small pool of participants, there is limited generalizability. Furthermore, every parent who has a child with ASD will have a different experience unique to their own child and family. The participants in this study were mostly mothers except for one father. Additionally, participants were primarily middle or upper class living status. Future researchers could duplicate this study and include more fathers and lower-income families. That would allow for counseling professionals to understand the experiences of caregivers who cannot afford many intervention services necessary for their child's successful development. The current study involved semi-structured interviews that took place once without follow-up of any kind. This can be considered a limitation in that we were unable to include artifacts such as documentation from parents. Future studies could utilize qualitative methodology such as a case study following one family. Researchers could also use an ethnographic study which could possibly allow for more exploration of artifacts and enrich the findings rooted in cultural beliefs and practices.

7. Conclusion

Educating counseling professionals about AL and its connection to ASD can provide better support to parents, caregivers, siblings, and autistic children. This research should urge professionals to seek more training and education on ASD so that families receive better quality care. Additionally, parents addressed the impact and need for more parent support groups to help them through diagnosis and ongoing care. While they indicated that Facebook support groups are helpful, a few parents said that it would be even better to have a group that meets in person with childcare provided during the meetings. More specifically, they would like to see a group designed to help fathers of children with ASD as there are very few that exist locally.

Family members often view their feelings as parts (flaws) of themselves instead of the situation (O'Brien, 2007). Clinicians and professionals can label the experience of AL to help families come to terms with their feelings and be emotionally available to seek out resources and support. Awareness in the counseling profession about AL and its connection to ASD can lead to better support for the family. Knowing the indicators of AL, challenges for families, and feedback of these participants adds to current literature in understanding the lives of families caring for children with ASD. All in all, participants have demonstrated determination and devotion in supporting their children. In return, guardians and their children deserve the resources to lead successful lives. Professionals, counselors, and clinicians can mitigate the isolating effects of AL through advocacy, early intervention, psychoeducation, and ongoing care.

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