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RESEARCH ARTICLE

Ambiguous Loss and Coping Strategies in Couples Raising a Child With Down Syndrome: A Qualitative Directed Content Analysis Study

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ABSTRACT

Despite years of research about developmental diversity, relatively little is known about the experience of couples raising a child with Down syndrome. Previous research has identified that Ambiguous Loss Theory can be helpful to understand the parents' process of navigating the uncertainty, challenges, stressors, and demands of raising a child diagnosed with a neurodevelopmental disorder. Building on previous research and the framework of ambiguous loss, this study sought to provide insight into the lived experience of couples raising a child diagnosed with Down syndrome. Using a qualitative directed content analysis of the paired responses to open-ended questions from 16 couples, the current study provides insight into the couple's experience of ambiguous loss and greater understanding about their coping strategies. Results indicated a process of dealing with ambiguous loss by most couples. Coping strategies reported by the couples included medical and educational advocacy, deepening and building connections, and gaining new perspectives on raising a child with Down syndrome. Implications for policy and practice are also included, based on the coping strategies, skills, and resources available to parents of children with Down syndrome or other neurodevelopmental disorders.

Key Words: Down syndrome, ambiguous loss, couples coping, qualitative directed content analysis

Introduction

Ambiguous loss[1-3] is a theoretical framework for understanding unexpected or catastrophic experiences where there is uncertainty that impacts relational boundaries and systemic processes.[1-2] Extensive work has addressed ambiguous loss in a variety of situations, including war, natural disasters, kidnapping, terrorism, incarceration, chronic mental and physical health issues, disability, and other areas.[2] The ambiguous loss model is comprised of two primary areas where the psychological or physical presence of a family member is unclear. In the first type of ambiguous loss, *physical absence* with *psychological presence*, the person is physically gone, but there is uncertainty about the member's physical status, as with missing persons in a disaster event or soldiers who are absent due to a deployment. The second type, *physical presence* with *psychological absence*, involves the person being physically present, but psychologically not available—emotionally or cognitively absent.[2] This second type may include situations in which an individual is experiencing chronic mental or physical illnesses, like Alzheimer's disease or a traumatic brain injury, and those diagnosed with a neurodevelopmental disorder (NDD), including Down syndrome (DS).

Parents of a child with DS may experience ambiguous loss, specifically the child being physically present, but psychologically absent. Parents must deal with the absence of a typically developing child, who is different from the expected baby.[5] The ambiguity that parents experience involves uncertainty about their child's level of impairment and future abilities or functioning, likely to involve an ongoing process of unresolved grief and loss.

As with other types of ambiguous loss, a DS diagnosis involves numerous unknown factors, including increased demands and responsibilities for the parents. In addition to the stressors of caring for a child with DS, immediate demands may include medical or health issues, financial stressors, and an uncertain future, which must be managed, along with reactions and emotions the new parents are experiencing. Previous research has addressed the complexity of needs and demands that can result in increased caregiver stress and reduced coping skills, and psychological and physical health issues for parents.[6-12]

Despite the initial ambiguity and pile-up that may occur, parents often report a process of adjustment to the DS diagnosis, initially experiencing feelings of grief and loss, and later reaching more acceptance of their child and of the diagnosis.[7,13] The experience for most parents of children with DS is one of resilience, growth, and positive outcomes.[14-19] Researchers have also found that the couple relationship is an important factor in promoting resilience for parents of children with DS.[20-24] The couple relationship can be a factor in reducing stress, providing support, and increasing connection, which may help parents manage the ambiguous loss, begin to build resilience, and promote positive outcomes necessary for greater family system functioning.

Pseudonyms are used to maintain confidentiality of participants.

Previous studies have assessed ambiguous loss among parents of children with a disability,[25] with several specifically addressing parents of children with autism spectrum disorder (ASD) and DS.[26-28] However, these previous studies addressed groups of mothers or fathers individually and did not employ a dyadic approach by comparing parental experiences within couples. The current study sought to expand previous research by exploring how couples navigate the ambiguous loss experience of a DS diagnosis together.

Purpose of the Current Study

The framework of ambiguous loss can be used to examine the experiences of parents raising a child with DS because their initial expectation of parenting may be challenged by their child's diagnosis, including moderate to severe developmental implications, and the ongoing health supervision required[29]. Diagnosis of a neurodevelopmental disorder may include a lifelong experience with an ambiguous outcome. This ambiguity influences the experiences of parents and other family members across the life span.

Several studies using the current dataset have been conducted[13,15,26-27,30-33]; however, no previous studies have examined the qualitative paired data from participant couples. Two previous publications[26-27] used the ambiguous loss framework to identify coping behaviors in fathers from the full dataset. The current study expands on this previous research by conducting a qualitative directed content analysis of the data from 16 couples who responded to open-ended questions about their experiences as parents of children with DS. Based on the ambiguous loss and systemic (dyadic) frameworks, our work was guided by the following research question: *How do couples who are parents of a child with DS experience ambiguous loss and cope with their child's diagnosis and co-occurring needs?*

Methods

Participants

As part of a nationally distributed study examining the experiences of parents raising a child with DS, a total of 651 parents completed a web-based survey including quantitative measures and open-ended questions. To recruit participants, contacts from regional and national DS groups, including the National Down Syndrome Congress (NDSC; ndsccenter.org), the Down Syndrome Guild of Greater Kansas City (kcdsg.org), Band of Angels (bandofangels.com), and the Council for Exceptional Children (cec.sped.org), provided recruitment information to their affiliate groups, which then distributed information about the study and a link to participate in the web-based survey to their local members. All study procedures were approved by the Kansas State University and Texas Tech University Institutional Review Boards.

From the larger dataset, previous research has shown that fathers' (n = 50) responses revealed themes of ambiguous loss as well as different strategies to cope with the ambiguous loss.[26-27] Using a person-centered cluster analysis with measures of hope and satisfaction, three primary clusters were found.[26-27] The clusters were then verified with the Family Crisis Oriented Personal Evaluation Scales (F-COPES).[34] The data analysis revealed three methods of coping in fathers: *mastering*, *connecting*, and *thriving*. The three clusters included fathers who addressed ambiguous loss by focusing on efforts to develop *mastery* for themselves and their child with DS, fathers who were *connecting* with others to both develop understanding and to give and receive social support, and those who were *thriving*, who viewed their journey as a privilege and an opportunity for personal and spiritual growth. Although all three types of coping reflected a level of resilience, the fathers achieved resilience through different routes.[27]

While the cluster analysis provided some structures for initial inquiry, a qualitative directed content analysis would reveal more emic information about how those clusters described each group of fathers. A qualitative directed content analysis begins with theoretical or other research findings guiding the initial efforts to find themes in the responses.[4] The guidance for the current study of couples came from Boss's theory of ambiguous loss[1,3,35] and the types of coping strategies these couples utilized.

Data Analysis

A qualitative directed content analysis allowed the researchers to examine the couple's lived experience of parenting a child with DS.[4,36] The purpose of the directed content analysis of the text data was to explore the emic accounts of couples through the lens of ambiguous loss theory and to identify coping styles.[1,3,27,35] None of the open-ended survey questions explicitly asked about ambiguous loss; however, previous work revealed that responses would provide a deeper understanding of each couples' experience as they described experiences characteristic of ambiguous loss. The researchers explored whether the themes of ambiguous loss were consistent within the couple relationship and examined the coping strategies described by participants. Key words from the ambiguous loss and the coping literature were used to create a codebook to guide exploration of the couples' responses. Concerns about the objectivity when exploring text data with a qualitative content analysis were addressed by independent reviews and confirmation.[4] Two research team members independently identified examples of ambiguous loss and coping and confirmed agreement on the represented quotes included in the final results.

Results

Participant Demographics

From the 50 fathers in the previous study, the researchers identified and extracted paired data identifying 16 couples for the current study, which were identified by code words the participants provided on the original survey, linking the dyadic data of couples within the larger dataset. In the current study, participants self-reported to be of European American descent, most in their first marriage (fathers 68.8% and mothers

81.3%), and employed full-time, with over half reporting their education beyond a Bachelor's degree. Participant ages ranged from 30–53 (*M* = 38.81, *SD* = 5.70). The average length of marriage was 11.25 years, ranging from 5–20 years for couples. All couples reported income levels over $40,000, with 50% reporting $100,000 or more a year. The couples had one to four children (*M* = 2.19, *SD* = .834), but only one child was diagnosed with DS (75% male). The children with DS ranged in age from two months to eleven years (*M* = 3.82, *SD* = 2.91), and half of the children with DS were 2 years old or younger. (See Table 1 for additional demographic data).

Table 1: Participant Demographics

	N (%)
Employment (*N* = 32)	
Full-Time	22 (68.8)
Part-Time	4 (12.5)
Not currently employed	2 (6.3)
Stay-at-home Parent	3 (9.3)
Religion (*N* = 32)	
Protestant	11 (34.4)
Catholic	1 (3.1)
Jewish	6 (18.8)
None	7 (21.9)
Education Level (*N* = 32)	
High School Diploma/GED	1 (3.1)
Some College	4 (12.5)
Bachelor's Degree	8 (25)
Some Graduate School	4 (12.5)
Master's Degree	10 (31.3)
Doctoral Degree	5 (15.6)
Total Number of Children Per Couple (*N* = 16)	
1 child	3 (18.7)
2 children	8 (50)
3 children	4 (25)
4 children	1 (6.3)

Ambiguous Loss

Previous research identified themes in the fathers' responses that supported a sense of ambiguous loss felt by the fathers.[26-27] In the current study, mothers also described this sense of loss, especially when describing the moment they learned about their child's DS diagnosis. Comparing the responses of fathers and mothers together, the same sense of ambiguity and loss was highlighted. A clear expression of an ambiguous loss came from a mother of little girl when she said,

> *I don't remember it as tragic but somewhat sad…perhaps for the unknown. I also recall a doctor on duty coming in asking me the night our daughter was born if I needed medication (like something for depression). I told her, NO, and asked if she would just let me grieve the child I thought I would have and I would be fine.* (Regina's Mother, 7-year-old girl)***

The ambiguity of her experience is clear as she asked for a moment to grieve her expectations. Her husband was more concise, and simply said, "*At first, my reaction was sad.*" (Regina's Father, 7-year-old girl)***

Another couple expressed initial and sometimes long-term issues with the ambiguity of their child's diagnosis:

> *I still have times of grieving the loss of normalcy with her. I sometimes wonder what she would be without DS, but I feel DS is part of who she is.* (Glory's Mother, 2-year-old girl)***

> *We both cried initially and asked why.* (Glory's Father, 2-year-old girl)***

The following quotes indicated concerns for the changed future the couple anticipated:

> *Just the realization that what we had planned for our futures, even though they were vague at best, were now shot.* (Gerry's Father, 2-month-old boy)***

> *I was devastated that day, but I began to do research and I accepted the possibility before he was ever born, and before we ever knew.* (Gerry's Mother, 2-month-old boy)***

Other parents described the ambiguous loss as a sense of uncertainty about the future because of the DS diagnosis:

> *In some ways I felt like it was worse than a death, because there was so much fear involved in not knowing what his life would be like.* (Gage's Mother, 2-year-old boy)***

> *Initially I began to think of all the things that our son would NOT be able to do or become.* (Gage's Father, 2-year-old boy)***

Only one couple, who learned during pregnancy that their child would likely have DS, did not express any sense of ambiguous loss. Their son was born with excessive fluid on his lungs, and their only comments were

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about the joy of his survival, after the successful medical procedures to drain the fluid. Perhaps having time to absorb the news of the DS diagnosis (in advance of their child's birth) along with their fear of his potential death after birth, served as a buffer from focusing on what the role of DS would be in their lives, and instead was illustrated by a perspective of gratitude for life.

For the other couples, ambiguous loss was a common experience described by both partners. Participants also provided examples of mutual support and the influence of their partner helping support them in dealing with the ambiguous loss. One couple expressed that their experience had a positive impact on their relationship. However, the mother initially expressed concern about her ability to handle the challenges they faced:

> *I probably was also scared (about) how my spouse was going to take the news and if he was going to be in for the long haul. I needed that reassurance. He took the news a lot better than me. He was actually looking forward to the challenge. That shocked me. But, I got my reassurance.* (Gino's Mother, 6-year-old boy)***

The father described that his current attitude toward their son helped him be a better parent to all their children, and helped him "*be a better spouse to my wife as well.*" (Gino's Father, 6-year-old boy)***

Ambiguous loss was described by both partners for 15 of the 16 couples. There were also examples of mutual support between both partners described by the participants. Thus, the construct of ambiguous loss serves as a primary component for couples dealing with a DS diagnosis.

Coping Strategies

Couples also found coping strategies and skills to move forward in their grief and develop resilience. To manage stress and consider available resources, people activate various coping strategies. Activating social networks, which may include extended family and friends, or problem-solving strategies, such as meaning making and reframing, coping strategies help in the process of adapting to long-term stress.[37] By identifying the source of stress for these couples, not as the presence of DS, but rather the ambiguity of the situation, it provides a framework for examining the coping mechanisms they activated in their daily lives.

The coping styles identified were *mastery, connecting*, and *thriving* for the fathers in the father only data. Within the couple data, there was no attempt to identify clusters, just an effort to examine the coping styles that these couples used. Coping styles varied across and between couples, as they dealt with the ambiguity of their child's diagnosis and the various stressors that came with that diagnosis, while they supported each other and their families to build resilience.

Medical and Educational Advocacy

There was little evidence of a mastery type of coping in the couples' responses. The idea

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of mastery has been viewed as a coping skill that helps people successfully cope with stress in their life.[37] By advocating for their child in various situations, some couples expressed the frustration and tension in their experiences with medical and educational personnel. Advocacy is an aspect of mastery style coping these parents described, taking place in both the educational and medical settings. One mother stated that she advocates for her son *"all the time! Getting him into certain therapies/pre-schools. IEP meetings. Doctor visits. Reading. Questioning"* (Grant's Mother, 5-year-old boy). The father's focus was slightly different, as he advocates in another manner: *"The insurance industry does not cover as much as they should, so we go to bat against their policies regularly"* (Grant's Father, 5-year-old boy). Another mother expressed, *"The IEP [Individualized Education Plan] meetings are any parent's (with disabilities) nightmare"* (Gino's Mother, 6-year-old boy).***

For parents of younger children, their focus was different as they learned to advocate for their child as they traversed new territory. They shared their frustrations about facing new issues, circumstances, and unfamiliar contexts. Some felt their providers were insensitive, sometimes even negligent, and wanted their child's needs and personality to be taken into consideration related to their treatment.

> *My son has tons of medical issues and I advocate for him every single day with his 23 doctors. I constantly have to battle doctors who are ignorant and hurtful.* (Bryant's Mother, 2-year-old boy)***

> *A parent is forced to question every decision or test a physician makes to determine if it is based on [an] existing problem or because he has Down syndrome. Recently one of my son's specialists/physicians referred us to a medical ethicist because he felt we should discontinue trying to address our son's medical problems and "let nature take its course." This was based on his review of charts only and not actually interacting or examining our son.* (Bryant's Father, 2-year-old boy)***

This same couple identified the primary role that their son's medical issues played in their coping experiences. As the mom stated, the DS diagnosis was the least of their worries, at the time, as they faced some serious health problems and overcoming or accepting them demonstrates a mastery style of coping:

> *DS is the least of his issues as he has some health problems and has had some medical error issues that have caused a great deal of stress for our family. He is very delayed but that is okay.* (Bryant's Mother, 2 year-old boy)***

> *I am surprised at how excited I can get over the smallest milestones he demonstrates. Unfortunately, having to address numerous medical complications detracts from some of the joy and add(s) a considerable amount of stress and strain on my relationship with my spouse.* (Bryant's Father, 2 year-old boy)***

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Another couple described their most negative experience as:

> *Medical issues. Dealing with doctors and THEIR schedules. Having to wait for hours after an appointment time to be seen for 2 minutes. Also dealing with insurance companies and fighting for benefits.* (Geo's Mother, 20-month-old boy)***

> *Being helpless during all of the surgeries that [our son] has gone through. Watching him be in pain, uncomfortable, tubes in his nose and down his throat, bloody.* (Geo's Father, 20-month-old boy)***

Another couple described challenges they experienced with medical personnel:

> *After bringing him home from the hospital and dealing with the initial pulmonologist who we still believe today wanted to make our child dependent upon a ventilator to live his life. Needless to say, we quickly switched doctors to one who was as intent as we were of not having our child dependent upon a ventilator.* (Gino's Father, 6-year-old boy)***

> *When my son came home from the hospital after spending 5 months there fighting for his life. He came home with a tracheostomy and on a ventilator. We had to have home nursing for a year and a half. Dealing with the home nursing agency was awful – very unprofessional and nursing skills were performed poorly in most of the nurses.* (Gino's Mother, 20-month-old boy)***

Coping strategies of the mastery style can also be demonstrated by efforts to improve education, job placement, and supportive family relationships that provide a sense of caring and inclusion, which can contribute to a sense of well-being. More evidence of the mastery mindset was demonstrated when the following couple was asked about how they were most impacted by their child's diagnosis:

> *I've also changed my work - staying in the same career field, but changing my focus to start working more with people facing serious life challenges (including kids with disabilities).* (Bruce's Mother, 2-year-old boy)***

While Bruce's father focused on advice of supportive family relationships and asking for help, Bruce's mother's advice focused on being honest and loving with herself, her partner, and her child indicating a different focus on coping by turning to others versus connecting with others. Bryant's mother also encouraged finding communities who share in the experiences that contribute to one's sense of well-being, and stated, "*Find them and ignore those who are ignorant or not helpful.*"

Boss[1-2] cautioned that coping styles that look like an effort to solely solve the problem can interfere with the grieving process needed for an ambiguous loss and therefore weaken resiliency. For resolution there must be, at some point, an acceptance of the ebb and flow that is inherent in raising a child with DS. Since the ambiguity of daily life will not go

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away, it may lead to chronic dissatisfaction rather than resiliency. This individualistic determination to succeed strategy may be a less effective coping style when there is ambiguity.

Deepening and Building Connections

Most participants described connecting with others who were also living with DS in their life, including other parents, mental health professionals, or other experts. By connecting with supportive others, this coping mechanism created a course of action toward building resilience. A key theme in the participant responses was creating connections with both their spouse and their children, as represented in the following quotes:

> *I believe that my wife and I truly came together through this process and I couldn't have gotten through it without her. I really believe that we became each other's best support team, which I believe that everyone needs to have in times like these…Be sure to support your spouse and make sure there is two-way communication.* (Geo's Father, 20-month-old boy)***

One father described his partnership by stating, *"I was there for her and she was there for me. Our relationship is closer and stronger than before"* (Gus's Father, 2-year-old boy).***

In terms of connecting with their child, Gus's father described the bonding that occurred during their son's hospitalization:

> *We focused on what was important and that was human life...our son's life. Given those 12 days in the hospital allowed us to pray, bond, and fall in love with our son. It was always easier when we were around him and were loving him.* (Gus's Father, 2-year-old boy)***

Another example of building a connection with their child, speaks to a focus on his daughter's life, rather than the Down syndrome diagnosis: "*Once I held Glory, her diagnosis no longer mattered. She was my daughter, and I was her Dad*" (Glory's Father, 2-year-old girl).***

In addition to connecting with one's partner or child, couples also described creating relationships with professional providers whom they greatly appreciated:

> *Our son has such a great team of therapists who think he is doing wonderfully and we have a wonderful network, some very close friends, who have kids with DS. Our son is so well loved by family, daycare, us.* (Gus's Mother, 2-year-old boy)***

Creating connections with others was illustrated in the following quotes from a paired couple involving community-based support and extended family:

> *Seek out local organizations. Other parents can become friends and extended family members.* (Gus's Father, 2-year-old boy)***

> *Overall, we have met many awesome people through our support group; we*

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> *have had some of the best physicians care for her and become our friends; we have awesome therapists working with her; I reconnected with my mother after not speaking to her for 8 years.* (Gus's Mother, 2-year-old boy)***

Creating connections through their faith was also important to many couples. Despite being surrounded by supportive others close to them, one father shared a deeply spiritual moment that he experienced:

> *During this time we met with our pastor, some friends, family, and the hospital social worker. All were nice and tried their best to say comforting things. However, the significant occurrence in adjusting to our son's diagnosis was when God gave me a scripture: Psalm 139. In this psalm God was telling me that [Gage] has been 'fearfully and wonderfully made'. He was not born lacking in anything.* (Gage's Father, 2-year-old boy)***

Connecting efforts at coping with a DS diagnosis included connecting more deeply with one another, bonding with their child, building community-based connections and connecting with one's higher power. Each served as valuable ways of developing their coping process. Thus, when stress was addressed with a willingness to connect with others, this served as a different type of commitment to action. This sense of direction to connect with their spouse, as well as finding support groups and seeking knowledge, helps one to deter a sense of devastation, and changes it into short and long-term achievable goals. This coping style shows a willingness to live with the unknowns and to take responsibility for daily life.[1]

Gaining New Perspectives

Finally, there were couples who optimistically saw the best in everything and saw their situation as an opportunity, which indicated a thriving coping style. These parents indicated a level of resilience and personal transformation that occurred when their child was born. Both mothers and fathers demonstrated their resilience through transformation by focusing on positive elements of change and understanding:

> *My son has changed me, and I like who I am now.* (Reginald's Mother, 3-year-old boy)***
> *He has helped me understand what is important in life.* (Reginald's Father, 3-year-old boy)***

When asked about their most positive experience with their child, couples highlighted the daily joy their child brings to them and others:

> *The most positive experience in my journey with my child happens every day. Every day when I walk through my front door, my daughter exclaims "Daddy's home!" and runs to give me a hug.* (Barbara's Father, 5 year-old girl)***
>
> *She is perfect to me. She makes people have a better day. How many people do you know who can do that?* (Barbara's Mother, 5 year-old girl)***

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> *The happiness and smiles he brings.* (Rand's Mother, 7 year-old boy)***

> *There are so many. I can only narrow it down to when I see him in the morning and when I come home from work, I have a big smile, hug and kiss every day. No matter what happens, those three things are a part of my life that will probably never go away and will never get old.* (Rand's Father, 7-year old boy)***

When offering advice to other families expecting a child with DS, the same couple offered the following:

> *Have peace because great joy is coming!* (Rand's Mother, 7 year-old boy)***

> *Have faith that God has chosen you to be blessed with a child that will love unconditionally. There will be some rough patches but have patience, listen to the experts on child development and learn more about what makes your child a little different than others. You'll never regret having this child.* (Rand's Father, 7-year old boy)***

Boss[1] identifies responses, such as the ones illustrated by these couples, as their way of making sense of their situation and the ambiguity that comes with it. Their experiences of ambiguity were evident in their descriptions, especially when they first learned of the DS diagnosis; however, the couples found ways to make it meaningful. That sense of meaning helped them move forward in positive ways and enjoy the experience of parenting. For some couples, this acceptance came from their faith, for others it was simply a matter of embracing the positives, which guided their meaning-making from grieving the unknown future to witnessing the beauty of their child's presence. They possess a peaceful acceptance of the positive attribution of DS to their life experiences. Boss[1] refers to this behavior as *meaning making*. They reframe their circumstances to give purpose and meaning in their life as well as the life of their partner and their child.

When reviewing the responses from the couples, sometimes coping involved an effort to control life with direct action and work toward more favorable outcomes. Other times it involved an effort to connect with others who are walking on a similar path. Parents connected with others through community-based support groups to share successes and obtain guidance for specific challenges. There were also those who were able to address difficulties in stride and thrive in the midst of it; essentially, meaning making was the coping style that defined their resilience. Descriptions of this nature (i.e., DS having a positive impact on couples) contradict many negative references that often emphasize the stress of having a child with a NDD diagnosis. Nonetheless, these findings are specific to these paired couples, and yet helps to inform the ambiguous loss and coping processes couples may face following a DS diagnosis.

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Discussion

One of the most significant experiences for parents can be receiving a neurodevelopmental disorder diagnosis for their child, like Down syndrome. This study sought to capture a deeper perspective about the varied responses couples have in facing life-altering news. For some parents, they faced their fears in anticipation of the many unknowns about their child's future. For others, the diagnosis was met with fortitude to create the best life possible for them, their child, and family. Not all couples respond equally to such an unexpected reality, as it is not possible to predict the future.

The current study involved a qualitative, directed content analysis, which allowed the research team to learn about the ways in which 16 couples responded to the diagnosis and life afterwards, both within their partnerships, as well as within their family system. The couples in the current study described the ambiguous loss they were each experiencing, while also supporting each other in the grieving process. They united to respond as needed to adjust to this reality, which they described was initially filled with fear, sadness, and grief for the child they expected, while also serving to bring them closer. The ambiguity in their experience was evident within their responses related to the perceived lack of normalcy, or *psychological absence* (i.e., intellectual limitations) that they anticipated for their child's future.[1]

The primary contributions of this study involved: 1) the value of paired data to inform the ambiguous loss experiences of couples (as opposed to relying on mother only or father only data), and 2) support for rejecting the negative narrative[16] that often accompanies a diagnosis, like DS. Some partners described a mutual sadness, and others described being supported by their partner amidst their own fears. Other couples reported finding acceptance of their child's limits, while pushing toward *mastery* of key milestones or overcoming medical challenges, and recognizing the positive attributes of their child with DS. Some couples were active in *connecting* with others in an effort to cope, whether it was with their own spouse or family members, other parents in the DS community, or professionals who provided intervention services. Then there were those who seemed to possess the ability to, almost effortlessly, adapt to raising a child with DS, but these couples demonstrated an ability to *thrive,* where the DS diagnosis held less of a focus, or at least was not experienced as a threat. These couples made references to having a greater purpose or discovering things about themselves as a result of DS entering their lives, and they described an awareness of the positive impact their child has had on them and their partners.[38]

Implications for Practice and Policy

Ambiguous Loss Continuum for Neurodevelopmental Disorders

Boundary ambiguity, as originally introduced in the literature, was specific to "how families perceived who was in and out of the family system".[39] As a member of the system, the child diagnosed with DS, introduces the potential source of ambiguity, which can vary based on the extent to which the child's medical and developmental needs define their physical and psychological presence. The parent's perception of their child's presence/absence serves an important role in how they navigate the child's unique needs, as well as the ongoing nature of uncertainty in this parenting experience. One implication from the findings is to consider whether ambiguous loss for some families is more complicated or nuanced when there is ambiguity in both realms, physically and psychologically, within the same family member.

More specifically, are there differences for families who are experiencing the combination of both *physical absence* and *psychological absence*, to greater degrees? Physical absence may not occur in its fullest expression, like in the case of missing persons,[2] but researchers and providers should consider what it might mean in terms of the range of physical ability, along with co-occurring medical needs. Many NDDs contribute to impairment in both physical and psychological realms, potentially requiring more from caregivers (physically, emotionally, and financially) in meeting the unique needs of their child.[40] Therefore, the researchers are suggesting that physical and psychological presence be viewed on a continuum, rather than an either-or category, for neuro-diverse populations.

Although the physical presence of the child exists, there are often limitations with regards to physical functioning, occurring across a continuum (e.g., speech/language, hearing, and mobility).[29] When considering the realm of psychological presence, there can also be a range in cognitive capacity, which affects important aspects of learning and social-emotional development. In addition, many elements of physical and psychological presence do not clearly fall into one realm or the other. For example, speech impairment can be due to physiological differences related to a chromosomal aberration. Speech delays are also influential in the role of social development, aligning more with the realm of psychological presence, potentially complicating the nature of ambiguous loss. Therefore, given the developmental delays and limitations typically associated with DS, determining ways to assess the combined impact of differing levels and manifestations of physical and psychological presence/absence for these families seems warranted. This is particularly relevant when co-morbidity of various life-threatening conditions can exist for a child diagnosed with DS.

Screening and Intervention for Families

The value of assessing relationship quality and adaptability seems pertinent for better understanding the level of risk or resilience available to couples who are coping with life-changing diagnostic news. Being able to determine a couple's ability to navigate ambiguity may be particularly beneficial when working therapeutically with parents raising a child diagnosed with an NDD, which can have very specific, unfamiliar or atypical elements to it. Assessing the level of tolerance for ambiguity could be useful for identifying parents who might be at greater risk for adjusting to the loss of the life they envisioned for their child.[41] Screening for how parents perceive their parenting capacity or effectiveness, amidst the unknown or unclear path ahead of them, could be valuable. Providers should consider ways to identify when parents hold ideals based on a need for clarity or knowing what is to be expected. The reality of which does not truly exist for any parents, but particularly not for parents of a child diagnosed with an NDD.

Although the current study offers a glimpse into the lives of couples raising a child with DS, the researchers did not directly ask about what participants did day-to-day to cope, how they supported their neuro-typical children, or what ways their extended family members and others responded to their child's DS diagnosis that they found helpful or challenging. Research that addresses these realms within and across various neuro-diverse populations could help inform strategies for enhancing relational and family functioning. If professionals can establish what strategies and skills are most useful during the diagnosis and post-adjustment process, for unique populations, they can better help couples and parents develop skills they may be lacking, or enhance the skills they already possess, by incorporating specific resources, implementing grief-focused interventions, and expanding relational support for their family's overall well-being.[5,13,42]

Research with Spectrum Disorder Populations

The question remains: What about these couples allowed them to imagine and engage in life beyond the future unknowns or at least not become paralyzed by the ambiguity? A recent Interpretive Phenomenological Analysis (IPA) study[43] included family interviews about their Autism Spectrum Disorder (ASD) experiences, and found that *parental self-efficacy* emerged as an important theme in managing the demands of life while raising a child with an ASD diagnosis. Another theme that emerged from this study was intentionality or *targeted efforts* made by parents to plan ahead for certain activities, take breaks from the diagnosed child, and spend exclusive time with their neuro-typical children. These families described an *active communication* style, as it related to better understanding the nature of ASD and its impact on the family, as well as proactively adjusting to the specific needs of their loved one. Some themes from this study align closely with specific parental efforts described and were characteristic of mastery and connecting coping strategies noted in previous studies,[27] where their focus was on using certain strategies for managing the needs and potential challenges associated with DS. Hence, the research is beginning to better capture the ways in which parents from both the ASD and DS communities experience and respond to the ongoing, persistent set of unknowns inherent in their parenting journeys.

Study Limitations and Implications for Future Research

It is important to recognize the limits of generalizability in the current study. Of over 650 participants in the larger study, only 50 fathers were eligible for inclusion, and of those, only 16 father participants could be matched with their partner. The sample of 16 couples was too small for conducting dyadic analyses, and demographically speaking, was quite homogenous. Although efforts were made by the researchers of the original study to recruit more fathers and more ethnically diverse populations, future research needs to recruit participants that capture the lived experiences of more diverse backgrounds and various relationship statuses, as there could be unique differences in how they experience loss and cope with an NDD diagnosis.

Further exploration of how couples perceive their child's physical and psychological presence/absence and in what way it may inform their ambiguous loss experience during the diagnosis phase and beyond would be an ideal next step for future research. In addition, developing a brief screening tool for ambiguity tolerance to be used by medical and other professional providers could serve to help identify those potentially at greater risk, early on, to support successful grieving and subsequent parenting. Other considerations for gaining a greater understanding of family responses to the presence of an NDD would be to include the use of interviews with the diagnosed child, neuro-typical siblings, extended family members, teachers, and medical providers, assessing for concurrent life stressors or other losses (i.e., finite or non-finite), and using longitudinal methods to explore how these families effectively address the needs of all adults and children in the family, across the life span.[33,44]

Conclusion

In closing, these couples have been intentional in their efforts to meet their child's developmental needs through medical and educational advocacy, deepening and building connections, as well as gaining new perspectives in their discovery of greater meaning and purpose in becoming a parent of a child with Down syndrome. Despite their experiences of ambiguous loss, inherent in the beginning, they have seemingly demonstrated a remarkable ability to move forward on their parenting journey, together.

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Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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