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The Mental Health Experience among Parents of Children with Autism

Thao Tran

California State University, Northern California Consortium Doctor of Nursing Practice

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ABSTRACT

THE MENTAL HEALTH EXPERIENCE AMONG PARENTS OF CHILDREN WITH AUTISM

Parents of children diagnosed with autism spectrum disorder (ASD) face challenges, stress, and mental health issues than parents of children without autism. Mental health experience of parents in underserved communities are not adequately studied. This qualitative study used a phenomenological approach to understand the mental health experience of eight parent caregivers residing in San Joaquin Valley, California. All parents reported the journey was stressful but not all parents described the point when they received the diagnosis as being more stressful than before and after the ASD diagnosis. Parents' responses to the semi-structured interview that assesses for the degree of ambiguous loss indicate all parents have some degree of ambiguous loss in having a child diagnosed with ASD. Results of the thematic analysis using an inductive conventional approach yield four themes: mixed emotions, uncomfortable, helpless, and growth. In contrast to what is historically delivered to parents as a personal tragedy to have a child with ASD, the current study indicates there is a positive side to having a child with ASD. All parents in the study were offered no mental health support throughout their pre-diagnostic, diagnostic, and post-diagnostic journey. The study highlights the need for healthcare professionals and educators who work with parents of children diagnosed with ASD to offer parents' mental health support throughout this journey.

Thao Tran
April 2020

THE MENTAL HEALTH EXPERIENCE AMONG PARENTS OF
CHILDREN WITH AUTISM

by
Thao Tran

A project
submitted in partial
fulfillment of the requirements for the degree of
Doctor of Nursing Practice
California State University, Northern Consortium
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APPROVED

For the California State University, Northern Consortium
Doctor of Nursing Practice:

We, the undersigned, certify that the project of the following student meets the required standards of scholarship, format, and style of the university and the student's graduate degree program for the awarding of the Doctor of Nursing Practice degree.

Thao Tran
Project Author

Dr. Denise Dawkins, DNP, RN, CNL, CHSE
Chairperson's name Nursing

Dr. Helda Pinzon-Perez, PhD, MPH, FNP-BC, MCHES Nursing
Committee member's name Department name

Dr. Lisa Ann Walker-Vischer, DNP, CNS, RN, CCRN Nursing
Committee member's name Department name

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research that we advocate for the neurodevelopmental disability community who are the most vulnerable and underserved members of our society. I am paying more attention to individuals who are non-verbal because the non-verbal individuals diagnosed with autism spectrum disorder are often mistreated, stigmatized, or portrayed inaccurately by society.

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Most importantly, my daughter inspires me to work hard to help children and adults. The United States needs work to improve the physical and mental health of our children. Your smiles, hugs, kisses, laughter, and peaceful ways to look at life motivate me to do whatever I can to make your world a better place.

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I end here with my favorite quote from the best UCLA basketball coach, John Wooden. Coach Wooden said, “Seek opportunities to show you care. The smallest gestures often make the biggest difference.” I certainly hope we will contribute small acts of kindness to parents of children (pediatric and adult) with neurodevelopmental disabilities, especially autism spectrum disorder.

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CHAPTER 1: INTRODUCTION

Background

Autism spectrum disorder (ASD) is the fastest growing neuro-developmental disability that is very difficult to diagnose due to the complexity and heterogeneity of symptoms. The *Diagnostic and Statistical Manual of Mental Disorders V* (DSM-V) describes the features of ASD to include “persistent deficits in social communication and interaction across multiple contexts; restricted, repetitive patterns of behavior, interests, or activities; presence of symptoms in early developmental period; and symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning” (American Psychiatric Association [APA], 2013, p. 50). For some of these ASD children, they may demonstrate hyper- or hyposensitivity to sensory (auditory, tactile, visual, olfactory, gustatory) stimuli (APA, 2013). A child diagnosed with ASD may have either language or intellectual impairment or both (APA, 2013). These developmental delays usually appear before the age of 3 and may last a lifetime (Centers for Disease Control and Prevention [CDC], 2019)

No two children with ASD share similar symptoms. The range of symptoms vary in terms of social interaction, communication, sensory stimuli, motor skills, behaviors, and measured intelligence (CDC, 2019). The degree of symptom severity ranges from mild (level 1) to severe (level 3). Unlike DSM-IV, the DSM-V requires clinicians to indicate the level of symptom severity for two core features: “social communication and social interaction (Criterion A) and restrictive, repetitive patterns of behavior, interests, or activities (Criterion B)” (APA, 2013, p. 53). A child with a symptom severity at level 3 indicates that the child requires a “very substantial support” to help the child with ASD navigate for services in various settings (APA, 2013, p. 52)

Worldwide and nationally, there is an increased prevalence of individuals diagnosed with ASD within the last three to four decades (May, Sciberras, Brignell, & Williams, 2017; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). Since 2000, The CDC has been funding the Autism and Developmental Disabilities Monitoring Network (ADDM), a surveillance tracking system (CDC, 2018). In March 2020, the CDC released its 2016 prevalence data on 11 sites across 11 different states selected for active surveillance of children diagnosed with ASD (Maenner et al., 2020). The CDC estimates 1 in 54 8-year-old children in the United States has ASD (Maenner et al., 2020). This translates to a prevalence of 18.3 per 1,000 8-year-old children (Maenner et al., 2020), a 10% increase in prevalence compared to 2014 CDC prevalence data at 16.8 per 1,000 8-year-old children (Baio et al., 2018).

The Problem

Parents spend a significant amount of time navigating a complex, uncoordinated system to obtain educational, medical, and behavioral health services for their children diagnosed with autism spectrum disorder (ASD) (Calleja, Islam, Kingsley, & McDonald, 2019; Lavelle, Weinstein, Newhouse, Munir, Kuhlthau, Prosser, 2014; Rogge & Janssen, 2019). These services serve to help the child improve their ability to function in the community, home, and school (Benevides, Carretta, Ivey, & Lane, 2017). Because of the amount of time and resources spent to coordinate numerous medical appointments and home-based or center-based care, usually one of the parents experiences a loss in income or is unable to work full-time in order to be available to take the child diagnosed with ASD to many scheduled appointments (Saunders, Tilford, Fussell, Schulz, Casey, & Kuo, 2015; Vohra, Madhavan, Sambamoorthi, & Peter, 2014).

Compared to children with other developmental disorders (DD) or mental health conditions (MHCs), caregivers of children with ASD may spend 10 hours or more in coordinating services in the home or center or taking the child to various medical appointments (Vohra et al., 2014). The time required to attend and participate in all applied behavioral analysis (ABA) therapy sessions could be an average of two to six hours daily for three to five days each week (Granpeesheh et al., 2009).

Because parents of ASD children are very focused on doing whatever they can to secure services in place for their child and attend several therapy sessions, these parents have inadequate time to address their mental health. These parents are prone to experience poor psychological well-being and low resilience, resulting in stress and feelings of despair (Desmarais, Barker, & Gouin, 2018; Ooi, Ong, Jacob, & Khan, 2016). While parent support groups give parents a sense of community to share ASD-related concerns, they do not provide cognitive and emotional restructuring therapy which is central to how parents view their children with ASD. The lack of a professional to facilitate these parent support groups may introduce despair and non-acceptance (Da Paz, Siegel, Coccia, & Epel, 2018). Studies have shown that cognitive behavior therapy (CBT) is an effective evidence-based mental health intervention that focuses on changing thoughts, emotions, behaviors which may possibly benefit parents' perception and coping of the child diagnosed with ASD (Clevenger, 2014; Izadi-Mazidi, Riahi, & Khajeddin, 2015).

Having a child with ASD is associated with higher costs than other children without ASD. The higher costs are associated with loss in parents' productivity and frequent use of healthcare services, special education services, respite care, out-of-pocket expenses, and therapy services (speech and language, occupational

therapy, ABA) (Rogge & Jannssen, 2019). In addition, parents' busy schedule in coordinating services and the elevated costs in raising a child with ASD put parents at risk for experiencing financial strain and a poor quality of life (Lavelle et al., 2014; Narula & Srivastava, 2019; Saunders et al., 2015). Due to financial strain and limited personal time, one could assume that these problems deter parents from seeking professional mental health for themselves. When parents' mental health is impaired, this hinders the parent from fully participating in the care of the child diagnosed with ASD (Whitehead, Dorstyn, & Ward; Zablotzky, Anderson, & Law, 2013).

Purpose of the Study

The aim of this study is to understand the mental health experience of parents with children diagnosed with autism spectrum disorder from underserved communities. San Joaquin Valley, California is a predominantly underserved area compared to the rest of the other regions in California. Despite several studies showing the high percentage of unresolved reactions to a child with ASD diagnosis, there are studies that do not acknowledge the high percentage of unresolved parental reactions to ASD diagnosis (Poslawsky et al., 2014). Because there is limited medical and nursing research on effective psychological treatments to improve the well-being of parents with ASD children, this study will provide insights into their mental health and at which point (pre-diagnostic, diagnostic, or post-diagnostic phase) parents begin to experience a high degree of mental health impairment.

The research questions to be explored in the study are as followed:

- What are the mental health issues parents have before, during, and after receiving an ASD diagnosis?

- Which point in the ASD journey do parents find to be most stressful?
- Were parents offered professional mental health interventions during the most stressful point of their journey?

Most of the literature on autism are not representative of the general population. Autism studies have been conducted in predominantly Caucasian families residing in high-income communities in developed countries in Europe or North America (Hoekstra, Fikirt, Bethlehem, & Yenus, 2018). This study will explore the experience of parents who reside in an underserved community in San Joaquin Valley, California where most families are low- or middle-income.

Ambiguous Loss Theory as Conceptual Framework

Definitions

The framework used in the current study is Pauline Boss' Ambiguous Loss Theory (ALT) to understand the mental health experience of parents with ASD children. The ALT can be applied to missing person's body, natural disasters, missing-in-action soldiers, terrorism, war, foster care, incarceration, chronic mental illness, complicated grief, depression, dementia, traumatic brain injury, or Alzheimer's disease (Boss, 2016) (see figure 1). Some parents describe their feelings of loss as they care for their children with ASD. Differentiating between the types of ambiguous loss and the construct of boundary ambiguity is needed to understand how these types of ambiguous loss effect the amount of stress parents experience at pre-diagnostic, diagnostic, and post-diagnostic ASD stages. Ambiguous loss is operationally defined as indeterminant loss that remains unverified and unresolved (Boss, 2016). An example of this type of loss may include the families of the Malaysia Airlines Flight 370 (MH 370); the families of

these passengers who may never know whether some or all 239 passengers died after the plane disappeared on March 8th, 2014. Type 1 is physical ambiguous loss which entails families' discomfort in not knowing whether their individual of interest is alive or deceased (Boss, 2016). While the individual of interest might be physically absent, psychological memories of the individual remains very active in the families' mind (Boss, 2016). Families refer to this Type 1 as "gone, but not for sure" (Boss, 2016, p. 270). In contrast, Type II is psychological ambiguous loss characterized by the individual of interest being physically present but psychologically absent due to illness, cognitive impairment, injury, or other factors (Boss, 2016). Families refer to Type 2 as "here, but not here" (Boss, 2016, p. 270). If the lack of closure and resolution persists, those afflicted by Type 2 would be susceptible to experience high levels of stress, loss, and mental health issues (grief, depression, anxiety) and impair one's ability to care for the affected family member (Gopal & Ting, 2015).

PHYSICAL ABSENCE with Psychological Presence	PSYCHOLOGICAL ABSENCE with Physical Presence
Examples:	Examples:
War, terrorism (missing soldiers, civilians)	Alzheimer's disease or other dementia
Natural disasters (missing persons)	Traumatic brain injury
Kidnapping, hostage taking	Autism
Desertion, disappearance	Coma
Missing body (murder, plane crash, lost at sea)	Chronic mental illness
Incarceration	Addictions: drugs, alcohol, gambling
Immigration, migration, expatriation	Depression
Foster care, adoption	Complicated grief
Divorce	Homesickness (immigration, migration)
Work relocation	Preoccupation with lost person, with work
Military deployment	Obsessions: computer games, Internet
Young adults leaving home	Gender transitioning (also physical absence)
Mate or child moving to care facility	

In addition to the effects of loss on the individual family member, loss could have an impact on the family dynamics. Ambiguous loss is a stressor that could lead to boundary ambiguity (Boss, 2016). Boundary ambiguity occurs when all family members hold incongruent perceptions about ambiguous loss such that there is confusion about family roles and membership because families do not know “who is in or out of the family system” (Boss, 2016, p. 270). There is uncertainty on whether the individual would ever be able to return to the family

system. In the case of a child with ASD, parents wonder if their child will ever get better or should they prepare for a life of stress due to that ambiguity.

The presence and degree of ambiguous loss could impair the parents' ability to cope with ASD diagnosis across the lifespan. Additionally, the presence of ambiguous loss could hinder parents from arriving at informed, shared treatment decisions; seeking mental health treatment for the ASD child in addition to the parent; and maintaining hope for the child's future. A high level of boundary ambiguity could predict risk factors for depression, anxiety, family conflict, individual and family well-being (Boss, 2016) (see figure 2).

FIGURE 2. THE CONTEXTUAL MODEL OF FAMILY STRESS.

Source: Adapted from Boss (2002c).

Figure 2. Ambiguous loss and its relation to the Contextual Model of Family Stress (reprinted with permission from John Wiley and Sons, Inc.)

Premise

The lack of resolution and verification of loss is a feature of ambiguous loss. This makes ambiguous loss the least favorable and most difficult type of loss to cope (Boss, 2016). Because those with ambiguous loss are unable to find closure, they are criticized and stigmatized (Boss, 2016). Furthermore, the caregiver is “left to cope on their own, isolated and trapped between hope and despair, with lingering grief that is often unfairly diagnosed as personal or family pathology” (as cited in Boss, 2016, p. 271).

Assumptions

The Theory of Ambiguous Loss has 10 assumptions (Boss, 2016):

1. The phenomenon of ambiguous loss is immeasurable, yet it does exist.
2. Because one will never attain the truth, one must learn how to live well.
3. Ambiguous loss involves relationships such that there is an unresolved, indeterminant loss to the missing individual.
4. Values and cultural beliefs influence how individuals, families, and communities respond to and perceive ambiguous loss.
5. The source of pathology is contingent on the type of ambiguous loss (Type 1 or Type 2).
6. There is no closure and as a result, loss and grief persist for many years or across generations.
7. Coping begins when the individual is able to identify the stressor as ambiguous loss.
8. Attaining meaning is possible even though the loss may be ambiguous or unclear.

9. Resilience, defined as one's adaptability to loss, has a precise meaning in ambiguous loss. In ambiguous loss, one must tolerate the ongoing presence of ambivalence.
10. As sources of resilience, families both serve as psychological and physical entities.

Significance of the Study

In comparison to parents of other neurodevelopmental disorders, parents with autism spectrum disorder (ASD) children exhibit a high level of stress. Some studies have found that these families report more depressive and anxiety problems to the point where parents experience poor physical and psychological health (Lai et al., 2015). The diagnosis of ASD is not associated with decreased parental health utilization unless the child has severe symptoms of ASD (Lavelle, Weinstein, Newhouse, Munir, Kuhlthau, & Prosser, 2019). Parents who have mental health issues may impair their ability to develop positive coping skills, thereby giving these children with ASD mixed messages or hinder efforts for improvement through early intervention. Furthermore, parents' unresolved mental health issues are associated with increased anxiety which results in a severity of ASD symptoms and behavioral problems in children (Barroso et al., 2017; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Previous research on parents of children with ASD has focused mainly on increasing parent's knowledge about autism and management of behaviors and improving child's language skills (Da Paz & Wallander, 2017).

CHAPTER 2: LITERATURE REVIEW

Raising a child in the United States is not easy, but raising a child diagnosed with autism spectrum disorder (ASD) presents itself with unique psychological experiences for the parent caregiver. There is sufficient evidence to show that parents with children diagnosed with ASD are at increased risk for developing “caregiver stress” or “caregiver syndrome” characterized by exhaustion, guilt, rage, and anger stemming from ongoing delivery of care to the loved one with a lifelong neurodevelopmental disorder (Catalano, Holloway, & Mpofu, 2018). Although the literature does provide various perspectives of parents rearing a child diagnosed with ASD, most of these reports are based on parents’ self-reports. Some studies indicate that parents with a high degree of stress could impede the positive effects of early child intervention while the child is on increased treatment intensity (Osborne, McHugh, Saunders, & Reed, 2008). Because parents play a central role in how a family functions and adapts to having a child with ASD, it is essential to know their mental health experience and make appropriate referrals for intervention. This section will review the literature about parents’ mental health experience with respect to themes about psychological distress versus psychological eustress, mental health in the context of culture, and the positive aspect of having a child diagnosed with ASD.

The search for primary articles was performed using specific databases (CINAHL, PubMed, PsychInfo, ScienceDirect, and Google Scholar). The key words to yield the current articles in the literature review were “autism spectrum disorder,” “ASD,” “developmental disability,” “parents,” “parent caregivers,” “caregiving,” “mental health,” “parent mental health,” “reaction to diagnosis,”

“grief,” “loss,” and “children with autism,” and “stress.” Articles that were within five to six years were reviewed for inclusion in the literature review.

Parents’ Psychological Distress vs. Eustress

Da Paz, Siegel, Coccia, and Epel (2018) conducted a longitudinal study examining three dimensions (self-blame, acceptance, and despair) of maternal psychological adjustment in the presence of their child diagnosed with ASD over an 18-month period. The study hypothesized that the mother’s adaptive adjustment of the child’s ASD diagnosis is a protective factor towards resilience and is associated with positive psychological well-being. A high level of adaptive adjustment indicates the mother accepts the child and shows minimal or low levels of despair and blame towards the child for having ASD. The sample was selected from the Stress, Aging, and Emotions (SAGE) prospective study, and consisted of 92 mothers who raised a child diagnosed with ASD and 93 mothers who raised a neurotypical child. Participants were recruited from a local university autism treatment center, a child development center, and schools using social media, public postings, local parenting publications, and mass mailings. Inclusion criteria included having major depressive disorder or taking antidepressants. Participants were excluded from the study if they were using steroid medications, currently diagnosed with post-traumatic stress disorder, eating disorders, bipolar disorder, or chronic diseases (e.g., cardiovascular, stroke, brain injury, diabetes, endocrine problems, cancer, or autoimmune disorders). Participants completed several questionnaires to measure several outcomes:

- parent’s adjustment to child with ASD
- parent’s perceived severity of child’s ASD symptoms
- caregiving burden, severity of depressive symptoms

- perceived parental stress pertaining to parenting an ASD child
- perceived overall stress
- psychological well-being and acceptance
- relationship satisfaction
- satisfaction with life

Results of the factor analysis indicated a direct relationship between acceptance and the level of ASD symptom severity: the greater the ASD symptom severity, the greater the degree of parent's acceptance of the child with ASD. The study found parents who experienced despair and self-blame from the time of initial ASD diagnosis had increased feelings of caregiver burden, depression, emotional distress, low psychological adjustment, and low levels toward satisfaction with life. A limitation of this study was reliance on parents' self-reported questionnaires, and the sample was not representative of the general population. The mothers in the study were college-educated White mothers with high income. A strength of this study was observation of mother's adaptive adjustment for 18 months and how acceptance towards the ASD diagnosis could have a positive psychological effect, reducing her risk of developing depression, emotional distress, or other poor mental health outcomes.

Fernandez-Alcantara, Garcia-Caro, Perez-Marfil, Hueso-Montoro, Laynez-Rubio, and Cruz-Quintana (2016) designed a qualitative study to explore the feelings of loss and grief in parents with children diagnosed with ASD. Purposive sample was used to recruit five fathers and 15 mothers to participate in semi-structured interviews lasting 45 to 80 minutes in duration. Inclusion criteria consist of being a parent to a child aged 3 years or older who had a DSM-V diagnosis of ASD. Participants were excluded from participating in the study if their child had another developmental disorder in addition to ASD. Example of another

developmental disorder would be social communication disorder. The study looked at 22 ASD children between the age of 3 and 18 years. Parents described their initial reaction to the diagnosis of ASD as highly emotional, characterizing their feelings as “unexpected child loss” and parents’ inability to accept the ASD diagnosis (p. 316). After obtaining the ASD diagnosis or hearing the word “autism,” the study found that parents reported ongoing cyclical changes in their emotions with moments of happiness and acceptance interspersed with distress and sorrow. A limitation to this study was there was no mention of whether all the children share similar level of ASD symptom severity or social-communication deficits. Furthermore, most of the parents in the study had ASD children younger than 12 years of age. This study demonstrates its strength in being the first study to formulate a theoretical model based on the analysis of parental feelings of loss and grief in parents of child diagnosed with ASD.

Although most of the literature reports parents having grief and loss as a result of raising a child, there is an unclear understanding between grief and distress. Wayment and Brookshire (2018) conducted an exploratory study on 362 mothers to examine the predictors of grief and distress in the context of a child having an ASD diagnosis. The study was done on mothers because mothers experience more stress from their role as a caregiver and are more likely to display depression and grief in response to addressing the challenges of having an ASD child. The study found grief was associated with “perceiving ASD as a loss and as unjust” and “distress was positively associated with previous mental health issues, mothers’ reports of their child’s aggressive behavior, and identity ambiguity” (p. 1153). Results of the study indicate mothers who have a positive cognition of their children as evidenced by “not perceiving their child’s diagnosis as a loss, or as unfair, or their fault were less likely to report feeling grief” (p. 1153). A limitation

to this study was the sample was predominantly White educated mothers with an average household income of \$101,364.

Parental Experience with Respect to Culture

There is a cultural aspect of ASD showing there are disparities in getting diagnosis, referrals, and early intervention, and center-based or home-based therapy for some racial groups which add stress for caregivers. Dababnah, Shaia, Campion, and Nichols (2018) conducted a qualitative study in an urban area in Baltimore, Maryland using the Public Health Critical Race Framework to understand the Black/African American caregiver's experience in obtaining diagnosis and receiving referrals from their primary care provider. The authors performed semi-structured interviews on 22 caregivers (18 mothers, 4 female caregivers). The study found many providers were inattentive to caregivers' suspicion that the child might have ASD. The providers were likely to provide an ASD diagnosis later or deliver a misdiagnosis to Black caregivers. Hence, not receiving a timely diagnosis for ASD or receiving a misdiagnosis contribute to children's delay in receiving early child intervention services. A strength in this study was it provides insight to Black caregivers who felt racial bias from their providers. Regardless of level of education (high school to graduate degree), these parents had to repeatedly ask their providers for the ASD diagnosis. Additionally, the caregivers deterred themselves from seeking referrals for ASD intervention services due to cultural stigma (shame and denial). A limitation to this study was it only sampled mothers from an urban part of Baltimore.

Zuckerman et al. (2014) qualitative study looked at individual, family, and system barriers to obtaining an ASD diagnosis in Latino children. One of the themes they have identified is the poor understanding Latino parents have about

ASD. A parent in the study reported that autism is non-existent in Mexico. Because it is not formally recognized in Mexico, there is a lack of understanding about the disorder. Furthermore, the study shows many Latinos have shame and embarrassment for having a child with a disability. The stigma associated with a child with a disability hinders Mexican parents from comfortably admitting and accepting the child's behavior. Another highlight to the study is the concept of *machismo*. *Machismo* is a concept that uniquely defines the Latino male as one that serves to protect, provide, and defend the family. The mothers in the study reported that the fathers' view of *machismo* impedes mothers from seeking help. Fathers were often discrediting the mothers' concerns. The fathers want to hold the view of a strong man that protects and defends his family but having a disabled child indicates the father is "weak." A limitation to this study was the use of retrospective data and the experience of Latino parents may not be a true representation of the Latino population in the United States. This study demonstrates the challenges Latino parents face in getting an ASD diagnosis and the importance of detecting ASD early through screening at every well child visit. Most importantly, parents need assistance to navigate the system to obtain the diagnosis and get referral for services, but they cannot get assistance without support from community members and providers who understand that many Latino parents do not have accessible information about ASD.

Positive Aspects of the ASD Experience

On the contrary, few research studies highlight the parental experience as one that is not entirely negative. Whitehead, Dorstyn, and Ward (2015) explored levels of female caregivers' distress, families' resilience, and the accessibility of individual and community resources for caregiver's psychological adjustment in

the context of a child with ASD. The sample consisted of mostly 438 female participants completing a nationwide survey. Inclusion criteria were caregivers with ASD children aged 0 to 18. The study used the following scales: depression, anxiety, and stress (DASS); individual resilience; developmental behaviors; perceptions toward internal locus control versus external locus control; individual coping skills; degree of community social support; and obstacles to receiving services. Limitation of the study includes the presence of recall and selection biases and the use of self-reported surveys. The authors had a strong bias towards including only female caregivers. The findings of this study demonstrate how avoidant coping strategies (denial, self-blame, emotional venting, and disengagement) contribute to caregiver's stress, anxiety, and depression but the presence of action-oriented coping strategies (acceptance, planning, and positive reframing) contribute to the caregiver's resilience.

Despite the challenges to manage a child with neurodevelopmental disabilities, parents eventually develop a sense of psychological adaptation to work with their unique parenting difficulties. Waizbard-Bartov, Yehonatan-Schori, & Golan's (2019) qualitative study used a semi-structured interview to examine the Israeli parental experience in rearing a child diagnosed with ASD. The initial stages of rearing a child diagnosed with ASD is challenging and in some instances, interspersed with traumatic elements. Despite this unfavorable experience, parents of children diagnosed with ASD do see the positive aspects of having a child with ASD. The study found four growth themes: parents reported having a positive transformation marked by personal strength and empowerment, enhanced spiritual-emotional experience, improved interpersonal experience, and increased political and professional involvement. A limitation to this study is the parents who participated in the study came from middle- to high-income families in Israel.

Gaps in the Literature

Most studies on parent caregivers' experience are predominantly based on Western culture. Participants in several ASD studies have been predominantly middle-class or affluent, educated, Caucasian mothers in resourced communities. Few of these studies have integrated the experience of African American/Black, Hispanic/Latinx, Asian American, or Native American parent caregivers. For many of these ASD studies, Caucasian mothers provided insights about their experience through self-reports. Parents' self-reports have been largely described as negative experiences using words such as "stressful," "challenging" and "emotionally strenuous" (Lushin & O'Brien, 2016). Several of these studies focus primarily on understanding the parent's stress but few examine the current mental health experience.

Several of these qualitative studies recruit parents with ASD children but do not specify the level of ASD support for the child. Because of the heterogeneity of ASD symptoms, it is essential to report the level of severity so that supports and services could be in place to help the child with ASD needs. For example, an ASD child with a level 3 support indicates the child requires "very substantial support" compared to an ASD child with a level 1 support which indicates the child requires "support" (American Psychiatric Association [APA], 2013).

The relationship between parental stress and child's ASD symptom severity is poorly understood. A child with severe ASD symptoms does not necessarily result in parents having poor mental health. Da Paz et al. (2018) study indicates that there is no direct relationship between level of ASD symptom severity and poor maternal psychological adjustment. When it becomes very apparent that the child's ASD symptoms are severe, parents cannot deny the ASD (Da Paz et al.,

2018). Parents have no other choice but accept the child with severe ASD (Da Paz et al., 2018).

The diagnostic experience of parents who have received the ASD diagnosis for their children is difficult, confusing, and stressful. As of writing this manuscript, the author consulted with Dr. Pauline Boss and did a literature search. No studies have used ambiguous loss as an identified stressor contributing to the parent's mental health experience before, during, and after obtaining the diagnosis for ASD.

Summary

Autism spectrum disorder (ASD) is a complex and lifelong disorder. Because no two ASD children are the same, each parent may not have experiences similar to what is found in the literature. The literature primarily finds that many of these parental self-reports come from middle-income to high-income Caucasian mothers in urban communities who generally describe their experience as negative. Although there is a consensus that parenting a child diagnosed with ASD is more stressful than parenting neurotypical children and children of other disabilities, the psychological state of parents prior, throughout, and after the diagnostic journey is poorly understood. Because the diagnostic journey is uncoordinated and chaotic, it is expected that parents will experience some degree of stress.

The incidence and prevalence of ASD in San Joaquin Valley is likely to increase. The exact prevalence rate is unknown. Based on services and expenditures for 2018-2019, San Joaquin Valley, which is commonly referred as Central Valley, spent \$15,473,317 on 4,130 clients diagnosed with autism (Central Valley Regional Center [CVRC], n. d.). It is important to understand the mental

health experience of parents before, during, and after obtaining the diagnosis and whether professional mental health is offered. This knowledge about the parents' mental health experience can help researchers identify effective psychological interventions to improve parent caregivers' experiences in rearing children with ASD.

CHAPTER 3: METHODS

The purpose of the study was to understand the mental health experience of parent caregiver before, during, and after receiving an ASD diagnosis; determine which critical point in the ASD journey does the parent caregiver experience psychological stressor(s); and identify any evidence of professional mental health support and intervention offered to parent caregivers of ASD children. A qualitative study based on a phenomenological approach was selected to allow the author to focus on the lived experiences of these caregivers and identify common characteristics they all share using a small sample. Morse (1994) noted six participants is the average size for a phenomenological study (as cited in Powers, 2015). Furthermore, a qualitative study is appropriate in uncovering new knowledge about the mental health of parents with ASD children. A grounded theory was not utilized because its purpose is “to generate theory about how people deal with life situations that is grounded in empirical data and that describes the processes by which they move through experiences over time” (Powers, 2015, p. 144).

Setting

A small private pediatric office in Reedley, California was used for the in-person, virtual, or phone interviews.

Participants

Population and Sample

A convenience sample of eight parent caregivers participated in the study. Study inclusion criteria were the single or married biological parent(s) must reside in San Joaquin Valley which is part of Central Valley. San Joaquin Valley consists

of mainly rural communities and eight counties of Central Valley, California. The eight counties are Kern, Merced, San Joaquin, Fresno, Kings, Stanislaus, and parts of Tulare and Madera counties. The parent(s) must have a child medically diagnosed with ASD for at least six months. One or both parents might be unemployed or employed part-time or full-time. The parent caregiver could be Hispanic, Latinx, Caucasian/White, Asian American, African American/Black, or Native American. Each parent was able to read and understand conversational English. Exclusion criteria were having another developmental delay, speech delay, social communication disorder, or any major medical condition as a diagnosis. Parents came from diverse communities in San Joaquin Valley, California with some residing in small agricultural towns.

Procedures

Recruitment

After obtaining approval from Fresno State IRB on September 8, 2019 (see Appendix G), the author recruited parent caregivers through a posting of a recruitment flyer (see Appendix C) on various online autism support groups not limited to Fresno Autism Network, Central Valley ASD Mamas Support Group, Autism Speaks, Autism Society, and Families for Early Autism Treatment on social media platforms (Twitter and Facebook). Recruitment flyers were shared with the San Joaquin Valley Neurodevelopmental Collaborative, occupational therapy clinics, speech therapy clinics at schools or independent offices, applied behavior analysis vendors, local colleges, and Family Resource Centers. Parent caregivers were given an opportunity to review the informed consent form (see Appendix F). After they provided their signed informed consent form, the author invites the parent caregivers to participate in the semi-structured interview via

phone, Zoom, or in person at the pediatric office in Reedley, California. Informational flyers about the study were placed at the pediatric office in Reedley, California. A copy of the flyer was given to the Director of Communication Sciences and Deaf Studies who approved the content on the flyer and agreed to post the flyer at the Fresno State Speech, Language, and Hearing Clinic.

Techniques

For this study exploring the mental health experience of parent caregivers, the author received permission from Dr. Pauline Boss, Professor Emeritus of the University of Minnesota, to use and adapt her questions on ambiguous loss for the current study. The author formulated questions for the semi-structured interview based on the literature and input from DNP project committee (see Appendix E). The interview lasted between 60 and 90 minutes. Demographic data was collected at the start of the semi-structured interview (see Appendix D). The semi-structured interview gave the author the structure and control while maintaining a dialogue with the participants (Powers, 2015). A semi-structured interview provided some flexibility and offered a comprehensive approach to data collection (Powers, 2015).

Data Collection

The data from semi-structured interviews were collected from September 18, 2019 to March 1, 2020. The author did minimal notetaking while recording or audiotaping the interview. Recorded interviews were transcribed within 72 hours.

Data Analysis Plan

Because this is a qualitative study using semi-structured interviews, a thematic analysis would be an appropriate approach to identify themes shared

among parent caregivers of ASD children. The Braun and Clarke's (2006) six-phase framework for thematic analysis was utilized. The first step in analysis of the raw data was to transcribe the recorded interview using a conventional approach. The transcribed data was checked twice against the recorded interview for accurate transcription. After transcribing the data, the author read each transcript. The first reading of the transcript was a quick read like reading a novel. The second time the author read the transcript carefully, using an inductive approach to highlight key words that described the participant's mental health experience.

A grid with three columns was created. The first column was raw data, second column was preliminary codes, and the third column was the final code. The data was assigned preliminary codes in order to describe content. Coding is a vital way to put meaning to the data by organizing the codes into concepts. After coding was complete, the author looked for themes across different interviews. Themes were reviewed and then defined. A thematic analysis was performed across different interviews.

Ethical Consideration (Human Subject Protections). If participants experienced any psychological distress during the semi-structured interview, participants were allowed to withdraw from the study. Participants would be referred to a psychiatric nurse practitioner at the pediatric clinic or the Substance Abuse and Mental Health Services Administration (SAMHSA) national helpline at 1-800-662-4357. This national hotline is free and confidential, operating 24/7. The SAMHSA did not provide counseling but would connect participants to local facilities that could provide local mental health support. There was no social, physical, economic, or legal risks as a result of participating in the study.

Confidentiality. At the start of the study, all participants signed an informed consent form acknowledging potential risks and benefits of the study and that all interviews were recorded for transcription. Participants' privacy and confidentiality were maintained at all times. The interview was conducted with the parent caregiver and author in the room, on Zoom, or via phone. No personal health identifiers (date of birth, full name, address, etc.) were collected from the participants, and no actual identity were used in the recorded interview or transcription. The author's laptop computer was used to record the interviews. Audio recordings, transcribed interviews, and study materials would all be stored password-protected in the Fresno State Box (<https://fresnostate.account.box.com/login>). The Fresno State Box is similar to DropBox. Study materials and data would be deleted from Box one year after IRB approval.

Bias. Bias affects the validity and reliability of qualitative research. To reduce investigator bias, the author refrains from giving opinions and remain neutral in dress, body language and tone of voice. The order of the semi-interviewed questions could introduce bias. Minimizing question order bias is achieved by asking general questions before specific questions, positive questions before negative questions, unaided questions before aided questions, and behavior questions before attitude questions.

Summary

This study used semi-structured interviews to gather information about the mental health experiences of eight parent caregivers of children with ASD using a phenomenological approach. The study identified the need to recognize the mental health experience of parent caregivers as they undergo critical points (before,

during, or after obtaining an ASD diagnosis) when parent caregivers report experiencing varying degree of stress.

This high degree of stress impairs their ability to provide care or blocking parents' ability to cope effectively. A thematic analysis was used to help the author identify common experiences shared among parent caregivers. The next section lists themes commonly found across the interviews.

CHAPTER 4: RESULTS AND DISCUSSION

Table 1 represents demographic data about the parent participants enrolled in the qualitative study. Sixty-three percent of the parents identified themselves as Caucasians and 37% identified themselves as Asians. None of the parents reported their ethnic groups; however, during the semi-structured interview, two Asian American parent (a mother and father) participants voluntarily reported that they associated themselves as Chinese Americans and another Asian American mother described about the rituals pertaining to her Hmong culture. In terms of education, mothers and fathers comprised 63% and 37% of the total sample, respectively. While participants ranged in educational levels, the predominant educational level attained was a bachelor's degree at 50%. Three-quarters of the participants were female parent caregivers and one-quarter of the participants were male parent caregivers. Among the eight parent caregivers, 63% were employed while the other 37% were unemployed. Among the employed parent caregivers, 80% worked full-time and 20% of the working parents worked part-time. Fifty percent of the parents were mothers who worked full-time while their spouses remained in the home as a stay-at-home father. The other 50% of employed parents comprised of a father working full-time while the mother chose to work part-time in order to take the child to various therapy sessions and healthcare visits. Fifty percent of the parent participants were in the age range of 30 to 39 and the other fifty percent were in the age range of 40 to 49.

Table 1.
Parent Caregiver Demographics

Variable	n	(%)
Gender of Caregiver		

Male	2	25%
Female	6	75%
Race		
Asian	3	37%
African American/Black	0	0%
Hispanic/Latinx	0	0%
Native American	0	0%
Caucasian/White	5	63%
Other/Mixed	0	
Highest Level of Education		
Some associate-level education (no degree)	1	12.5%
Associate degree	1	12.5%
Bachelor's degree	4	50%
Master's degree	1	12.5%
Doctorate degree	1	12.5%
Employment		
Yes	5	63%
No	3	37%
Work Status		
Full-time	4	80%
Part-time	1	20%
Marital Status		
Single	0	0%
Married	8	100%
Divorced	0	0%
Separated	0	0%
Co-habitated	0	0%
Age Range		
18-19	0	0%
20-39	4	50%
40-49	4	50%
50-59	0	0%
60-69	0	0%

Conventional approach to thematic content analysis revealed four themes: mixed emotion, growth, uncomfortable, and helpless. Table 2 shows the frequent subthemes found under each theme.

Table 2.
Themes and Sub-themes

Mixed Emotions

Sad and relief

Shock and anxiety

Numb and disappointed

Denial and surprised

Anger and self-blame

Uncomfortable

Lack of transparency

Unpredictability

Self-sacrifice

Helpless

Intrusive

Change in “Oregon Trail”

Growth

Advocacy

Education

Compassion

Empathy

Patience

Love

This study is different from other studies. The national characteristics of parents with children diagnosed with autism spectrum disorder (ASD) come primarily from urban communities. For instance, the Autism and Developmental Disabilities Monitoring (ADDM) Network selects 11 sites from different states based on accessibility to educational or medical records. No site from the westernmost region (California, Oregon, Washington, Nevada) was part of the latest Centers for Disease Control (CDC) and Prevention prevalence report which primarily focused on 2016 data from urban communities. Data reported on each state is not representative of the entire state's ASD population (CDC, 2020).

Parents residing in urban communities face more stressors than parents in rural and underserved communities. Little do we know what the lived experience of parents is residing in rural and underserved communities. The current study called for an exploration of the mental health experience of parents with children in San Joaquin Valley, California. San Joaquin Valley has a long history in Central Valley, California as being a region consistently faced with persistent poverty throughout California (Sierra Health Foundation, W. K. Kellogg Foundation, & University of California, Davis Center for Regional Change, 2017). One-third of the children under 18 in the San Joaquin Valley live in locations where one-third

of its residents live in poverty, a proportion that is two times higher than the state (Sierra Health Foundation et al., 2017).

The conventional, inductive approach to thematic analysis identified four themes and 16 sub-themes. The major themes were mixed emotions, uncomfortable, helpless, and growth. All parent caregivers in the study had two children and among those who had two children, five of the parent caregivers reported have both children diagnosed with ASD. Despite having both children on the spectrum, the parent caregivers in the study found one of the two children being less severe than the other child with ASD. Among the eight parents, three parents had fraternal twins. For the three parents with fraternal twins, two parents reported the girl being less severe than the son and the other reported that one of the two fraternal twins were diagnosed with ASD requiring very substantial support. Consistent with the literature, ASD symptoms in boys are apparent and boys are four times likely to be identified with autism than girls (Maenner et al., 2020) The ASD symptoms in girls are not as easily identifiable as boys; girls' symptoms are masked (Milner, McIntosh, Colvert, & Happe, 2019).

Theme 1: Mixed Emotions

This theme captures the conflicting emotions the parent caregivers have throughout the ASD journey. Some of the frequent subthemes were “sad and relief,” “shock and anxiety,” “numb and disappointed,” and “denial and surprised.” Fifty percent of the parents described feeling “sad and relief” of having a child with ASD. The feeling of “sad and relief” occurred at the time of the diagnosis when either a school official or the provider delivers the news that the parent’s first-born child has severe autism. Eighty-eight percent of the parents in the study received the diagnosis of ASD either through the school or Central

Valley Regional Center (CVRC). This is consistent with what is commonly reported about the diagnostic process and outcome as one that is very unpleasant, incohesive, uncoordinated, and chaotic (Oswald, Haworth, Mackenzie, & Willis, 2017). The lengthy and unclear process of what to expect during the diagnostic process, the poor communication from providers, the lack of information on ASD from provider, and provider's disregard for parental concerns about the child's delayed development add to the parent's frustration and stress (Oswald et al., 2017). This aligns with the current problems with the diagnostic process where many providers did not acknowledge the parents' initial concern of the child's developmental delay but refer the parent to the school district for a disability diagnosis of ASD under the Individuals with Disabilities (IDEA) Act (Oswald et al., 2017).

An Asian American mother reported about how the Asian American community is not kind to those who have children with disabilities. She discussed how in her culture, "if a child is delayed, it's like a burden on the parents or looked down upon." This supports the general agreement about Asian American community feeling shameful about having a child with a disability and less reluctant to receive help from the community (Zhou, Wang, & Yi, 2018).

A Caucasian mother shared her experience in how the school district did not provide any mental health support for her. She described her son as a child performing well in a general education curriculum but demonstrating "moderate to slightly less than high functioning with all social stuff." The mother described her feeling as a "mixture of relief and also, like, sadness" but no appropriate supports were in place at the time of the school's diagnosis. In the words of the Caucasian mother, she reported her experience:

The school district didn't even offer, like, mental health support for you because for some parents they are in shock, but they're in a state of "Where do I go?" There was no person there at the moment. They need to orient you that it is not that bad. There is still life after autism. I do appreciate the opportunity to pre-read it, but I feel like news like that should be delivered in person and maybe go over the report together, which we did. That would be the part I would recommend they probably do a better job because that can be quite a shock when you're reading about all these, you know, findings and IQ scores, which are ridiculous to test on the spectrum for IQ. Once we had the meeting, I asked them how do we get a medical diagnosis. Because I didn't know and they gave me a CVRC brochure but that was the extent of help I received. The struggle to get the diagnosis and services have an impact on the parents' mental health. It's like when you finally do realize years later what you could have been doing and that gap, you beat yourself up because you think you failed your child.

For the Asian American mother, she recognized the early evidence of her first child having developmental delays. She described receiving the official diagnosis of ASD had her in tears and made her blame herself:

I should have eaten my multivitamin pill every day. I should have gotten the flu shot. What did I eat to cause my daughter to have autism? I should have gone to the doctor sooner because my water was leaking at 3, 4, or 5 am in the morning and we didn't have a car seat and husband had to make sure he buy one and I had to pack to prepare for the delivery. Was it where I worked it had asbestos or that the way to work had lots of orchards and pesticides is what I inhaled that caused her to be like this?

Theme 2: Uncomfortable

This theme consists of three subthemes: lack of transparency, unpredictability, and self-sacrifice. The three subthemes were reported in 88% of the parent caregivers. Consistent with the literature, the parents in the study reported some degree of stress but did not characterize the experience of having a child with ASD as negative. One Caucasian mother described the lack of transparency between her and her mother:

I think the roles have changed like for a while with my mom. My mom is a retired speech language pathologist, and she never picked up any signs. I think it definitely shifted my relationship with my mom. I don't believe that she was transparent as she should have been when she said 'I know the future for those kids' turns out it is a very ignorant and narrow view. This is her grandson, not her patient. She definitely put him through the lens of autism.

Depending on the level of ASD severity, ASD comes with some degree of unpredictability. A Caucasian father stated:

People like predictability, like working from 9 am to 5 pm job here. Being unpredictable is scary for many people. Autism is a big bowl of unpredictability. Every day I experience fluctuation of my emotions. Your whole mind changes and you're switching into this mode of fight or flight. The next thing you're running down in the middle of the street running after your baby. It's a wonderful challenge, but also very exhausting.

All of the parents stated many self-sacrifices were made to adapt to life with a child diagnosed with ASD. Three of the parents did not work in order to commit to provide ongoing care in the home and attending the numerous therapies the child with ASD has. One Caucasian father reported, "Since when I was 14

years old, I had a full-time job. With two kids on the spectrum, we had to make a difficult decision. My wife was more financially stable, so we agreed to let me stay home. It was normal reaction to my pride.”

Theme 3: Helpless

Sixty-three percent of the parents reported having some degree of feeling helpless. The parent caregivers described feeling overwhelmed and helpless in response to working with the challenges the young child with ASD has. All the parent caregivers in the study reported how crucial it was for parents to have a good social support. A Caucasian mother described the importance of having a good support in place:

My husband is very involved and supportive, so we share the responsibility of caring for our twin boys. Family support is essential. I would be a wreck if my husband wasn't available or willing to help with the day to day work of having a special needs child. I rely on his support and he relies on mine. We support each other emotionally on the really tough days. We have come together as a team to bring in money to pay for the therapies he is receiving.

A particular subtheme that was not mentioned in the literature but found in the study was feeling intrusive. One Caucasian mother described how she felt intrusive and the lack of control over her environment with regards to the ongoing therapies that occurred in the home.

Starting ABA and speech therapy has put our family under the microscope, which has been unnerving. We have had to fill out multiple assessment forms and always have several people in our home to work with our son. It feels intrusive and unwelcome sometime. The people who come into our home for ABA therapy have never once asked how I am handling all this.

They come straight in and start therapy. The supervisors of the ABA therapy company drop in unannounced. The supervisor gives us parent training and she is not a parent herself. There is a mountain of small frustrations that have collected over time. Sometimes I'm happy for the help, other times I just want to kick them all out of my house and lock the door.

An Asian American mother reported feeling helpless on some days when she went to the bathroom and cried when days were very difficult. She would never cry in front of her children and family members. She was also the one who reported the most patience with her two sons with varying degree of ASD symptoms. This mother stated "I owe debt to my boys in the past life so now I have to pay back the debt. It is my duty to take care of them." Instead of seeing her two children as a burden to her and her family, the Asian American mother found a meaningful purpose and her responsibility to provide dignified care to her two sons diagnosed with ASD.

One father reported that it surprised him that his very verbal daughter has ASD. In the current study, three parents stated their sons having more severe symptoms than their girls. One of the Caucasian fathers identified himself as a primary caregiver whereas most caregivers in the literature identified mothers as the primary caregiver with increased levels of stress (Frye, 2016). Because most of the resources mainly target mothers, the father described his experience as:

The support for ASD stay-at-home dads is non-existent. I can't ask, like, questions. I have no guidance on what I am doing to raise a child with ASD is correct. Is this what it is supposed to look like? I'm a big guy weighing 170 lbs. To some people, I look intimidating, so that didn't work in my favor. When I go out in public and my son jumps up and down, no one

wants to confront with me and ask me whether I need help. It's been really difficult.

Theme 4: Growth

Regardless of how challenging the experience in raising a child with ASD, all parents agreed the experience is not completely a negative or painful experience. Common subthemes noted during the review of the transcription across all parents' interviews include advocacy, education, compassion, empathy, patience, and love. This is consistent with Waizbard-Bartov et al. (2019) that in spite of all the hardships parents endure, parents experience a period of growth in spirituality, increased personal strength, improved interpersonal relationships with spouses, children, friends, and increased growth in knowledge and advocacy in helping the ASD community. In relation to the current study, parents in underserved communities in San Joaquin Valley can experience growth and the positive aspects of having an ASD child.

One Caucasian mother reported her experience in advocating for others to understand the characteristics of ASD such that not all ASD children fit the description of a child with severe ASD. The mother stated:

How many times do I have to tell a teacher to understand that is the other side of autism and not everyone has that severe features that we hear, pick up, and associate with a negative experience. If you have the right support in place, it's a very doable, wonderful child." This statement was coded as "advocacy" and "love" because the mother described her ongoing efforts to advocate for her son while maintaining her unconditional love to support him.

The distribution of services between child and adults diagnosed with ASD are unequal. The current care for services and research for those with ASD is too focused on children (Shattuck, Roux, Hudson, Taylor, Maenner, & Trani, 2012). Because there were many services for the parent caregivers to attend, 75% of the parents in the study reported having mental health problems and that mental health support should be offered during this stressful journey. It is important to note that all parents reported some degree of ambiguous loss in having a child with ASD throughout their journey.

There is no particular point that is more stressful than other points of the journey. Twelve percent of the parent caregivers felt stressed before the diagnosis. A mother reported trying to get her child's pediatrician to acknowledge the developmental delay but eventually the provider dismissed the mother's concerns adding to her frustration. While 50% of the parent caregivers reported having feelings of "sad and relief" for having at the time of diagnosis, parents expressed the need to have a mental health professional present at the time of the diagnosis to help parents sort through their emotional reaction.

None of the studies on parents' perspectives on raising a child with ASD revealed professional mental health support was offered to the parents. The research indicates a greater emphasis on getting parents involved in the child's treatment, but few studies investigate on how to deliver effective mental health support to all parents of children with ASD (Bradshaw, Koegel, & Koegel, 2017). The current study reveals no mental health was provided to parents to overcome the ambiguous loss they experience throughout their ASD journey. No providers are able to identify the parent caregiver's stressor as ambiguous loss. While all the parents in the study might not experience the same degree of ambiguous loss at the time of the diagnosis, this study highlights the need to for providers to recognize

the parent caregivers' experience as ambiguous loss early in the ASD journey. By helping parents be aware that they may never know the trajectory of the child, this creates opportunities for mental health professionals to identify the stressor and allow other professionals to work with parents to process their mixed emotions. It is through this gradual process of working with the parents to process all these emotions (anger, shame, disappointment, depression, anxiety, grief, despair) while they accept that they will need to learn how to accept the ambiguous loss. Like the stages of grieving, parents of children with autism need time for professionals to work with them to accept the ambiguous loss in having a child with ASD and that is it not a personal tragedy. For all parent caregivers in the study, having a child with ASD brought challenges but it also helped parents grow and seek positive meanings in having a child with ASD.

There are inconclusive results on the effectiveness of mental health interventions for parent caregivers as many of these mental health interventions for parents of children with ASD are still in their infancy stage (Kuhanek, Madonna, Novak, & Pearson, 2015). While there is promise in using acceptance and commitment therapy (ACT) and mindfulness-based interventions, these studies on mental health interventions rely on self-reports and lack a randomized control trial design and a heterogeneous sample (Lunsky, Fung, Lake, Steel, & Bryce, 2018). Identifying standardized guidelines and utilizing evidence-based interventions for mental health are important because they would promote the delivery of cost-effective services to parents who need assistance. The lack of replication on mental health interventions for parents makes it difficult to know which intervention is effective and at which stage (pre-diagnostic, diagnostic, or post-diagnostic) does the parents experience a high level of ambiguous loss.

CHAPTER 5: CONCLUSION

All parents in underserved communities in San Joaquin Valley did not characterize their experience rearing a child diagnosed with autism as a personal tragedy. Historically, parents described their experience with children diagnosed with autism spectrum disorder as stressful, isolated, disappointing, depressing, and overall, least desirable (Zablotsky et al., 2013). However, in the current study, the questions assess for ambiguous loss with respect to role, ritual, or family ambiguity. Regardless of the child's ASD symptom severity, the parents' responses to the semi-structured interview questions indicate there was some degree of ambiguous loss. There is (psychological) ambiguous loss to having a child with ASD. For instance, the effect of ambiguous loss means the parents will never get the answers due to the ambiguity of ASD. Parents will never have an answer to whether the child will get worse. The prognosis for children with ASD is unknown with response to therapy. To cope with ASD as an ambiguous loss, parents must learn to live their life by accepting the ongoing unresolved loss of having a child with ASD. Because ambiguous loss is traumatic (Boss, 2009) for parents who have a physically abled child with mental and cognitive impairment, parents do grieve. Whether before, during, or after the ASD diagnosis, the parents in the present study found the journey to be challenging. Despite the challenges surrounding the ambiguity in raising a child diagnosed with ASD, parent caregivers did view this journey before, during, and after the diagnosis as one of continuous growth.

Consistent with the literature, parents of children with ASD are prone to poor mental health outcomes than parents of neurotypical children or parents of other developmental disabilities (Zablotsky, Bradshaw, & Stuart, 2013). Because

there is no closure to the grief of having a child that is mentally absent but physically present (psychological ambiguous loss), the only way for parents to cope with this type of loss is to be able to recognize this loss as a stressor and work with professionals to cope and tolerate the ambiguity. If parents do not cope with the ambiguous loss, this will lead to conflicts (divorce, separation), mistrust of professionals, poor mental health (depression, anxiety, despair, anger, denial, grief), and withdrawal from celebration (Boss, 2009; Boss, 2016).

All parent caregivers in the current study want professional mental health support. Some of the parent caregivers in the study reported having a professional mental health readily available at the point when parents experience the most stressful point of the journey would be appropriate. However, there is a lack of acknowledgment from educators, therapists, and health services providers to recognize that parents are prone to poor mental health as a result of not being able to tolerate the ambiguity surrounding what life would be like having a child with ASD.

Limitations

The current study has several limitations. There was a concern among parents' perception of the inclusion criteria. On September 6, 2019, the author posted the recruitment flyer on various online autism support groups not limited to Fresno Autism Network, Central Valley ASD Mamas Support Group, Autism Speaks, Autism Society, and Families for Early Autism Treatment on social media platforms (Twitter and Facebook). Mothers from Central Valley ASD Mamas Support Group on Facebook responded to the author's post that they disagreed with the study's exclusion criteria. The exclusion criteria applied to parents who have a child with a developmental delay, communication disorder, or speech delay

diagnosis. Parents on the thread provided disrespectful statements to other parents advising them to not participate in the study because they strongly felt all children with ASD have a speech and language disorder, multiple co-morbid mental and physical problems,

Co-morbidities occur with individuals diagnosed with ASD. The *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (DSM-5) notes one co-morbid mental health disorder occurs in 70% of all ASD individuals and two or more co-morbid health disorders occur in 40% of all ASD individuals (American Psychiatric Association [APA], 2013). The author understands the conditions that co-exist with individuals diagnosed. Not all children with ASD have a speech impairment or language impairment and this has been noted as one of the specifiers in the DSM-5 (APA, 2013). Although presence of another genetic (Down syndrome, Rett syndrome, fragile X), neurodevelopmental (attention-deficit hyperactivity disorder, cerebral palsy, intellectual disability, learning disability), or mental or behavioral (anxiety, depressive disorders, conduct disorders, bipolar disorder, sleep disorder, tics), not all individuals have these conditions (APA, 2013). In the case of a major medication condition, the author wanted to exclude children who have cancer, diabetes, traumatic brain injuries, or other chronic conditions. The presence of diabetes is a stressor to the parent and the author would have no way of knowing whether the parent's mental health experience is due to the diabetes or ASD.

Parents who have children with speech delay were excluded. The author was particular in excluding apraxia. Children with apraxia understand speech command but they are unable to get their brain to execute the sound. It is a challenge to pinpoint whether the apraxia is due to a brain injury, congenital defect, or brain lesion (American Speech-Language-Hearing Association, 2015).

Some parents from Central Valley ASD Mamas Support Group were unhappy when they saw presence of a language disorder as an exclusion criterion. The DSM-5 states:

In some forms of language disorder, there may be problems of communication and some secondary difficulties. However, specific language disorder is not associated with abnormal nonverbal communication, nor with the presence of restricted, repetitive patterns of behavior, interests, or activities. (p. 58)

Autism is a spectrum of disorders. Not all nonverbal autistic children have a language disorder. There were some parents who strongly disagreed with the author for excluding language disorder in children diagnosed with ASD. The author replied to all parents that the exclusion depends on what is the child's diagnosis and that parents were advised to directly contact the author if the parent needed clarifications. Parents with ASD children who have a communication disorder such as speech sound disorder (phonological disorder), social (pragmatic) communication disorder, or childhood-onset fluency disorder (stuttering) are excluded from the study. A child diagnosed with social communication pragmatic disorder lacks the repetitive, restricted activities, interests, or stereotypy frequently seen in children diagnosed with ASD (APA, 2013). To help parents overcome confusion about the exclusion criteria, the flyer received IRB amendment to include the word "another" so that it read "the child must not have another developmental delay, communication disorder, or speech delay diagnosis."

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The small sample size of eight parents may not be representative of all the mothers and fathers of San Joaquin Valley, California. Consistent with many studies on parent caregivers of children with ASD, many of the parent caregivers in the current study were Caucasian parents, predominantly mothers. There were a few Asian American parent caregivers. Historically, recruitment of Asian American parent caregivers to participate in research studies is a challenge. However, due to the author being Asian American, this could have made the Asian American parent caregivers willing to participate in the study to get others to understand the experience of Asian American parent caregivers.

California is the only state in the country that has the Lanterman Developmental Disabilities Services Act commonly referred as the Lanterman Act

(Mager-Mardeusz & Kominski, 2016). This landmark act was an important legislation that created entitlement services and service delivery systems for those with developmental disabilities so they can be empowered to live a productive, meaningful, healthy, and dignified life in their communities (Frank D. Lanterman Regional Center, n. d.). The Lanterman Act laid the groundwork for the establishment of 21 regional centers (Frank D. Lanterman Regional Center, n. d.). These regional centers are private non-profit corporations that funded by the California Department of Developmental Services (DDS) to provide services for individuals with developmental disabilities. All parents who suspect a child has developmental disability may be referred by a provider or school's assessment team to go to Central Valley Regional Center (CVRC) to have a contractor clinical psychologist to assess the child for an ASD diagnosis. It would make sense to recruit parent caregivers from CVRC because a large proportion of clients receive funded services for their child with ASD through CVRC. At the start of the study, the author did not receive support from CVRC program manager to share a hard copy of her flyer in the receptionist area or on the CVRC Facebook home page to recruit study participants. The CVRC program manager did not understand that this was a voluntary study and that no information would be shared with the author without the parent caregiver's signed informed consent to participate in the study.

Nursing Implications and Future Research

Most parents with children diagnosed with autism spectrum disorder (ASD) experience some degree of ambiguous loss. This type of loss is psychological where the parent may perceive the child being physically present but mentally absent. Ambiguous loss is traumatic for parents (Boss, 2016). However, Boss (2016) states many people do recover from ambiguous loss if family interventions

and community supports are in place (Boss, 2016). For instance, a Caucasian mother in the study whose son was recently diagnosed with ASD shared with the author during the interview how she could not have a meaningful conversation with her son. The son may possibly not be verbal. Instead of parents grieving over what they want to see in their ideal child, coping begins when the parent or the nurse recognizes the ambiguous loss as a stressor. By identifying this stressor, parent caregivers can work with mental health professionals on becoming aware of distress, immobility, and confusion about the ambiguity surrounding the situation of having a child with ASD. Parents work to overcome the traumatic loss of the child they envision to have. Ultimately, the parents will tolerate that ambiguous loss of having a child with ASD such that they will never have closure or an answer as to how their child has ASD.

Support is crucial for parents of children with ASD. Before, during, and after the diagnosis for ASD, mental health intervention was never offered to parents in the study. One future direction is examined the level of comfort among psychiatric mental health nurse practitioners, family nurse practitioners, providers, and nurses to talk about ambiguous loss with family members. These family members need assistance from professionals to work with them to understand the impact of having a child with ASD in processing their mixed emotions about the child diagnosed with ASD. The parents with children diagnosed with ASD need to view strengths, meanings, and positive aspects of having a child with ASD and not view the ASD child as the parent's personal tragedy. A second direction is exploring the perspectives of family members (grandparents, siblings) toward the family with children diagnosed with ASD. As seen in the study, the parents want the support and view the challenges and stresses in having a child with ASD regardless of level of severity. Family and social support are crucial for their

mental health but as one Caucasian father stated, one anticipates seeing changes in the “Oregon Trail.” Eventually the social circle of friends and family gets smaller and smaller as families of children with severe ASD symptoms report seeing few occasions when they participate in rituals because no one invites the parents and their child with ASD.

Conclusion

Parents with children diagnosed with autism spectrum disorder (ASD) have ongoing challenges, putting these parents at increased risk for poor mental health outcomes. The stressor parents have is ambiguous loss, yet many parents cannot easily identify the ambiguity of the situation as a loss without resolution and closure. Many parents were never offered mental health support. The study highlights the need to identify and acknowledge the ambiguous loss as a stressor for families and the importance for healthcare professionals, educators, community, and family members to not view ambiguous loss as pathologic. Recommendations are made to have healthcare community and families find opportunities to help the parents of children with ASD cope with ambiguous loss. This identification and recognition of the stressor as ambiguous loss and introduction of early mental health intervention throughout the journey can help parents’ mental health as they continue face challenges and growth in raising a child with ASD.

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APPENDICES

APPENDIX A: HUMAN RESEARCH CERTIFICATE

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Thao Tran** successfully completed the NIH Web-based training course "Protecting Human Research Participants".

Date of completion: 03/10/2018.

Certification Number: 2624823.

APPENDIX B: SITE RESEARCH APPROVAL

**Dr. Javier Amu, MD
Professional Corporation
1093 11th Street
Reedley, California 93654**

August 10, 2019

Committee for the Protection of Human Subjects (CPHS)
Division of Research and Graduate Studies
Frank W. Thomas Building, Room 130
5241 N. Maple Ave. M/S TA51
Fresno, CA 93740

Dear Members of the Protection of Human Subjects Committee:

I have reviewed Ms. Thao Tran's proposal to do her research project on "The Mental Health Experience Among Parents of Children with Autism" at my pediatric clinic. She will use my site to do semi-structured interviews via phone, Skype/Zoom, or in person. This letter indicates my approval to use the clinic to do her study until Spring 2020 semester.

Ms. Tran will begin her study on human subjects as soon as I receive the approval letter from CSU Fresno IRB Committee. If I have any concerns about her project, I will contact Fresno State Committee for the Protection of Human Subjects at (559) 278-2448 or Theresa Taliaferro, CPHS Coordinator, at theresataliaferro@mail.fresnostate.edu.

For any questions, you may contact me at my office number below.

Sincerely,

Javier Amu, MD
Pediatric and Adolescent Medicine
Clinic CEO
Phone: 559-743-7340
E-mail: amujas@gmail.com

APPENDIX C: RECRUITMENT FLYER

California State University Northern California Consortium of Doctor of Nursing Practice

Parents with Autistic Children Needed for Research Study

Fresno State and San Jose State University researchers are recruiting parents with children diagnosed with autism spectrum disorders (ASD) to participate in a study exploring the mental health experience of parents before, during, and after obtaining an ASD diagnosis.

The participant must have the following:

- Have a child diagnosed with ASD for at least six months
- Live in Central Valley, California
- Parent(s) must be able to read, speak, and understand English
- Child must not have another developmental delay, communication disorder, or speech delay diagnosis
- Participate in phone, Skype/Zoom, or face-to-face interview after informed consent is signed

No cost to participate. For more information, contact Thao Tran at thao2019@mail.fresnostate.edu

Photo credit: <https://www.pexels.com/photo/man-love-people-woman-53590/>

APPENDIX D: DEMOGRAPHIC DATA

Demographic Data

1. Which racial group(s) do you closely identify yourself?

Asian African American/Black
Hispanic/Latinx

Native American Caucasian/White Other/Mixed

2. What is your highest level of education?

3. What is your gender? Female Male Other

4. Are you working? Y N

5. If you answered yes to #4, are you part-time or full-time?

6. What is your marital status?

Single Married Divorced Separated Co-habitated

7. What is your age range?

_ 18 – 19	_ 20 - 29
_ 30 – 39	_ 40 – 49
_ 50 – 59	_ 60 – 69
_ 70 – 79	

APPENDIX E: QUESTIONS TO GUIDE SEMI-STRUCTURED INTERVIEW

Questions to Guide Semi-Structured Interview

1. What age did you obtain an autism diagnosis for your child?
2. What is your child current level of functioning (low functioning, medium functioning or high functioning autistic)?
3. How many children in your family has autism?
4. Tell me your reaction at the time of autism diagnosis.
5. Describe your experience in caring for a child with autism.
6. What family roles have you gained?
7. What family roles have you lost?
8. Is the family adopting a team approach to care or do you do everything for your child?
9. If applicable, how has the meaning of family changed for good or bad due to having a child with autism?
10. What family celebrations or rituals do you do with your autistic child?
11. Which part of your journey (before, during, and after the diagnosis) did you feel the most stress?
12. Were you offered any professional mental health support before, during, or after the diagnosis?
13. What other help do you need?

APPENDIX F: INFORMED CONSENT FORM

Title: The Mental Health Experience Among Parents of Children with Autism

Investigator: Thao Tran, MSN, APRN-CNP, FNP-BC, RN-BC, PHN, CHISP

Informed Consent

Introductory Statement:

You are being invited to volunteer as a participant for a research project. The doctoral student investigator, Thao Tran, is conducting a study that is being supervised by Dr. Denise Johnson-Dawkins, assistant professor at California State University, Bakersfield and a faculty in the Northern California Consortium of Doctor of Nursing Practice. The investigator is expected to follow research guidelines for ethical research established by Fresno State University Nursing Institutional Review Board and the Committee for the Protection of Human Subjects.

Below goes into the research study in detail. Please stop the investigator if you have any questions about each section of the informed consent. Sign the informed consent at the end if you fully understand

Purpose of Research:

The purpose of the study is to understand the mental health experience of parent caregivers before, during, and after receiving an autism spectrum disorder (ASD) diagnosis. You will be asked about your experiences and identify which point in

your journey you experience the most conflicting emotions. You will also be asked whether you were offered any professional mental health support and intervention during the point in time when you have the most conflicting emotions.

Procedures:

After a signed informed consent is obtained in person or via email during the Zoom meeting, you can schedule on the same day or another visit to complete the remaining parts of the study. Some people prefer to complete the informed consent and semi-structured interview in one sitting, but others prefer to do the informed consent and semi-structured interview on two different days. You will spend 5 to 10 minutes to provide demographic data. Then you will participate in a 60- to 90-minute semi-structured interviews consisting of 13 questions with the investigator. Most of these questions are open-ended questions. If you don't feel comfortable answering the question, do let the investigator know.

You have the right to withdraw from the study at any time. Depending on your preference, interview can be conducted via phone, face-to-face, or via Skype/Zoom. Interviews will be recorded in the pediatric office and then transcribed within 72 hours for analysis. You are allowed to have your autistic child in the room if you are unable to find a caregiver or nanny to watch your child.

Potential Risks and Discomfort

If you experience any anxiety or psychological discomfort as you describe your experience, do let the investigator know. We can stop the study, refer you to the on-site psychiatric nurse practitioner for counseling, or refer you to the Substance Abuse and Mental Health Services Administration National Helpline at 1-800-662-4357. The National Helpline is open 24/7 for 365 days a year. This helpline does not provide counseling but will provide you resources for local mental health support in your area. No social, physical, economic, or legal risks are anticipated.

Potential Benefits

Individual Subjects

You will not receive direct individual gain. You will develop interest in contributing your perspectives on a research area that is largely understudied.

Patient Population

As the rates of ASD increase, this study will benefit society and humanity in identifying parents who may show impaired coping skills in dealing with a child diagnosed with ASD. Because these parents experience more stress than parents of developmentally disabled children not affected by ASD, it is important to identify and refer parents in a timely manner to professional mental health interventions as soon as they begin to experience signs of poor psychological adjustment or conflicting emotions about having a child diagnosed with ASD.

Society/Humanity in General

As the rates of ASD increase, this study would benefit society and humanity in identifying parents who may show impaired coping skills in dealing with a child

diagnosed with ASD. Because these parents experience more stress than parents of non-ASD children, it is important to identify and refer parents in a timely manner to professional mental health interventions as soon as they begin to experience signs of poor psychological adjustment to having a child diagnosed with ASD.

Alternative Treatments

No alternative treatments will be used in the current study.

Extent of Confidentiality

At the start of the study, you will sign the informed consent form acknowledging potential risks and benefits of the study and that all interviews are recorded for transcription. Your privacy and confidentiality are maintained at all times. The interview is conducted with you and the investigator in the private room of the pediatric office in Reedley, California. Based on your preference, interviews can be done in person, on Skype or Zoom, or via phone. Parents are allowed to have their child with them during the interview. No personal health information will be collected from you. Study materials and collected data will be stored as password-protected files on Fresno State Box, a cloud-based storage account similar to DropBox. All recordings and study materials will be destroyed on May 20, 2020.

Voluntary Participation

Your participation in this study is voluntary. You are allowed to withdraw from

the study at any time without penalty or explanation. You will not experience any potential risks as a result of you deciding to withdraw from the current study.

Assurance of Investigator's Readiness to Answer Questions

The investigator is available via email at thao2019@mail.fresnostate.edu or via phone at [REDACTED] should you have any questions about the study.

Terms of Compensation

As a result of your participation in the study, you will receive \$10 in the form of cash

Who to Contact to Report Risks or Injury as a Result of Your Participation in the Study

If you have concerns about how this study is conducted, you may contact California State University Fresno Committee for Protection of Human Subjects at 559-278-2448 or Theresa Taliaferro, CPHS Coordinator, at theresataliaferro@mail.fresnostate.edu.

Results from the study will be published on the San Jose State University ScholarWorks at <https://scholarworks.sjsu.edu/dnp/>

I have read the above subject's informed consent. Please check one of the two boxes below.

☐ I consent.

☐ I do not consent.

The investigator has given me the opportunity to ask questions about the study, informing me of the risks and benefits of the DNP project. A copy of this consent form has been given to me. My signature below indicates I give consent to participate in Ms. Thao Tran's study.

Subject's Signature	Date
---------------------	------

Witness	Date
---------	------

APPENDIX G: IRB LETTER OF APPROVAL

College of Health and Human Services

California State University,
Fresno School of Nursing
IRB Approval

Date: September 8, 2019

RE: DNP1906: The Mental Health Experience Among Parents of Children with Autism

Dear Thao Tran,

As the Chair of the Department of Nursing Research Committee, serving as the Institutional Review Board for the Department of Nursing, I have reviewed and approved your review request for the above-referenced project for a period of 12 months. I have determined your study to meet the criteria for Minimal Risk IRB review:

Under the Policy and Procedures for Research with Human Subjects at California State University, Fresno, your proposal meets minimal risk criteria according to section 3.3.7: Research in which the risks of harm anticipated are not greater, probability and magnitude, than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.

The Research Committee may periodically wish to assess the adequacy of research process. If, in the course of the study, you consider making any changes in the protocol or consent form, you must forward this information to the Research Committee prior to implementation unless the change is necessary to eliminate an apparent immediate hazard to the research participant(s).

This study expires: September 8, 2020

The Research Committee is authorized to periodically assess the adequacy of the consent and research process. All problems having to do with subject safety must be reported to the Research Committee. Please maintain proper data control and confidentiality.

If you have any questions, please contact me through the CSU, Fresno School of Nursing Research Committee at tereag@csufresno.edu.

Sincerely,

A handwritten signature in black ink that reads "Nisha Nair".

Nisha Nair, DNP, RNC, CNS, CNE, IBCLC
School of Nursing, Research Committee, Chair

APPENDIX H: COPYRIGHT CLEARANCE LETTER TO USE
FIGURE 1, FIGURE 2, AND TABLE 1

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Title	Mental Health Issues Among Parent Caregivers of Children with Autism Spectrum Disorders
Expected presentation date	May 2020
Portions	Figure 1, Figure 2, Table 1

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FIGURE 1. TWO TYPES OF AMBIGUOUS LOSS.

PHYSICAL ABSENCE with Psychological Presence	PSYCHOLOGICAL ABSENCE with Physical Presence
<p>Examples:</p> <p>War, terrorism (missing soldiers, civilians)</p> <p>Natural disasters (missing persons)</p> <p>Kidnapping, hostage taking</p> <p>Desertion, disappearance</p> <p>Missing body (murder, plane crash, lost at sea)</p> <p>Incarceration</p> <p>Immigration, migration, expatriation</p> <p>Foster care, adoption</p> <p>Divorce</p> <p>Work relocation</p> <p>Military deployment</p> <p>Young adults leaving home</p> <p>Mate or child moving to care facility</p>	<p>Examples:</p> <p>Alzheimer's disease or other dementia</p> <p>Traumatic brain injury</p> <p>Autism</p> <p>Coma</p> <p>Chronic mental illness</p> <p>Addictions: drugs, alcohol, gambling</p> <p>Depression</p> <p>Complicated grief</p> <p>Homesickness (immigration, migration)</p> <p>Preoccupation with lost person, with work</p> <p>Obsessions: computer games, Internet</p> <p>Gender transitioning (also physical absence)</p>

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FIGURE 2. THE CONTEXTUAL MODEL OF FAMILY STRESS.

Source: Adapted from Boss (2002c).

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Table 1. *Differences Between Ambiguous Loss and Boundary Ambiguity*

	Ambiguous Loss	Boundary Ambiguity
Definition	Event or situation of unclear loss that has no closure	Perception of event or situation about who is in or out of the family
Theory base	Social construction (see Berger & Luckmann, 1966; Gergen, 2001)	Neo-structure functionalism (see Boss, 2007; Kingsbury & Scanzoni, 1993)
Assessment	Qualitative primarily (see Boss, Dahl, & Kaplan, 1996; Dahl & Boss, 2005; Fravel & Boss, 1992; Robins, 2010)	Quantitative (see Boundary Ambiguity Scale in Boss, Greenberg, & Pearce-McCall, 1990, and www.ambiguousloss.com)
Variable	Categorical	Continuous
Goals for treatment and intervention	Resilience via meaning (both-and thinking)	Resilience via structure (roles, membership)

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