Experience of Parenting a Child With ASD

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Table of Contents

List of Tables

Abstract

This research study explored the lived experience of fathers who have a child with autism spectrum disorder (ASD). The reason for this exploration was due to lack of available research on how parenting a child with ASD impacts father's lived experience. The importance in understanding fathers' experiences was to gain awareness and, ultimately, offer additional ways to support fathers. Six participants were recruited and, through a qualitative methodology, were asked to complete a brief demographic questionnaire and participate in a semistructured interview to gain a sense of their experience parenting a child with ASD. Various themes arose that offer greater understanding of fathers' lived experience, such as how they make sense of an ASD diagnosis, the impact on the family system, and the stressors fathers experience. Future research studies may benefit from changing the methodology to make research more generalizable.

Keywords: Autism spectrum disorder, qualitative methodology

Chapter 1

Problem Statement

Fathers who parent a child with autism spectrum disorder (ASD) have a unique lived experience as they may face challenges pertaining to parenting, mental health, marriage, finances, and so on. Fathers' experiences parenting a child with ASD are relevant to explore through research because of the prevalence of ASD and how little research there is on the experience of fathers raising a child with ASD (Altiere & Kluge, 2009). There is a large body of research on individuals with ASD and mothers' experiences raising a child on the spectrum; yet, there has been little research on the impact of fathers' experiences raising a child with ASD. Due to lack of available research and individual perspective of fathers, there may be little insight as to what extent fathers are impacted by various challenges. The vast majority of parents who raise typically developing children may have difficulty understanding the experience of raising neurologically diverse children. Individuals sharing their personal experiences of raising a child on the spectrum may lead to reducing stigma associated with ASD and increasing the resources offered. Additionally, fathers who raise a child with ASD may realize others who are encountering similar challenges, thereby experiencing a sense of community (Alsedrani, 2017).

To gain a greater understanding of fathers' perspectives, experiences were assessed through Bronfenbrenner's (1979) ecological system, a framework to gain greater understanding of individuals' relationships within various communities and the larger society. According to this theory, individuals are influenced by various communities such as their microsystem, mesosystem, exosystem, macrosystem, and chronosystem. The microsystem is the immediate environment that influences an individual such as nuclear family, work, colleagues, and religious organizations (Sincero, 2012). According to Bronfenbrenner, the next stage is the mesosystem, which includes interactions among the microsystems. Exosystem is the next stage within the model, pertaining to impact of connections between multiple settings. The macrosystem consists of social and cultural values. The final stage within Bronfenbrenners' ecological system is the chronosystem, which pertains to the impact changes have on an individual over time. The examination of the larger ecological system displays a holistic understanding that helps clarify the factors of how fathers make meaning and their experiences of parenting a child with ASD. This ecological system was developed by Bronfenbrenner to examine how relationships within different environments influence the individual (Sincero, 2012). The larger ecological system of ASD includes characteristics of ASD, cultural considerations, effect on family systems and parenting, effects on mothers, and lastly, examination of the perspectives of fathers.

Characteristics and Prevalence of ASD

The impact of ASD is important to understand among families because of the prevalence of the diagnosis. ASD occurs in all racial and ethnic groups, and it has been reported ASD is more prevalent in certain populations. The Autism and Developmental Disabilities Monitoring (ADDM) Network assesses for prevalence of ASD among children aged 8 years old, whose guardians reside in close proximity to one of the 11 ADDM sites (Baio et al., 2018). Researchers examined results for 2014 and found overall prevalence of this disorder among 11 ADDM sites were 16.9 per 1,000, or one in 59 children aged 8 years old.

To understand sex prevalence of individuals with ASD, parent-reported diagnoses, school and medical records, and diagnostic evaluations were also examined. Researchers also examined 54 studies conducted worldwide that demonstrated a ratio of boys being 4 times more likely to be diagnosed with ASD than girls (Zeliadt, 2018). Caucasian individuals are more likely to have ASD than African American individuals, and both populations are more likely to have this disorder in comparison to Hispanic individuals by nearly 70% (Baio et al., 2018). Researchers have found the 2014 ADDM reports of prevalence had increased in comparison to previous years. However, researchers emphasized these findings from ADDM are not representative of the United States, rather various states in the country. Regarding general U.S. prevalence, according to ADDM Network, an average of 1 in every 44 (2.3%) 8-year-old children were found to have ASD in 2018 (Baio et al., 2018).

According to the fifth edition of the *Diagnostic and Statistical Manual* (DSM-5), ASD is a neurodevelopmental disorder. One of the characteristics of ASD is having an impairment in social communication. Examples of social communication include, but are not limited to, taking turns and conversing, staying on topic, maintaining eye contact, facial expressions congruent with speech, and using greetings (The Children's Hospital, 2017). ASD is also marked by participating in repetitive patterns of behaviors, interests, or activities (American Psychiatric Association, 2013). Examples of repetition include lining up toys, echolalia, being inflexible regarding changes to routines, and hand flapping (Alsedrani, 2017). This spectrum disorder ranges from mild to severe symptoms, with the course of the disorder varying by individual over time and across different contexts (Enwefa & Enwefa, 2017).

Additional signs of ASD include difficulties in social interactions, preference for being alone, delayed speech and language skills, and rocking from side to side (Alsedrani, 2017). Individuals with ASD do not meet the same developmental milestones or develop at the same rate as typically developing children (Shen & Piven, 2017). For example, children with ASD may have decreased verbal skills, using a few single words by 24 months, and the typical developing child, on average, speaks 50 words or more in addition to two-word phrases (Edison, 2019). Also, individuals with ASD do not respond the same way as typically developing individuals, as displayed through difficulty maintaining eye contact, being unresponsive to their names, and withholding smiles toward their caregivers (Gilda, 2020). They typically have difficulty understanding various concepts, such as understanding an opposing viewpoint or another individual's perspective (Shen & Piven, 2017). Individuals with ASD can also struggle with emotion regulation and maintaining control (Shen & Piven, 2017), including upholding attention, focus, organization, memory, time management, and emotional control (Gilda, 2020).

Individuals may develop various comorbidities along with ASD such as epilepsy, ADHD, gastrointestinal disorders, feeding/eating challenges, obesity, sleep disorders, and mental health disorders (The Children's Hospital, 2017). Epilepsy affects 25% to 40% of individuals with ASD, in contrast with 2% to 3% of the affected general population (Hyman et al., 2016). Individuals with ASD are more susceptible to epilepsy due to cognitive delays, intellectual disabilities, an underlying neurological disorder, and a family history of epilepsy (Spence & Scneider, 2009). Gastrointestinal disorders impact roughly 85% of individuals with ASD but no genetic or neurological connections have been detected to explain this prevalence (Mulloy et al., 2017). Selective eating and obesity are two of the most common feeding and eating challenges for individuals with ASD (Hyman et al., 2016). Research displays 30% of children with ASD are obese in comparison to 13% of the general population (Spence & Schneider, 2009). Regarding sleep disorders, 50% to 80% of children with ASD are impacted by chronic sleep difficulties (The Children's Hospital, 2017). Sleep difficulties include problems falling asleep, waking up frequently throughout the night or waking up very early. Some possible explanations for children with ASD having sleep difficulties are related to genetics, medication, and anxiety (The Children's Hospital, 2017). Research displays 85% of children with ASD have some form of comorbid psychiatric diagnosis, including anxiety, depression, ADHD, and bipolar disorder (Romero et al., 2016). Studies have shown individuals with ASD have a significantly shorter lifespan than typical developing children, which is not a result of an ASD diagnosis but rather the mental and physical illnesses that follow (Romero et al., 2016). Also, a diagnosis of a comorbidity can be difficult to assess, as individuals with ASD may have difficulty recognizing or communicating their symptoms (The Children's Hospital, 2017). Due to lack of recognition or communication of symptoms, individuals may engage in self-soothing repetitive behaviors such as self-harming behaviors or aggression. Despite difficulty in deciphering an ASD diagnosis due to comorbidities intertwined with ASD symptoms, there are ways to distinguish ASD as early as infancy (Shen & Piven, 2017).

An early biological sign that indicates the presence of ASD is an enlarged brain size at 2 to 3 years old (Shen & Piven, 2017). The first MRI evidence of brain enlargement among infants occurred during a longitudinal study measuring 55 infants who were given MRIs between 6 and 24 months of age. Infants who were later diagnosed with ASD had significantly larger brain volumes (Shen & Piven, 2017).

Various twin and family studies have suggested some individuals have a genetic predisposition to ASD (Gilda, 2020). For families with a child with ASD, the chance of having another child with ASD in the family increases (Gilda, 2020). More specifically through identical twin studies, evidence has supported the notion if one twin has been diagnosed with ASD, there will be a 36% to 95% chance the other twin will also be affected (Shen & Piven, 2017). Genetic mutations can also increase the risk of developing ASD, which can occur sporadically in a parent's sperm or egg cell during fertilization (Gilda, 2020).

A diagnosis is often pursued when behavioral impairments emerge during the second year of a child's life; yet, a formal diagnosis is typically only provided after 3 or 4 years old (Edison, 2019). The differences in developmental areas for children with ASD within the 1st year of one's life are typically apparent in motor skills, visual reception, language, and eye gaze patterns. More specifically, early indications of ASD include avoiding eye contact, decreased interest in peers or caretakers, limited display language, and escalated during minor disruptions in routine (Bawalsah, 2015).

Infants who have impairments in fine and gross motor skills at 6 months old are closely observed to assess for ASD. Children with ASD also have diminished language skills that are seen as early as 12 months old (Edison, 2019). Through autism-specific brain imaging, features of ASD have been identifiable as early as 6 months old (Edison, 2019). Developmental monitoring includes observing how children grow and change over time to assess whether they meet typical developmental milestones in areas of playing, learning, speaking, behaving, and moving (Jackson, 2016). During well visits, doctors or nurses will do developmental monitoring where parents are asked about their child's development through a series of questionnaires. Well visits are recommended at 9 months, 18 months, and 30 months (Jackson, 2016). Children are recommended to be screened specifically for ASD at 18 months and 24 months (Jackson, 2016). Although a screening tool does not offer substantial evidence for a diagnosis, it can introduce a formal developmental evaluation (Jackson, 2016). At 2 to 3 years old, defining diagnostic features will emerge, providing the opportunity for a valid diagnosis (Edison, 2019). A formal developmental evaluation entails observing the child, giving the child a structured test, asking parents or caregivers questions, or having them complete additional questionnaires (Edison, 2019). Based on results from the formal evaluation, children are given early interventions or special treatments (Burt et al., 2016).

Interventions for ASD

Although a cure for ASD has yet to be discovered, there are various treatment interventions and services offered to assist individuals with ASD. Interventions assist in symptom reduction, improvement in cognitive abilities and tasks related to daily living, and maximizing individuals' ability to function independently (Helt et al., 2008). Some common types of treatments include behavior and communication, dietary, medication, and alternative medicine (Helt et al., 2008). Behavior and communication approaches that help individuals with ASD include services focused around structure, direction, and organization (Romero et al., 2016). Examples of behavior and communication approaches include applied behavioral analysis (ABA), occupational therapy, social skills therapy, and speech therapy. There have been dietary treatments that have been implemented to assist with ASD symptoms; however, there is little evidence to support this treatment method (The Children's Hospital, 2017). Regarding medication, there is no medication to cure ASD; however, there are medications available to help individuals with ASD to function better (The Children's Hospital, 2017). These medications can help manage inattention, anxiety, depression, seizures, and self-injury (American Speech-Language Hearing Association, 2018).

Individuals with ASD can live independently as an adult; however, this independence may not look the same for all individuals. The primary focus of intervention services is to help assist individuals in achieving their highest level of independence and will not look the same for all individuals (American Speech-Language Hearing Association, 2018). There are various stages of independence and rather than focusing on meeting milestones, an emphasis is placed on one's journey toward growth (Bawalsah, 2015). Children with ASD can grow up and go to college, date, get married, become a parent, buy a house, or have a career; however, it is dependent on the individual. Through analysis of various studies, research displays 87% of young adults who have a diagnosis of ASD move back in with their parents at some point post high school in comparison to 21% of typically developed individuals (Edison, 2019). Five times as many individuals in their early 20s with ASD lived with their parents compared to those who lived independently or in an assisted living program (Burt et al., 2016). Individuals with ASD had the lowest rate of independent living in comparison to peers with other disabilities (Jackson, 2016). Factors that may be related to individuals' living arrangements include household income of the family system, race and ethnicity, and their ability to communicate (Jackson, 2016). From individuals with ASD who lived independently, 40% were from upper income households, 27% identified as White, and 45% of young adults who live independently had considerably very high conversation skills (Bawalsah, 2015).

There are various skills individuals ought to encompass to live independently, including, but not limited to, striving toward emotional awareness, communicating and managing emotions, performing daily tasks (e.g., dressing, personal hygiene, housekeeping, cooking), and managing money (Edison, 2019). Although individuals may not reach mastery of these various skills, an emphasis is placed on working toward achieving independence and understanding oneself and the world around them.

Relevance of Current Research Study

The high prevalence of ASD lends an urgency to understand how the disorder impacts individuals, specifically fathers, as they parent a child on the spectrum. ASD directly influences fathers, causing various stressors to impact fathers' lives in various ways. These stressors include worrying about their child's well-being, inability to communicate with their child, sudden increase in financial responsibilities, and feeling like their child does not fit in with everyone else (Altiere & Kluge, 2009). Different stressors manifest in fathers' lives in various ways; some examples of these stressors are through mental health, physical health problems, and relationships.

There has been some research pertaining to the lived experience of fathers raising their child with ASD that helps guide new research about understanding possible stressors fathers experience and impact of the child's condition on the family system. Exploration of previous research pertaining to ASD and fathers' experience can help in shaping new research to look at where there may be some similarities and contrasts in research.

Research shows fathers are more prone to repressing their feelings (Medelyan et al., 2019). Fathers may feel like they must be the glue that holds the family together during such strenuous times, especially when carrying the mindset that they are the head of the household and the provider. However, that feeling may cause bitterness, feelings of isolation, and impact their physical and mental health (Shen & Piven, 2017). There may also be an emotional impact, as they may have resentment toward their child on the spectrum and guilt about experiencing this resentment (Altiere & Kluge, 2009). Due to ASD being a spectrum disorder and the expression of symptoms varying based on the individual, fathers have a unique experience as a result of being impacted in distinct ways. Some individuals with ASD may have difficulty verbalizing what they need, leading to individuals with ASD using behaviors, such as aggression, to express themselves. For example, it is common for a child with ASD who has difficulty verbalizing their needs to engage in self-harming behaviors out of frustration, such as hitting their head on the floor (Edison, 2019). Inability to understand their child can lead fathers to feel frustrated and confused, questioning their capabilities as a father (Bawalsah, 2015). Another way fathers can be impacted in distinct ways dependent on their child's expression of ASD symptoms is their difficulty in social skills that results in fathers lacking social connectedness from their child (Jackson, 2016). Parents who raise a child with ASD oftentimes notice disengagement and lack of connection in their relationship with their child with ASD (Jackson, 2016). For example, their child may not get excited when their father walks into the room or does not want to engage in play with their father. This experience can lead to fathers feeling sadness and even some isolation, especially if the child and mother appear to have a stronger bond (Bawalsah, 2015).

Individuals on the spectrum oftentimes develop at different rates in comparison to typical developing children, specifically regarding meeting their developmental milestones. Children with ASD commonly have difficulties completing everyday tasks independently, such as getting dressed, going to the restroom, brushing their teeth, or making a meal for themselves (Edison, 2019). Children with ASD take more time than typically developed children to get toilet trained (Burt et al., 2016). Fathers who are raising a child with ASD may experience the stress of their child having an accident in public or having their child wear a pull-up diaper well past the typical age range, finding little support from others. These various scenarios impact fathers in ways that are harder for those who raise typically developed children to understand due to contradiction of expectations related to development.

In addition to understanding distinct ways fathers are impacted by having a child with ASD, it is also important to consider the cultural framework that informs how individuals interpret and perceive ASD. Cultural factors are important to consider, providing a deeper understanding of what additional factors may impact how others respond to ASD.

Cultural Differences in Conceptualization of ASD

Culture influences how ASD is viewed in various perspectives that shape how individuals consider this disorder (Edison, 2019). There may be cultural myths regarding ASD that cause others to perceive this neurodevelopmental disorder in a negative light, such as a curse or something that brings shame upon the family (Kim, 2001). These perspectives are relevant to consider as culture is the lens in which individuals behave, think, and make decisions centered around their children (Obeid et al., 2015). Culture impacts how ASD is understood and conceptualized, and the degree to which it is accepted (Jackson, 2016). In the Asian culture, for example, mental illnesses are viewed as a curse brought upon by the family (Obeid et al., 2015). As a result, individuals who have a mental illness are considered crazy and treated as a disgrace in the family (Kim, 2001). In Latino cultures, ASD is oftentimes viewed as a spiritual battle and individuals will spend time praying for the disorder to be removed (Burt et al., 2016). This approach to ASD may harbor one's unacceptance of the reality of the disorder (Edison, 2019). In the mainstream culture, ASD appears to be more socially acceptable as it is more common to see individuals with ASD throughout society (Edison, 2019). This can cause individuals with ASD to feel more accepted (Burt et al., 2016). In various cultures, a common response to ASD may be wondering what caused the child to have a diagnosis of ASD (Burt et al., 2016). However, in other cultures, although initially following a diagnosis there may be questions as to why, individuals may quickly transition to acceptance and the next course of action (Kim, 2001).

There may be a stigma associated with different mental health illnesses in various cultures, including ASD, that impact individuals' desires to obtain the services they need. A research study examined the experience of individuals in Los Angeles who had a child with ASD (Obeid et al., 2015). After semistructured interviews and questionnaires were completed and analyzed, results indicated non-White individuals or recent immigrant families were more likely to have a difficult time getting connected with counseling and diagnostic services, delaying the process of getting an appropriate diagnosis, further delaying receiving the appropriate treatment (Bauer, 2016). Non-White individuals and recent immigrant families cited denial, resentment, grief, and lacking psychoeducation as reasons for not pursuing treatment (Obeid et al., 2015). If ASD is not socially acceptable in one's culture, it may create resentment and avoidance in one's journey toward acceptance of this diagnosis. In Iran, parents' beliefs toward ASD are feelings of disgrace, due to the great amount of stigma associated with this disorder (Samadi, 2020). In cultures like Iran, it can be assumed disorders like ASD are dismissed, with a refusal to accept the reality of the situation at hand. As a result, there appears to be little psychoeducation regarding ASD and an increase of undiagnosed cases (Samadi, 2020).

Cross cultural research displays how strong of an impact culture plays in one's life, including dictating one's thought process and actions, specifically through their level of involvement in pursuing a diagnosis and treatment options (Obeid et al., 2015). Analysis of various research informs individuals of how parents' lived experiences may differ based on the culture in which they are rooted. Individuals parent their children through the lens in which they view their culture.

Culture is the larger framework that guides family systems (Samadi, 2020). In collectivistic cultures, the family system may be composed of extended family versus in individualistic cultures, family system may be composed of the nuclear family. Culture impacts the family system and overall lived experience of individuals as it redefines what individuals view as the norm (Obeid et al., 2015). By understanding how culture plays a multifaceted role in one's lived experience provides greater context for how others create meaning and ultimately, the ways in which parents are impacted (Samadi, 2020).

Effect of Having a Child With ASD on Parents

A diagnosis of ASD has a large impact on parents as parents' expectations change. The diagnosis may be perceived as a loss for some parents, as dreams they once upheld for their child suddenly appears impossible (Hooyman & Kramer, 2006). Dreams of a child living independently, having a successful job, getting married, and having children of their own may suddenly appear unattainable. Coming to the realization expectations parents have for their children may be more difficult to attain than expected can have an impact on parents' overall mental health, physical health, finances, and marriage, and create shifts in their family system, which ultimately impacts parents' overall lived experience (Hartmann, 2012).

Parents who have a child with ASD experience more parental stress than parents of typical developing children (Rao & Beidel, 2009). One reason is because children with ASD demand more of parents' attention (Hartmann, 2012). Children with ASD need more assistance and monitoring than typically developing children due to displaying behavioral problems and difficulty completing different tasks independently (Bawalsah, 2015). Parental stress has been found to be dependent on the characteristics of the child (Rao & Beidel, 2009). Characteristics of the child include how ASD is expressed in the child's functioning, including whether symptoms elicit behavioral problems, and how social interactions and language are impacted. Different ways ASD is displayed in children can impact fathers' level of stress.

Fathers may manage stress they experience using different resources. It is essential to consider various resources made available and how these resources impact parents' level of stress. Having this understanding may provide deeper enlightenment on how to support parents, particularly fathers as they navigate through parenting a child with ASD. A pilot study was done to assess how different resources impact parents' abilities to cope with their child's diagnosis (Banach et al., 2010). The study examined implications of providing six sessions and a support group on advocacy and self-efficacy skills. Treatment results report additional support, such as counseling sessions and support groups help relieve stress and tension for parents. Individual therapy and support groups offer opportunities for openness and transparency among parents, leading to greater empowerment. Results also revealed that shortly after a diagnosis has been given to a child, 53% of parents experienced relief, 43% experienced grief, and 10% experienced guilt (Banach et al., 2010). Results display parents' responses vary based on individual differences depending on the parent, child and the family system. Research displays parents may internalize emotions as they want to appear strong and be an emotional support for other members of the family (Hartmann, 2012).

Parents with a child with ASD appear to have lower self-esteem in comparison to those with typical developing children (Bawalsah, 2015). Older parents in their late 50s with children with ASD had the lowest self-esteem in comparison to the norm group, particularly fathers (Bawalsah, 2015). This may result from parents' burn out, discouragement and loss of hope with their children with ASD. Marital satisfaction tends to decrease as parents' attention shifts to their child with ASD (Higgins et al., 2005). Parents may feel like their world revolves around their child with ASD, constantly monitoring their behavior, safety, and overall happiness (Langley et al., 2017). This creates less date nights and quality alone time with their partner. In addition, relationship satisfaction was negatively correlated with problem behavior of siblings, number of children in the house, and socioeconomic status of the household (Langley et al., 2017). Having a child with ASD may increase friction within the family, as the house may seem divided. One parent may offer more time and energy with the child with ASD, causing remaining family members to feel abandoned and create built in resentment (Rao & Beidel, 2009). These shifts within family system can ultimately create chaos and conflict, leaving one's quality of life to be diminished. Recognizing impact of having a child with autism and the implications on parents' mental health and marriage is vital. Being aware of the effects this diagnosis has on various aspects of one's life provides insight into parents' quality of life or lived experience.

Parenting a child on the spectrum impacts one's quality of life in different ways. Children with ASD have different needs and limitations. Parents work to meet the needs of their child, taking a toll on their own quality of life. Researchers did a quantitative study that examined the psychosocial well-being of parents who have a child with ASD (Gray & Holden, 2009). Different factors examined were socioeconomic status, treatment status of the child, and coping behaviors of the parent. Coping behaviors include depression, anxiety, and anger. Results indicated parents who receive more social support have lower scores of depressions, anxiety, and anger (Gray & Holden, 2009). Caregivers with older children and with larger families were found to have lower scores of anger, anxiety, and depression. Results highlighted the importance of strong social support for parents, as this can relieve stress and internalized feelings of anger, anxiety, and sadness. Having this frame of reference underscores how crucial it is for parents to avoid social isolation, especially when considering impact this diagnosis can have on parents' mental health.

For this reason, parents' mental health was assessed to examine impact of having a child with ASD. Mental health is any psychological disorder, including but not limited to depression and anxiety. Researchers reviewed questionnaires given to parents to assess mental health as a product of raising a child with ASD (Enwefa & Enwefa, 2017). Results displayed psychological acceptance acting as a mediator between child problem behavior and parents' mental health difficulties (Enwefa & Enwefa, 2017). Therefore, as child's problematic behavior increased, parent psychological acceptance decreased. Additionally, as parent psychological acceptance decreased, there became an escalation of parent mental health problems. Research displayed psychological acceptance and empowerment were negatively correlated to parent mental health (Enwefa & Enwefa, 2017). Even if parents were high on acceptance and empowerment, child's problematic behavior still had a strong impact on one's mental health. This may be contrary to the assumption that if parents have all the right tools and a positive mindset, such as empowerment and acceptance, their child's behavioral problems will appear more manageable. However, pattern of parental acceptance found in the Enwefa and Enwefa study should be further investigated to determine its generalizability.

Another study examined the overall lived experience of individuals who parent a child with a disability through group discussions (Pelchat & Lefebvre, 2003). Two themes included were roles in the family system and normalization of child's diagnosis. Regarding family and parenting, fathers created expectations outside of the family system, such as gathering resources for their child with ASD and excelling at their place of employment. However, mothers' expectations focused inwardly, wanting to be a good parent and, as a result, setting high standards for oneself. Mothers felt like their partners were hesitant to freely discuss their child's disability or ask for help. Mothers interpreted this as their husbands wanting to appear strong.

Research findings are relevant to understand the perspective of fathers' lived experience through addressing expectations. Expectations mentioned in the study are self-imposed on fathers (Pelchat & Lefebvre, 2003). Results displayed that fathers in the study were desiring an atmosphere of normal family life, wanting to go on family vacations and dates with their spouse. Fathers appeared to crave more support from their extended family than the mothers. Regarding normalization and stigmatization, fathers appeared stressed when confronted by family, friends, and professionals about the child's behavior. Both mothers and fathers believed having a child with a disability caused them to be more compassionate toward others. Further studies related to gender roles and normalization among family systems should be explored to assess for generalizability.

Effect of Having a Child with ASD on Family Systems

To understand the experience of fathers, it is important to understand impact of the family system considering this is the microsystem fathers are rooted in. The microsystem, or direct environment of the individual, is derived first and foremost, by their family. According to Bronfenbrenner, the microsystem is what shapes individuals, their personality, demeanor, and outlook on life (Paquette & Ryan, 2001). Each individual is impacted when there is a change or rupture in the family system. This is especially true when there is a diagnosis of ASD within the family. Family systems can be impacted by time, money, and support (Hartmann, 2012). A diagnosis of ASD may limit family vacations as children with ASD may have difficulty with travel and change in routine may create an increase of behavioral problems (Burrell et al., 2017). In addition, various therapies needed for children with ASD can take a toll on family expenses, limiting various family activities (Hartmann, 2012). Researchers examined the different stressors families experience when raising a child with ASD and identified finances and interpersonal relationships being two of the major stressors among some families (Paquette & Ryan, 2001). Results from this study found due to large expenses spent for children with ASDs' various therapies and medications, family vacations, purchasing toys for their children, and doing costly activities may seem out of the question (Paquette & Ryan, 2001). Siblings may experience neglect from their parents and embarrassment from their peers due to having a sibling who is seemingly so different than typically developing individuals (Bernstein, 2016). Siblings may also feel a lack of support from their parents, as their needs appear secondary in comparison to their sibling on the spectrum (Higgins et al., 2005). They may not be able to receive help with their homework or engage in after school activities due to conflict with their sibling on the spectrum's schedule. Siblings' hopes and dreams of having a playmate and best friend may appear more difficult. As a result, clashing of personalities and expectations among siblings may create even more chaos within the family system.

Additionally, chaos within the family may persist in response to children with ASD's challenging behaviors. A longitudinal study examined bidirectional influences of family environment and behavioral observations of the child with ASD to create a family program that reduces family stress through addressing behavioral problems, ultimately, improving quality of life of the child with autism and the families (Smith et al., 2014). Through interviews and various questionnaires administered, researchers found parents who criticize their child with ASD more frequently increased child behavioral problems, which increased overall problems in the family system. Evidence has also supported the notion of increased levels of warm and positive remarks are related to reductions in problematic behaviors, leading to less stressful family environments (Smith et al., 2014). Ultimately, ways in which family systems communicate with one another influences their child with ASD and has a role in the degree of behavioral problems displayed, resulting in a direct impact of the family system. This research has shown the relevance in targeting family systems as an entity, which not only creates a reduction of behavioral problems but also overall family distress (Smith et al., 2014).

Although it is important to consider family system as an entity, it is just as important to consider internal characteristics of family members which directly impacts the family system they are integrated in. There appears to be lower marital satisfaction, family cohesion, and family adaptability for families who have a family member with ASD (Higgins et al., 2005). This could be a result of internal characteristics, including but not limited to low self-esteem, difficulty managing stress and rigidity (Higgins et al., 2005). Understanding effect ASD has on the family system and different stressors pertaining to the internal characteristics of the individual are various aspects that contribute to the lived experience of the individual. From understanding the experience of family system, a closer examination of parents can be studied.

Parenting Styles

Structure, family dynamics, and expectations derived within family systems are heavily influenced by parenting styles. Parenting styles impact how family members interact with one another, setting the tone for the climate of the family system. Similar to culture and understanding the family system, parenting is also a derivative of

Bronfenbrenner's ecological system, the microsystem that dictates how individuals create meaning. Understanding parenting styles offers a greater understanding of the approach parents take regarding child rearing, specifically when parenting a child with ASD. Parenting is the larger context of how parents make decisions, function, and take care of themselves and therefore, are relevant to consider.

Baumrind (1966) recognized three parenting styles: authoritarian, permissive, and authoritative. Individuals who practice authoritarian parenting take on a directive approach which values obedience. Permissive parents provide children with a great deal of autonomy, placing little demands and punishment on their children (Olivari, 2013). Parents who live out authoritative parenting are individuals who seek a collaborative approach, listening to needs of the child and setting boundaries for the well-being of the child (Olivari, 2013). Various parenting styles are shown by the way parents speak, interact, and discipline their children (Olivari, 2013). Research has shown authoritative parenting has successful outcomes in a child's overall development, including when parenting a child with ASD (Hay, 2016).

A recent study exhibited authoritative parenting as being a successful parenting style for children with ASD through several weeks of in-home observations and interviews with parents (Mullins, 2018). Authoritative parenting entails being responsive to their children, yet maintaining high demands (Mullins, 2018). This form of parenting shows consistency and boundaries while responding to the emotional needs of the child (Mullins, 2018). The research displayed in addition to authoritative parenting being helpful with children with ASD, it is also helpful throughout the entire family system, instilling order and peace (Mullins, 2018).

Another study examined impact of authoritative parenting on children with developmental disabilities and found parents who raise a child with ASD struggled to balance their own expectations for their child versus what they felt their child was capable of (Navot & Webb, 2017). Research has indicated parents of children with ASD may have an internal battle when parenting their child, wanting to challenge and discipline their child without pushing their child too far. Difficulty with parenting a child with ASD may be lack of attunement, as it may be unclear what the child needs (Navot & Webb, 2017). For instance, findings from a qualitative research study displayed that children with ASD may have temper tantrums or cry uncontrollably, lacking the ability to verbalize what it is they want (Garvey, 2010). This can create frustration for parents, wanting to appease their children but unable to understand what they need (Hay, 2016).

In addition to authoritative parenting, positive reinforcement is another concept parents can use to assist in parenting, displaying high effectiveness among children with ASD (Synapse, 2016). Positive reinforcement includes behavior specific praise, maintaining consistency, and using reinforcers (Garvey, 2010). Shaping behaviors through positive reinforcement has been proven to be effective in assisting individuals with ASD to work toward their potential (Garvey, 2010). Studies have found positive reinforcement is more effective than other disciplinary approaches, especially for children with ASD (Synapse, 2016).

Despite incorporation of authoritative parenting and positive reinforcement, parental stress is inevitable. When considering parental stressors, it is also important to notice the individual response of each parent toward their child with ASD. A study investigated behavioral problems and parenting styles among children with ASD (Hay, 2016). Researchers found fathers displayed less affectionate interactions with their child on the spectrum than mothers. Mothers were found to be more affectionate with their child with ASD. Mothers also devoted more time with their child than fathers. Observing differences in responses between mothers versus fathers pertaining to parenting is relevant as this plays a factor in one's lived experience. Fathers may observe their wife's parenting, including their child with ASD's bond and feel resentment, guilt, or feel isolated from the family (Gray & Holden, 2009). Fathers may also question their own parenting skills, wondering why there is such a disconnect between himself and their child. These are important aspects to consider, providing the opportunity to gather background information on what insecurities or stress fathers may be battling.

Effect of Having a Child With ASD on Mothers

When studying implications of fathers parenting a child with ASD, it is important to gain insight into other factors involved which may impact fathers' experiences, including mothers' experiences. This was relevant to the larger study being investigated by providing knowledge on the lived experience of other members of the family. Each individual within the family system is impacted differently, with their own individualized experience. Mothers are affected by having a child with ASD in different ways, including but not limited to, their mental, physical, emotional, and spiritual well-being. Although impact on mothers varies depending on the individual, there has been some research to assess the lived experience of mothers who have a child with ASD.

Mothers have been reported to generally have more anxiety than fathers (Hastings, 2003). A partial correlation analysis indicated a child's behavioral problems along with fathers' mental health was correlated to mother's stress (Hastings, 2003).

However, a child’s behavioral problems and mothers’ mental health was not associated with fathers’ stress. Results suggested mothers who have a child with ASD may have stress corresponding to family members’ psychological health although fathers’ stress is more dependent on external factors outside of the family system.

Another study, which went into detail about various implications of mothers’ experiences when parenting a child with ASD, analyzed diary responses by mothers and found different domains in mothers’ lives were impacted by raising a child on the spectrum (Smith et al., 2014). Mothers were asked to complete a diary entry over an 8-day period regarding their everyday life experience as they parent an adolescent with ASD (Smith et al., 2014). Diary responses were analyzed, and different themes arose. The daily diary study displayed that mothers who have a child with ASD are 3 times more likely than mothers who are parenting an adolescent without a disability to more frequently experience a stressful event. These stressful experiences create a negative impact on mothers’ emotional and physical health. Mothers with an adolescent with ASD tend to report more joint pain, fatigue, headaches, and gastrointestinal problems than mothers with typical developing adolescents. Individuals from the study also displayed significantly elevated cortisone levels in comparison to mothers who had typical developing children. Results indicated mothers with a child with ASD appear to have a chronic stress response that resembles individuals with posttraumatic stress disorder (Smith et al., 2014). These posttraumatic stress disorder symptoms include nightmares, feeling isolated, negative affect, exaggerated blame of self for causing the trauma, difficulty in sleeping and concentrating, and an increased startle reaction (Smith et al., 2014).

To further assess lived experience of mothers who raise a child with ASD, another study involved maternal experience of raising a daughter with ASD (Navot et al., 2017). There were 11 participants involved, all mothers of daughters with ASD ranging from 10–19 years old. Semistructured interviews were administered in naturalistic environments, exploring maternal experience. Results were coded by two sections, maternal experience of raising a child with ASD and mother-daughter relationship as impacted by ASD. Some themes identified from interviews regarding maternal experience of raising a daughter with ASD include delayed diagnosis, unbelief from others, little psychoeducation, and worries about daughters' future. Some themes found regarding impact of ASD on mother–daughter relationship was desiring a close relationship, guilt, and having a different relationship with their daughter than what was expected. Impact on mothers and the themes arose create curiosity whether these conclusions apply to fathers as well.

Through exploration of various research studies as mentioned in the previous section, various themes have been derived related to experience of mothers when raising a child with ASD including impact on one's mental, physical, emotional, and spiritual well-being (Smith et al., 2014). The next section addresses research literature on the impact of fathers by comparing and contrasting what is known about mothers of children with ASD.

Effect of Having a Child With ASD on Fathers

Fathers are impacted in various ways by having a child with ASD and these findings can be discovered through exploration of different research studies. Research studies are important to consider as this provides greater context of various elements that contribute to fathers' lived experience when raising a child ASD.

For instance, one research study aimed to understand the lived experience of fathers who have an older child on the spectrum (Burrell et al., 2017). Eight participants were individually interviewed regarding rewarding and challenging aspects of their role as a father to a child with ASD, coping strategies used by the parent, experiences with different services, and assessment of gender differences observed by the parent. Four themes were construed from data: path to acceptance, independence and integration, battlefield fathers and heterogeneity of support. Pertaining to the theme of path to acceptance, fathers described soon after their child's diagnosis feeling frustration, guilt, and embarrassment. Prior to the diagnosis, fathers were aware of behavioral problems and there was a gradual realization of something concerning with their child. For most fathers interviewed, an individual outside of the nuclear family was the first to mention ASD. For fathers who had a child diagnosed at a later age, a formal diagnosis was the monumental point for the emergence of acceptance. For years of encountering problematic behavior, fathers were finally able to receive an explanation. The research study displayed that gradually all fathers' attitudes about ASD evolved over time toward acceptance and was evident through less embarrassment and decreased perceived judgement in public. The realization participants could not change the situation but how they viewed the situation was imperative during the narrative of acceptance.

The second theme from the study of Burrell et al. (2017) was regarding independence and integration highlights fathers' encouragement in fostering independence for their child with ASD. All participants felt it was their responsibility to lead their child toward the goal of independence. This entailed encouraging the child to practice basic life skills of cleaning, cooking, and personal hygiene. However, one father addressed this being an area of tension between parents. One father described his stance of when his son reaches 18, he should not be living at home but act like a capable adult. However, his wife believed their child should live with them his whole life. Fathers believe their role is managing both the child and the partner’s expectations. Managing spouse’s expectations along with a child’s expectations can lead to a great deal of pressure and, ultimately, negatively impact fathers.

The third theme in the research study of Burrell et al. (2017) was battlefield fathers, as all fathers used military terminology to describe themselves. All fathers described their role as an advocate, trying to gain as much support from other services. A hurdle some fathers encountered was feeling like an expert on their child; yet, they did not feel professionals allowed their voice to be heard regarding their child’s care. This may feel frustrating for fathers and disempowering as their own experiences with their child are not invalidated when not considered by professionals. The last theme that was construed is heterogeneity of support. This entails the way fathers cope and different support received. Most fathers were unwilling to engage in support groups, feeling impersonal, uncomfortable being vulnerable, perception that this took on a victim persona, or was too theoretical. One father felt fathers were an afterthought when it came to support for parents and is important to consider, as fathers may desire support groups but there are limited opportunities. Oftentimes, fathers may become their own support system, self-reliant on themselves, internalizing one’s problems, and creating pressure for oneself (Hastings, 2003). Peer support was found to be dependent on the father, as some wanted to compartmentalize work or friendships and home life. However, some fathers said being vulnerable with friends about challenges experienced were found to deepen the friendship. Friendships with other fathers who had a child on the spectrum was especially treasured due to feeling comfortable being open and honest about their experiences. For fathers to have transparency with other fathers is important as research exhibits those with a child with ASD to have a larger negative effect on their overall well-being in comparison to fathers of typical developing children and those with other developmental disabilities (Kim, 2001).

In fact, fathers with a child with ASD appear to have worse psychological well-being than fathers of other developmental disabilities, including down syndrome and fragile x syndrome (Doty, 2016). They also experience more depressive symptoms to great extent, which warrants clinical attention (Hay, 2016). Researchers wonder if pessimism about the future may contribute to these effects (Doty, 2016). These findings display fathers' experience of parenting a child with ASD is vastly different, with different stressors and unique ways to cope.

A research study investigated various ways in which fathers cope with different stressors, specifically the experience of South African fathers parenting a child with ASD using a phenomenological methodology (Isabirye & Makoe, 2013). Through semistructured interviews, researchers discovered the child's behavior to be the most prominent challenge fathers encounter as a parent. Three of five fathers mentioned their social interactions has been negatively impacted by their child's behavior. Another challenge fathers experience is the effect it takes on their marriage. Based on various responses, different coping strategies emerged. One of the ways in which fathers cope is through problem solving (Isabirye & Makoe, 2013). Fathers found practical solutions alleviate stress, especially as it relates to problematic behavior. Participants found researching information about ASD, especially different treatment options, was a common coping response. This equipped fathers with different tools and reassurance about future prognosis. Fathers also used positive reframing to cope with challenges of parenting a child on the spectrum. However, some fathers in the study used avoidance coping strategies. One father coped by minimizing challenges he and his family were experiencing. One participant used religion to cope, trusting in supernatural powers to help deal with challenges. Understanding how fathers cope in difficult situations, such as discovering their child has ASD, is valuable to assist other fathers who are in similar situations by offering additional tools to explore. One limitation of this study was fathers who participated in the study were all fathers to adolescent children who had ASD. There is not information pertaining to experience of parenting a younger child who has a diagnosis of ASD. However, the research mentioned above offers helpful insight in understanding different experiences fathers encounter.

Furthermore, the information provided above is relevant to already existing body of research and displays fathers may feel they need to appear strong by internalizing hardships, functioning from a problem-solving mentality, and having to resolve expectations may appear unrealistic (Hastings, 2003). Understanding the research already formulated pertaining to fathers who have a child with ASD displays what gaps there may be in research which have yet to be explored. Some gaps include lack of research into the lived experience of fathers, creating awareness and how best to support fathers who parent a child with ASD.

Study Rationale

The rationale for conducting the present study is to explore the lived experience of fathers who have a child with ASD, specifically when parenting a young child. Through review of literature, it is clear there is limited research regarding experience of fathers. Studies regarding experience of fathers investigate fathers parenting an adolescent to adult with ASD. There is little, if any, research studies which examine experience of fathers parenting a young child with ASD. There is more research elucidating the experience of mothers, who may be more willing to participate in research studies (Isabirye & Makoe, 2013). This may create an assumption that fathers' experiences of parenting a child with ASD is similar to mothers. However, the little research available suggests fathers' experiences are different than mothers. Experiences may be different due to the unique role they serve as being a father. A few examples of fathers' experiences differing from mothers as it relates to their role in the system are how fathers may generally feel like they need to be strong and have all the answers (Hastings, 2003). Existing literature describes the experience of ASD on mothers and families as a system; however, there lacks substantial data on the experience of fathers. The objective of this research study is to gain greater insight into the experience of fathers as they raise a child with ASD. Findings from this research study will create awareness of what fathers who raise a child with ASD go through, ultimately equipping clinicians, families, and society as a whole in better supporting fathers. The research study may assist other families in having a deeper understanding of what different members within a family system may experience and through this understanding, find additional ways to support one another. In addition, research explored can create awareness for clinicians and educators who serve families who have a child with ASD. The research provides more insight into stressors experienced and various family dynamics impacted.

Chapter 2

Philosophical Worldview

Social constructivism is a philosophical worldview by Vygotsky based on the premise that experiences are formulated through human activity and are influenced by social and cultural factors (Kim, 2001). This theory holds a framework that motivation is driven by both extrinsic and intrinsic values (Starks & Brown, 2007). Implications of this framework are internal and external factors drive an individual to behave a particular way. By learning through experiences, individuals formulate meaning, building upon previous information (Kim, 2001). One notion held by constructivists are individuals are active learners (Starks & Brown, 2007). Through various experiences, meaning is derived from prior information. This type of learning is achieved through social interactions, as Vygotsky believed community played a major role in the concept of making meaning (Kim, 2001). To best understand experience of fathers, specially being a parent to a child with special needs, social constructivism is the worldview that guided this research study.

Purpose Overview

The research study examined the experience of fathers who have a child with autism spectrum disorder (ASD) through a qualitative, phenomenological frame of reference. A phenomenological approach is studying the lived experience of a particular phenomenon (Paquette & Ryan, 2001). This approach was relevant to incorporate into the current research study as this study sought to understand the lived experience of fathers who raise a child with ASD.

The method used was an adequate strategy which aimed to understand, describe, and interpret how others make meaning (Kim, 2001). This research study was important as there has been a gap in research regarding experience of fathers who have a child with ASD. There has been very little information pertaining to how raising a child on the spectrum impacts fathers.

Research Question

The research question I focused my study on was: what is the lived experience of fathers who have a child with ASD, specifically stressors fathers experienced in their day-to-day life and impact of the child's condition on the family system?

Population and Sample

The population targeted for the research study were fathers who have a child with ASD. Fathers were recruited for the study with the desire to gain a better understanding of their lived experiences, particularly relating to raising a child on the spectrum.

Participants

Participants were recruited by having an email sent by the office manager at an ABA clinic. A sample email is listed in Appendix A for reference. The email was sent to all fathers regarding details of the study. Details of the study included what the research explores, purpose of the study and population targeted. In the email for recruitment, participants were told if they decided to participate in the study, their identity would remain confidential. Researcher's email was included, so any fathers interested in the study would have been able to email the researcher with their availability. Each participant was eligible to enter a raffle to win $25 gift card from Amazon. Population targeted for the study were fathers who have a child with ASD, ranging from 3 to 8 years old. The study was inclusive of all marital statuses, sexual orientation, and religious background. There were six participants recruited for the study.

Research Design and Methodology

The qualitative study examined experience of fathers who have a child with ASD, specifically focused on stresses they experienced and impact of child's condition on overall family system. Understanding the lived experience of fathers provides insight into how having a child with ASD has impacted their life, specifically different stressors that arose and effect on the family system. A phenomenological study examines how individuals experience a situation primarily through interviews, specifically by focusing on the lived experience of the participant, their lived body, lived time and their relationships because of the specific situation or phenomena (Giorgi, 2012).

Data Collection Process and Procedures

Participants were recruited via local community organizations in the greater Puget Sound area that offer services to families with a child with ASD. Following participant's approval to proceed with the study, a questionnaire and semi structured interview were scheduled via a secure online platform, specifically Microsoft Teams. The questionnaire entailed seven close-ended questions for the interviewer to gather more information to get to know the participant better, listed in Appendix B. The interview involved prepared questions that explored individuals' lived experience of parenting a child with ASD, specifically focusing on different stressors fathers experienced. Interviews lasted approximately 40–60 minutes. Participants were also offered the opportunity to ask questions or share their thoughts and/or feelings during the interview.

Based on the responses of participants. the researcher drew themes on fathers' experiences. Results were coded using in vivo coding. In vivo coding is an analysis commonly used for qualitative research, pulling out themes directly written or said during data collection (Medelyan, 2020). In vivo coding uses direct quotes from participants that appear to be significant or stand out to researchers. The overarching frame of reference used to code data was inductive reasoning. After data was collected, data was sectioned off into smaller portions. Codes were created which represent that portion of the data. The portion of data was reread, ensuring codes selected remained relevant and adding any additional codes if necessary. Then, the next portion of data was read. The same codes were applied to the next portion of data. Additional codes were created that also fit with the new portion of data. After the second portion of data was coded, to ensure validity, the data was recoded. The remainder of the data collected followed a similar procedure, reading the sample, applying codes where it seemed applicable, creating additional codes that seemed relevant and lastly, recoding the data to ensure validity.

Demographic Questionnaire and Semistructured Interview

At the start of the questionnaire, clients were informed they may skip any questions that caused discomfort. The questionnaires were close ended questions to attain specific details regarding the participant. The demographic questionnaire is included in Appendix B. The semistructured interview followed the questionnaire. Semistructured interviews have a set of topics already prepared which seem necessary for the interviewer to ask (Burt et al., 2016). Semistructured interviews were important for the research study, providing the opportunity for the researcher to ask about specific topics related to the larger research question and providing space for participants to share their own thoughts (Burt et al., 2016). There were different interview sections including questions about health, family, and finances. During the interview, experience of having a child with autism and its' impact on different areas of a father's life were noted. Sample interview questions is listed in Appendix C.

Credibility, Validity, and Reliability

I am in my 5th year of graduate school at Northwest University, working toward my PsyD. I worked as a behavioral technician at a small private practice where individuals with ASD are treated by providing applied behavioral analysis services. I worked with this organization for almost 3 years and have met several families who share details about their stressful lives, one of which is due to tending to needs of their child with ASD. I am interested in studying stressors fathers encounter regarding having a child with ASD because every person has a unique life story and I desire to gain insight into their experience. Also, I have found from working at an ABA clinic, fathers are overlooked. Mothers are usually the point of contact, the primary parent who helps with scheduling sessions and is more often than not, the one who picks up their child after sessions. This causes more interactions between mothers, causing the perception that mothers are the primary caregivers.

As a behavioral technician, I became increasingly fascinated with ASD. As a result, I would research various topics related to ASD. One reoccurring theme I noticed there was a gap in research pertaining to fathers' experience having a child with ASD. The research study I conducted enhanced my understanding of this population because there is limited research regarding fathers' experiences of having a child with ASD. From this study, I have been more equipped to work with families and sensitive to their needs. A potential bias during the study may have been most of my interactions have been with children with ASD and mothers. Unconscious biases about the role of fathers could have been formulated. This is necessary to consider as I may have used these preconceived notions to make assumptions about the families involved. However, to avoid this, I used member checking to ensure I was hearing the participant clearly. Member checking strengthened reliability and validity as responses are returned to participants to check for accuracy (Starks & Brown, 2007). Member checking eliminates any misinformation from being recorded. After coding and analysis of data was complete, results were shown to participants to verify what was found in the results is an accurate interpretation of their experience.

Because the company I worked at is a small private practice, a bias I might have had during the interpretation of results is writing in a way which defends the child or the parent involved, especially if I have worked with the family previously. This issue is best addressed by peer debriefing, in which someone ensures the coding system captures the themes of the data.

To avoid any bias, I had a colleague code a portion of data collected to have inter-rater reliability. Research studies that use inter-rater reliability builds high reliability, checking level of agreement among colleagues, ensuring a high level of accuracy when coding, and drawing conclusions (Starks & Brown, 2007).

The researcher took field notes on body language and nonverbal cues during the interview, which is considered an essential channel in collecting contextual data (Phillipi & Lauredale, 2017). Reflecting on what was observed during the interview is advantageous, providing more enriched data collection through gathering multiple dimensions of information (Roulston, 2017).

The use of triangulation is a method used to ensure reliability and validity. This method entails collecting and reviewing data through incorporation of different techniques such as through a questionnaire, an interview, and field notes (Oliver-Hoyo & Allen, 2005). Data, which overlaps or contrasts based on the use of triangulation, was important information to consider when analyzing the data.

Protection of Participants

Participants' rights were protected as signed consent forms, which are listed in Appendix D, were kept in a locked cabinet in an office at Northwest University. Data remained confidential and designated with identification codes to ensure no names, ages, and other identifying information could be linked to responses of the specific individual. Their rights will also be protected as were told they may skip any questions they are uncomfortable answering. Consent forms were separated from the data and matching identification codes with participants' names.

Chapter 3

Results

The purpose of this qualitative study was to explore experience of fathers as they parent a child with ASD to understand the stressors fathers experience in their day-to-day life and the implications on the family system. The study explored the experience of parenting a child with ASD by focusing on the experience of six fathers.

A phenomenological qualitative approach was considered most appropriate to structure the study as fathers were asked questions about their experiences to gain insight into what stressors fathers experience in their day-to-day life as a result of having a child with autism and impact of the child's condition on the family system. Interviews with six participants yielded different themes from participants' responses, including process toward acceptance of the ASD diagnosis, stressors, and impact on family system.

Data Collection and Coding Process

After interviews were completed via Microsoft Teams, transcripts were generated using recorded videos and imported into a Word document. The Word document was uploaded to Atlas.ti and interviews were coded to create themes. In vivo coding was used to develop themes. In vivo coding, also known as literal coding, refers to codes as literal words or phrases that were said by participants during interviews. A code is "the term used by participants themselves" (Strauss, 1987, p. 33). In vivo coding honors participants' voices, taking exact verbiage from transcripts and extracts what appears significant. Through reading transcripts, there were certain words or phrases that stood out, potentially attributed to impacting nouns, action-oriented verbs, descriptive vocabulary, clever phrases, or metaphors, and flagged for later reviewal (Saldaña, 2021).

After initial review of various flagged words and quotes, codes were organized into categories with similar messages. After codes were organized into different categories, codes were reviewed to ensure there was not a better category the code may have fit into. Each category was given a title, which was the essence of what was being said across all codes within each category. Each title was defined and compared to each code under the category to ensure the code fits with the category it is placed in or if the code may be better understood in another category to increase validity. Codes placed in multiple categories were identified and assessed to decipher which category best represents the meaning of the code, ensuring all codes were mutually exclusive.

To ensure reliability, various methods were conducted including member checking and peer debriefing. Member checking, also known as respondent validation, explores credibility of results by returning data to participants to check for accuracy of their experiences (Birt, 2016). Member checking was conducted during the data collection portion, specifically during semi-structured interviews, where responses of participants were summarized and questions followed a paraphrase such as, “did I hear you correctly?” or “is this right?” to ensure data being collected was accurate to participant’s experiences (Dawson et al., 2010).

Another way to increase reliability was the use of peer debriefing. Peer debriefing is when another individual is asked to code one deidentified manuscript to increase reliability. Peer debriefing increases reliability through focusing on accuracy of interpretations, preventing researcher bias and additionally increasing validity as researchers develop different ideas through new perspectives (Atladóttir et al., 2012). There are studies to support the most effective ways to conduct peer-debriefing, which is first and foremost, to select an impartial debriefer (Atladóttir et al., 2012). The impartial debriefer is asked to code a manuscript then discuss with the researcher initial impressions and questions the debriefer may have.

A fellow colleague was asked to be the peer debriefer for this research study. Although she was an outsider to the research topic, she was familiar with qualitative methodology through the completion of her own research dissertation study. The fellow colleague read through one transcript and then there was discussion on interpreting themes. After reading one transcript, the colleague identified different themes that stood out to her during her initial review.

During discussion with the colleague, she shared some of the key aspects that stood out to her were a derivative of questions asked during the semistructured interviews. She noticed specific questions where the participant had a lot of information to provide, such as questions about their family and stressors and certain questions where the father did not seem to have very much to say. From the peer debriefer's perspective, the father may not have had very much to say because he did not seem to resonate with the question asked. For example, from the peer debriefer's perspective, the father from the deidentified manuscript did not have very much to say about how cultural background and beliefs shaped how he viewed his child with ASD. As a result, cultural background and beliefs did not stand out to the colleague as a viable independent theme.

Some themes which stood out to the peer debriefer were how marriages were affected in addition to relationship with child, overall family dynamics, finances, relationships within the community, protective factors, and fathers' overall insights into how they make meaning of their child's diagnosis. During discussion, some themes were identified as sharing commonalities, leading to some overarching themes. For example, the peer debriefer noticed marriage, relationship with child, and overall family dynamics were consistently reiterated during the manuscript. As a result, the peer debriefer and researcher noticed an overarching theme could be impact on overall family system with subthemes of specific relationships within the larger family system, such as marriage, relationship with child, and family dynamics.

The peer debriefer also noticed the father from the deidentified manuscript mentioned difficulty in interpersonal relationships and not having very many people in the community to lean on for support. This stood out to the peer debriefer because when reviewing the transcript, she noticed in the father’s lens, it appeared the father and mother had to solely rely on one another for support. Discussion was had about the larger theme being stressors fathers experience as the peer debriefer also identified finances, health issues, stigma as other smaller subthemes that would be appropriately placed below stressors.

Lastly, the peer debriefer identified process of how fathers make sense of their child’s diagnosis as a theme because in the transcript, the father appeared to interweave his journey of making sense of his child’s diagnosis. The peer debriefer noticed the father shared initially experiencing disbelief, sorrow, and denial about his child’s diagnosis. However, the father appeared to quickly shift to problem solving by getting the child the appropriate services he needed which seemed to help with acceptance of the diagnosis. The researcher had identified one theme being acceptance toward the diagnosis; however, after discussion with the peer debriefer, the essence of the larger theme was reevaluated. The peer debriefer noticed throughout the manuscript rather than working toward acceptance, what appeared to resonate more was how the father gradually made sense of the child's diagnosis through learning more about ASD. Through discussion, the third theme was changed from working toward acceptance to process toward making sense of the child's diagnosis.

The fellow colleague also offered additional questions helpful to ask during the initial data collection process, specifically more demographic information related to religious backgrounds and age of fathers when they had their child with ASD. Overall, her input both confirmed and refined the processes and interpretation of coding. Peer debriefer's observations were consistent with researcher's interpretation of the data. The peer debriefer identified themes that addressed experience of fathers when parenting a child with ASD, which in fact overlapped with the researcher's themes.

The last method used to ensure high reliability was via intra-rater reliability. Intra-reliability was implemented as the researcher recoded one transcript and through SPSS Statistics, examined whether the researcher coded similarly during the first coding process in comparison to when coded the second time. A kappa analysis found extremely strong intra-rater reliability, $k = .925$, $p < .001$. The extremely strong intra-rater reliability displayed results were consistent and reliable.

The Fathers

Table 1 includes demographic information of all participants involved in the study. All participants (100%) were parenting a child with ASD between ages 5 and 8 years old. Four out of the six participants (66.67%) were the biological parent of the child with ASD, one out of the six parents (16.67%) was a stepfather, and one of the six parents (16.67%) had adopted their child on the spectrum. Five out of six participants identified as White (83.3%), and one of the six participants identified as Indian (16.6%). Four out of six participants had additional children alongside the child with ASD (66.6%). Four out of six participants' children with ASD were the youngest members of the family system (66.6%). One of six participants had a child with ASD who was the middle child (16.6%). All participants (100%) were married and received financial support from their partner in caring for the needs of their child.

Table 1

Demographic of Participants

Participant	Relationship to child	Ethnicity of father	Marital status	Sex of child	Age of child	Total # of children living in household
1	Birth father	White	Married	Female	5	1
2	Birth father	White	Married	Female	8	1
3	Birth father	White	Married	Male	5	1
4	Birth father	Indian	Married	Male	8	3
5	Stepfather	White	Married	Male	7	2
6	Adopted father	White	Married	Female	8	1

Overview of Themes

During the interview portion of data collection, each father was asked the same eight questions to gain greater understanding of their lived experience when raising a child with ASD. Despite different upbringings, family systems, cultural backgrounds, and religious beliefs, there were several underlying themes all fathers mentioned during interviews. Three major themes emphasized in each interview were related to process of making sense of their child's diagnosis, impact on family system, and lastly, various stressors fathers experienced.

Sense-Making About the Diagnosis

One larger theme that arose during interviews was the process of father's making sense of their child's diagnosis. Based on interviews, fathers' journeys toward making sense of their child's ASD diagnosis did not appear to be one pivotal moment but rather a collection of various moments. During the interview portion of data collection, fathers shared various factors contributed to how they made sense of their child's diagnosis. Each father's experience was different and yet shared some similarities. Fathers process of sense making of the ASD diagnosis began during the formal diagnosis.

Each father received the news about their child's diagnosis of ASD at different stages of life and in different ways. Participant 1 received a formal diagnosis for his child when his daughter was 2 years old and reported difficulty accepting the diagnosis initially. He and his wife both received master's degrees in business, and he shared his hope for child was she would receive continuing education, get married, and have children of her own. However, he shared soon after the ASD diagnosis, having a lot of concern for the implications of this diagnosis for her future.

Participant 2 had two adult children who moved out of the home when they had their daughter. He shared he and his wife had complications during pregnancy and had an idea their child could have a potential diagnosis, without clear details of what that may entail. He shared the pregnancy was stressful, and ultimately, he hoped for the safety and health of his wife and child. As a result of complications during pregnancy, Participant 2 shared some expectations of having a child with some special needs, which contributed toward his acceptance.

Participant 3’s child received an ASD diagnosis when the child was 24 months during a pediatric visit when the physician referred the child to get tested for ASD due to delay with certain developmental milestones. He shared feeling shocked and confused but quickly shifted to problem-solving mode, wanting to ensure his child got the services he needed.

Participant 4 and his wife had older children and so when Participant 4 noticed various unusual behaviors, he shared quickly knowing something was wrong. He began researching the symptoms his child displayed and got him tested shortly after, despite his wife’s objections, who was disbelieving.

Participant 5 was the stepfather to his son with ASD. He came into his son’s life when his son was a toddler and 1 year after, the family received a diagnosis of ASD for his son. Participant 5 viewed his stepson as his own blood son as he has been with him since he was a toddler.

Participant 6 was the last father who was interviewed. He and his wife adopted their daughter when she was 4 years old. During the process of adoption, their daughter did not receive an ASD diagnosis, but they were aware of some developmental issues. Soon after adoption, Participant 6 shared difficulty of not knowing how to communicate with his daughter as she was nonverbal. He shared she was aggressive and displayed behavioral concerns. The family took her to various clinics to get assessed and after a year, finally received a final diagnosis of ASD. The father expressed relief of receiving the diagnosis as the diagnosis gave them clarity as to next steps. After receiving a formal diagnosis, various factors played a role in their view of ASD, how they made sense of this diagnosis and their journey toward acceptance. The sense-making process fathers described was characterized by their outlook of the diagnosis, their response to the diagnosis, advocacy for their children, the protective factors involved, and their own personal growth.

Outlook

One aspect that shaped process of acceptance was outlook of how fathers viewed an ASD diagnosis. Participant 4 shared how his faith helped him move toward acceptance regarding his child's diagnosis. A pastor told him God looked from heaven at all the different places and decided Participant 4's family was the best home to take care of the little boy, which is why he was placed in their care. Participant 4 shared knowing this little boy was no accident, but God intentionally placed him with their family gave him peace. His faith and belief system shaped the way in which he viewed events that occurred in his life, specifically in this regard, his son's ASD diagnosis. Other fathers' outlook was also guided by upholding a broader perspective, such as other families are going through worse than them. Participant 3 said, "the grass is always greener on the other side." Participant 2 said, "we are on all this earth to be challenged." Participant 2 shared holding the belief individuals are on the earth to be challenged provided him with more acceptance, recognizing life will always bring hardships and difficulties but finding peace knowing tribulations produce perseverance. Participant 2's perspective on life impacts his outlook of an ASD diagnosis, "it's the way you approach life, you can be negative all the time or accept the situation is what it is."

Response to ASD

Based on fathers' outlook, fathers' responses to ASD shifted during process of sense-making of the diagnosis. Three out of six participants shared when they first received a formal diagnosis of ASD, they were in denial. Participant 2 and 5 shared they did not believe the ASD diagnosis initially. However, Participant 4 noticed early on some behavioral differences in his child and viewed the diagnosis as a missing puzzle piece. Three participants shared after receiving the formal diagnosis, their mindsets shifted to problem solving, such as next steps. These next steps included researching helpful forms of therapy for their child and getting them on waitlists for these services. In consideration of how fathers' response to a formal ASD diagnosis helps in the process of acceptance, Participant 1 shared he and his wife modify what they do based on their daughter's mood and are adaptable based on her needs. Two fathers indicated way in which they respond to their child is with flexibility and openness, ultimately putting their agenda on the wayside for the betterment of their child. These various responses provide greater context of ways in which these fathers navigated toward the direction of acceptance of their child's diagnosis.

Advocacy

Fathers addressed advocating on their child's behalf as another factor shaping their acceptance of their child's ASD diagnosis. The major way fathers advocated for their child using resources to provide their child with the best opportunities possible. Participant 4 disclosed prior to his son receiving a formal ASD diagnosis, he noticed some red flags were alarming in comparison to his other children's behaviors (e.g., rocking back and forth, walking on tippy toes, and echolalia) and did his own research of possible causes. After doing extensive research on possible causes, father shared how difficult it was to get his child on a waitlist to get assessed. Participant 2 shared one way he advocated for his child was ensuring she received academic support based on her diagnosis. Participant 4 shared due to some confusion from his child's IEP meeting, one year the school denied his child access to some resources (e.g., transportation aid). Participant 2 shared how he refused to leave the school until his daughter got the services she needed and not only that, but he wanted all new changes to be written down as he "wanted to be assured that this is done." Fathers also expressed advocating for their children in regard to health concerns. Participant 2 shared when his child was ill and unable to communicate with him what was bothering her, he told physicians to run all the tests until they figure out a solution. The persistence several fathers displayed in ensuring their child was well taken care of assisted them in coming to terms with the realization of an ASD diagnosis.

Supportive Factors for Fathers. Fathers' process toward acceptance was assisted by protective factors that enabled fathers to come to terms with their child's diagnosis. All participants shared a major protective factor in their life as being their social support system. Participant 3 disclosed to all his neighbors his child has ASD and are aware of procedures ought to be done if they ever find him wandering around the neighborhood unattended as he had a tendency to run away. He also shared having the support of his neighbors in addition to his family and friends has been very helpful. Four participants interviewed in the study expressed receiving a lot of support from their spouse. Participant 2 described the support he receives from his spouse as he said, "we are a team." Participant 4 reported giving his wife all the credit as they "tag team it." Participant 1 shared things would be different if one parent did not want to help out but because both parents work together, their lives seem manageable. Participant 4 shared a major protective factor for him was his faith in God. He recognized God trusted him and his family to watch over their son for a reason and God would continue to be faithful to them.

Personal Growth. The last aspect all fathers addressed when considering making sense of their child's ASD diagnosis is the ways in which they have grown during the journey. Fathers referred to various factors that impacted their personal growth. Some fathers recognized the way in which education contributed to their personal growth. Participant 1 shared he took a course in graduate school related to emotional intelligence and this class shaped how he viewed the world. He shared this course inspired him to broaden his outlook of the world and the people around him. Two other fathers shared they did a lot of research in the early stages of receiving their child's ASD diagnosis, which empowered them to have a better understanding of what the implication of an ASD diagnosis may have and ways to support their child.

Gaining a greater understanding of what ASD is and the implications for their child served as an area of personal growth as this journey toward learning moved participants to have a greater understanding and ultimately, grow as an individual. Participant 4 reflected being a better person because of his son's diagnosis, recognizing he was more kind, patient, and compassionate because of what he has learned from his son. Similarly, two fathers also noticed they were more compassionate toward others as a result of having a child with ASD. Participant 1 shared when his child was throwing a tantrum in a store, he noticed others looking at him and judging his parenting abilities. However, Participant 1 recognized he acted similarly prior to having children, sharing, "I would judge," but now he has learned to be more understanding. See Table 2 for additional participant quotes by subtheme.

Table 2

Sense-Making of ASD Diagnosis

Subtheme	Participant quote
Outlook	• To be honest, it's kind of just living in his world. It's not mine, we live in his world. • One time a Pastor told us from heaven God looked and said where is the best place to send him? God saw we were the best family to care for him and gave him to us so we will take care of him for as long as we can. • I feel like our kid fits in his own little world and we broke into it and are really happy to be part of it. • Because you have something bigger than us. • I feel like it's the way you approach life, so you can either just be negative all the time about it or you can accept what it is, and I think we've just accepted it. • We don't have complaints because God is with us. Yea, no complaints.
Advocacy	• Just like we're going to the doctor because something is wrong and we don't know what that something is and I don't care what test they run. Just run every test you could find. • We pushed hard to get her tested. • Expand our circle and then we tried to take others that are in our orbit and pull them to orbit into us so that they can get the resources they need.
Supportive factors	• I feel like my wife and I together as a team do really well. • So, I think I would say we surround ourselves with understanding people. • I think I have surrounded myself with pretty good and understanding friends. • We laugh a lot. • Everyone accepts him so we don't have that like negativity I guess. • And in Washington there's a lot of support. We have friends and family. So overall it's been a good experience. Like all my neighbors are aware, so everybody understands who he is. Everybody's been very understanding and helpful knowing that we might need some extra help for whatever reason. • So as a culture society, I feel like they're very understanding. • We don't have any complaints because God is with us.
Process toward acceptance	• Life throws you different things. • We chose her. • She was diagnosed with autism and that opened up a lot of doors for us. That's where you know, we got all the

Subtheme	Participant quote
	information on how to deal with her, what to expect and everything is pretty much spot on from what we've been told.
Response to ASD	• We did a lot of research on our own. • But then you see little glimmers every now and then something would happen and she would get sad and she would reach out for you. And you're like OK, there you go. • There is a connection. • It was difficult for me at first. I didn't really want to believe it. • We are blessed to have him. • Modifying like what you do based on like her mood and being very adaptable with what she needs. • I'm glad that we can do this for her. • We are committed for him. • Understanding that he has to fight every day to communicate and try extra hard in all that he does. I think we're trying to be appreciative of him.
Personal growth	• No, I mean I would see people or hear people say that it's a burden having a kid on the spectrum or you can't have fun anymore. I don't know, I feel like it's a different type of fun now, right? • So, I have never raised another "typical or normal kid" what they say. So, this is just normal to me. • I took as part of my graduate program, emotional intelligence classes and wrote a big giant paper about it and just being aware and seeing the world in a different perspective helped me not have tunnel vision. • It's hard but I was one of those people before we had kids. Yeah, I would judge. • There is more empathy and understanding now than before. • Priorities change.

Impact on Family System

Another major theme identified during interviews were the impact having a diagnosis of ASD has on the family system. Two of the six participants had one child, and that child has received a diagnosis of ASD. During interviews, both fathers expressed not being able to compare their child's behavior with others and as a result, this behavior was their normal. All behaviors and challenges with their child did not necessarily appear out of the ordinary as they expressed never raising a "normal child." Participant 4's child with ASD was the middle child and shared the entire family system centers around him. He shared how he frequently has advised one of his children to keep an eye on his son to ensure he is safe. Although Participant 4's son was the middle child, he shared it was as if he was the youngest child given how much extra attention he was given. Three of the six participants' children with ASD were the youngest in birth order. As a result, all three fathers knew what it was like to raise a typically developing child. Two of the three fathers shared parenting a child on the spectrum was more difficult because they knew what it was like to raise a neurotypical child. Although Participant 6 had older children, because they adopted their daughter and knew prior to adoption she had some behavioral and developmental disabilities, they went into the process of adoption prepared.

Changes to the Family System

One major way children with ASD impacted families was through the overall family system. Evidence from the current study supports Bronfenbrenner's (1979) ecological system theory that a change within the family system impacts all entities within the system. Aspects within the family system impacted includes marriages, role within the family, parenting style, relationship with child, and changes to expectations. As a diagnosis of ASD is given, all entities within the family system shift and find a way to adapt given this new change.

All fathers cited ongoing stress in marriages as their marriages become secondary in comparison to the needs of their child. Participant 4 described his marriage by stating, "we just lose ourselves where we just focus on what our child wants." Participant 2 shared how date nights have become difficult to plan as finding someone to watch their child has been difficult due to behavioral problems the child displays and if they could not find a sitter, they would have to bring their child with them. However, that means they have to choose a place kid friendly and if the child does not want to go, then plans will be canceled. Participant 1 shared his daughter insisted on sleeping between both parents, causing disagreements on parenting and frustration between spouses. Participant 6 held a unique perspective in comparison to the other five fathers, as he described his relationship with his wife previous to adopting his daughter as mundane and since adoption, he said, “our lives are no longer boring.” Four out of the six fathers viewed their child’s diagnosis of ASD as an added stressor in their marriage; however, the remaining two participants described the child brought excitement and fun to their lives. As some fathers shared a diagnosis of ASD impacted their marriage negatively, other fathers reported this diagnosis strengthened their marriage, as they had to learn to adapt and lean on one another.

When considering evolution of role of the father, two fathers described themselves as being “the fun parent,” full of tickles, wrestling, and constant games. Participant 2 described himself as “the rock” when he came home. He shared he has brought a different set of tools than his wife, who brings “the nurturing set of tools.” Participant 2 described himself as an enforcer and the disciplinarian within the family system. When considering parenting style, only Participant 2 described himself as the stricter parent, as the other five participants described themselves as the flexible parent.

Another consideration when examining changes to the family system is assessing the relationship with the child where fathers had varying perspectives. Two participants vocalized noticing a disconnect between themselves and their child. Participant 6 described this experience by saying, “[it is] a lot of heartbreak where you feel like nothing you do matters," and "the first year of adoption, it felt like she didn't care if you were dead or alive." However, over time, Participant 6 noticed glimmers of hope, such as if his daughter got sad and reached for her father, which indicated a slow progression of a relationship formulating. Two of the fathers reported no observable differences between their relationship with their child with ASD and other relationships parents may have with typically developing children as this child was their only child and it was "our normal." Participant 3 described his relationship with his son by saying, "he's the best friend that I ever had and I can't envision it any other way."

When considering expectations within the family system, two fathers described not knowing anything besides having a child on the spectrum and as a result, they had no expectations going into fatherhood. However, Participant 1, although having no other children, assumed his child would be similar to him (e.g., grow up to be athletic, go to college, have a family). Four of six participants who have additional children in the family all shared their expectations shifted when having their child with ASD. Two fathers expressed learning to be flexible with their expectations and being open to the child's capabilities.

Typical Week

Another subcategory derived from interviews when considering changes to family system is how a typical week is for a family. All fathers worked full time and shared different activities scheduled throughout the week for their child including various therapies and school. Two fathers mentioned no week was ever the same for their child as every day was dependent on how the child was feeling. However, four of the six participants emphasized routine being very important. Participant 6 shared how important he saw routine by saying, “It doesn’t matter what day it is; it doesn’t matter if it’s a holiday, it doesn’t matter if the house is on fire. Everything has to stay the same or the day is ruined.” However, Participant 6 described this routine as refreshing, unlike two of the other participants who described having this routine as difficult but being areas they were intentionally trying to improve. Both of these fathers mentioned they struggled with flexibility and adaptability but were learning not to be so set on their own ways. Participant 2 described this adaptability as losing his expectations and going with the flow and adjusting his expectations based on how his child is feeling.

Within a typical week, all fathers reported having various responsibilities required of them. As previously mentioned, all fathers worked full time and five out of the six participants mentioned difficulty in finding childcare if school or daycare was canceled for some unforeseen reason. Two participants shared their workplace offered them some flexibility to work from home; however, they shared watching their child and having to attend meetings was difficult. All six participants also addressed safety as being a responsibility they were to consider during a typical week. Fathers shared a pressure in constantly keeping an eye on their child with ASD, ensuring they were safe and engaged in a task.

Table 3

Impact on Family System

Theme	Participant quote
Changes Within Family System	• Sometimes we lose ourselves where we just focus on just doing what our son needs. • I hate to see my family go through the emotional stress of it. • We have to bring her everywhere. So, if she doesn't want to do it, we can't do it. It's too much stress for the rest of the family.
Marriage	• After the boys left the house, it was just me and my wife. And granted, we did a lot of traveling and other fun things. But honestly, until we adopted our little girl, our life was just kind of mundane. • Before she came into our life, our life was boring. Now, it's no longer boring. • The relationship gets put to the wayside.
Role Within Family	• I just look at things and I just want to fix it. • I'm always the rock when I come home. • I bring to the table a different set of tools and my wife brings to the table the nurturing tools. • She's the one doing a lot of heavy lifting, right? I just tried to help her when she needs it. • I just deal with things as they come. • I want to provide for my son and take away some of the emotional burden my wife is carrying. • I'm kind of the fun parent. • For the most part we try to cater to him and set boundaries. • There are two types of people in the world: people who have kids and those who raise kids. When you see parents with their children, you can easily tell who's raising kids versus having kids. My wife and I decided when we have children, we want to raise them, offering them tools and skills to be self-sufficient, good citizens.
Parenting Style	• Each one of them gets something proportionate to their attitude and who they are. • We try to have flexibility. Proportional discipline and proportional expectations based on each child's ability. We don't do one size fits all. • I try to pick my battles.

Theme	Participant quote
Relationship With Child	• We have a good relationship but it’s not in the traditional way as it would be for another parent who has a typically developed child and their relationship. • He’s my best friend. • We’re close but there’s always a disconnect like sometimes I feel like there are days where he doesn’t care if I’m there or not and then I just have to hope the next day will be better. • You know the first few years when we got her, she didn’t care whether you lived or died, whether you existed or didn’t exist. She didn’t miss anybody. She didn’t miss anything. • There was a lot of heartbreak where you where you feel like anything you do doesn’t matter; you know like it didn’t matter to her. You know, but then you see little glimmers every now and then she would something would happen and she would get sad and she would reach out for you. And you’re like OK, there you go. There is a connection. • There are days where he’s not emotionally there. • He’s closer to my wife but he is friendly and playful with all of us. • I have to be in tuned with him, kind of his every need and want. He’s my best friend that I had ever had, and I can’t envision it any other way.
Expectations	• We’ve done a good job of setting up the expectation that he is who he is. • We came to the acceptance that he’s not going to do things as fast as other kids. • I don’t know the difference since he’s my one and only kid and it’s just normal now. • My wife and I both have Master’s degrees and I thought, is my daughter even going to be able to go to college. • I took her to the zoo for the first time and thought we’d just walk around and look at all the different animals. But when we got there, all she wanted to do was look at the gift shop. • I thought he would be athletic like I was. • When we heard about the diagnosis, I kept thinking how she going to live? Because when my wife was pregnant, I had like I formed all these expectations in my mind. • My wife used to babysit a girl who was on the spectrum. She was nonverbal, pretty violent and a hand flapper. So,

Theme	Participant quote
	when our daughter got her diagnosis, I figured she'd be like that too. I thought all autistic kids were like that.
Typical Week	• I wake up and do the same thing every single day. • Every day is challenging. • If you spend one day with him, you know how stressful it is. • We have a morning checklist and an evening checklist of things for her to accomplish each day. • No week is ever the same.
Routines	• Routines are very, very important for a daily week. • She's pretty routine oriented and if we ever have to kind of change what we're doing, it's hard as transitions are difficult. • Everything has to stay the same. • You have your routines and everything needs to stay the same so it doesn't matter what day it is, doesn't matter if it's a holiday, it doesn't matter if the house is on fire. Everything has to stay the same. • It's kind of refreshing to have a solid routine.
Adaptability	• We have to bring her with us and if she doesn't want to do it then we can't really do it. • Modifying like what you do based on like her mood and being very adaptable with what she needs. • But being able to do things with her and keeping her attention on just whatever project or activity is a little difficult and I found that I have to be like really flexible in my thinking.
Responsibilities	• You know there are days where we get a little bit exhausted with everything and those might be the days where she has cookies for lunch. In those moments it's just like eat the cookies and leave me alone for a minute. • I'll come home from work and my wife will tell me he doesn't like this anymore and I take a mental note of it. • I've learned to accept that some of these things are just not that big of a deal and not worth getting upset over. • I feel like I kind of owe it to him to make sure that he has his best life and I don't want to ever look back and say I could have done something more for him. I guess it's a self-reflection of me wanting to provide for him. • But our eyes are always on him. Anytime he even goes to open the garage, you know, one of us follows him." • We are committed for him. • He can't sit at home on his iPad as we're doing stuff so he has to have constant care.

Stressors

The last theme derived from interviews were different stressors fathers experience when raising a child with ASD. All fathers shared unique perspectives of stressors based upon individual differences. Differences fathers mentioned are a derivative of the context of their own lived experience. Some subthemes fathers addressed as being stressors for fathers include service and resource management, stigma, health issues, behavioral problems, society, diagnosis, and time.

Service and Resource Management and Finances

All fathers mentioned their child receives various services such as applied behavioral analysis therapy, occupational therapy, speech therapy, in addition to services offered at school. As fathers described various services their child requires, the stress they experience is in relation to cost of services. All six participants acknowledged how expensive all the services are. Three of the six participants expressed thankfulness for their place of employment that provides them with good insurance and recognizing if they did not have good insurance, they are unsure how they would make various payments. Participant 2 shared despite receiving insurance from work, he and his family actively looked for drawings to enter to receive financial support. He shared his son needed an iPad to assist in speech and it was very expensive. He and his wife looked for alternate solutions. They entered a contest tailored to parents raising a child with ASD which was organized by the Seattle Seahawks team, offering a free iPad and won. Other fathers also shared being intentional about trying to use free resources offered to the public through entering contests, submitting applications to different organizations, etc. All participants expressed things that may be overlooked by the general public but takes a significant financial toll on the family, such as Participant 6 shared his daughter requires diapers, Participant 3 disclosed his son's speech therapist suggested he buy an app for his son's iPad to help with speech, which could be $300, and two participants shared buying their children a balance bike instead of a regular bike was also costly.

Stigma

Another stressor fathers in the study addressed was stigma associated with having a child with ASD. Four of the six participants noticed judging eyes when their child was displaying behavioral problems. Participant 2 observed receiving the most judgement from individuals who do not have children. In response to disapproving glances from strangers, Participant 4 shared feeling uncomfortable and recognizing "those people are jerks and [he] will never see them again." Another form of stigma associated with an ASD diagnosis fathers experienced were feeling misunderstood by others. When Participant 6 was in the process of adopting his daughter, there were a lot of warnings and the case worker who was assisting himself and his wife with the adoption process said if they change their mind in 90 days, they can let the agency know. Participant 2 noticed others referring to children with ASD as a burden or not being able to have any fun, but he denied this being his experience.

Physical and Mental Health Issues of the Parent

Physical and mental health issues were another stressor fathers brought up as four out of six fathers mentioned their health has declined after their child's ASD diagnosis. Participant 3 shared he had a heart attack a few months prior to the interviews and Participant 4 disclosed having high blood pressure and diabetes; however, neither father linked their physical health ailments as a result of their child with ASD. Three participants expressed anxiety over issues surrounding their child, such as who would take care of the child when either parent passes away, how they provide for their child, and would their child ever be independent. Three participants shared feeling the pressure of not only caring for the needs of their child with ASD but also feeling responsible for caring for the emotional needs of their spouse. Participant 1 described this pressure to take care of his family as a soda bottle constantly being shook to the point where the bottle explodes.

Behavioral Problems

Behavioral problems were a common stressor fathers addressed that impacted their overall lived experience. Behavioral problems father endorsed their child displays includes physical aggression, issues with safety, and difficulties with communication. Five of six participants shared their child engaged in physically aggressive behavior, such as hitting, biting, pinching, or throwing things. During one occasion at the park, Participant 5 shared his son was trying to say hi to another girl and he pinched her to gain her attention. However, fathers in the study disclosed their children were not solely physically aggressive toward their peers but also to adults. Participant 2, for example, shared about 6 months prior, his daughter slapped him on the chest, leaving a mark that lingered for several days. Stress of their child physically aggressing toward others was a concern for safety and was a stress when considering implications on services received. Participant 4 was asked to leave the daycare due to difficulty in listening and Participant 5 disclosed due to physical aggression displayed toward his peers, his son was expelled from school. In a limited amount of time, fathers have had to find new daycares and schools for their children to attend, being aware of the possibility a similar event could reoccur.

Safety is another stressor related to behavioral problems as all six participants shared the necessity to continually keep an eye on their child for safety reasons. Participant 2 disclosed they could never leave their child alone but continually kept an eye on him. Participant 4 reflected one day spent alone with his child was exhausting because he was constantly following him around. Participant 4 also shared concerns of safety of the child limits social outings as he recognized his child was very active and if visiting someone's home and they had a balcony or a 2-story house, if his son was not watched closely, he would try jumping off a ledge. Difficulty communicating with their child was another stressor as fathers did not know what their child was asking for, leading to an increase of behavioral problem. Participant 6 described his child as nonverbal; however, four of the other fathers shared their children talked a little bit through the help of different therapies and Participant 2 shared his daughter talked too much. Four of the six participants addressed their child would perform various nonverbal behaviors to communicate how they are feeling, such as pinching, throwing things or motioning with their hands if they want something. Participant 6 shared because his daughter was nonverbal, there were moments where she displayed behavioral problems, signaling to her father she was unhappy but her father expressed frustration at times due to not knowing what she was trying to tell him.

Table 4

Stressors

Theme	Participant quote
Service and Resource Management	• ABA, children's therapy, school, physical therapy, occupational therapy, speech therapy • Lucky for us, our pediatrician is on speed dial. • I don't know. I lose track of all the services he gets. • We've hired an attorney to help us negotiate with the school to help them pay for one of those other private schools. • We were we were in the fostering process and had a social worker that would come every month.
Finance	• Seahawks had a special program where they were giving away an iPad to a family who had an autistic child and we won. • She had some deformities in her mouth and so last July she went in and had surgery and had all that repaired. • Some of the educational apps to download for his iPad cost around $300. • She's in diapers still and so that definitely gets pretty expensive. • So, we privately paid for speech the whole time because we can only get so many services through insurance.
Stigma	• I think we get the most judgment from people that don't have kids. • There were a lot of warnings when we adopted our daughter, like are you sure you know what you are signing up for. They also said in 90 days if it feels like this isn't working, just let us know. As if she's like a puppy, and if you don't like her anymore you can give her back and we'll put her back in her cage. • We go to the supermarket and he knocks boxes off shelves right, and people get annoyed. Here's the thing. It is what it is. • Someone is starring at you, you know. It's likely I'll never see those people again.

Theme	Participant quote
	• And then people start looking. You know, there's those people that stare and it's like super uncomfortable.
Feeling Misunderstood	• We've been in public and people have said things and done things, not understanding her situation. Just seeing her as a little spoiled brat. • When my child is having a tantrum in public and people are starring, it's difficult to deal with in the moment. But after the tantrum is over, I just move on thinking those people were jerks. • When my daughter is with others, she's pretty well behaved and then when she's with us, it's like all the misbehavior she's been holding in all comes out. But nobody sees that side of her. People say she's perfect and don't know what we see.
Health Issues	• We're pretty active people and good health and able to give him everything he needs athletically in terms of chasing him, climbing, running around, picking him up, he's a very physical kid so I'm lucky I can keep up • I have health problems but it's just because I'm getting old, it's not his faut. • Sleep is difficult. • In December, I had a heart attack.
Mental Health	• No sleep issues, no anxiety issues, weight gain, nothing like that for me. • I'm in counseling to help deal with some of the anxiety and depression. • You know just little things can increase anxiety. • I imagine it's like a soda bottle like you're constantly being shook and then I imagine it's just too much sometimes. • You start losing sleep because you just worry.
Behavioral Problems	• She has a lot of meltdowns. • She used to pinch a lot but has grown out of that. One time, she slapped me with an open palm and there was a huge red mark across my chest. • She's like a tornado.
Safety	• We have a two-story home and I had to build the plexiglass wall up my stairs so he wouldn't jump off the stairs

Theme	Participant quote
Communication	• We have a hard time going out in public because it’s a safety thing right, he won’t hold your hand in public and he runs around all the time. • But you have to constantly be watching him right now. We don’t leave him. We cannot leave him alone. That’s exhausting. So very tiring. • She doesn’t speak well, she’s technically nonverbal. So, if she doesn’t want to do something, she can’t tell you that. Instead, she’ll throw a tantrum, throw something or walk by the coatrack and knock down all the coats. • She was becoming intolerant in school and we didn’t know what was happening so we decided to take her to the doctor to see if maybe she’s acting out because medically, something is wrong. • We’ve had plenty of tears in the morning because we are not meeting her needs.

Summary

The recent qualitative study examined the experience of fathers who raise a child with ASD to gain insight into their lived experience. Data were collected through demographic questionnaires and semi structured interviews and using in vivo coding, themes were formulated. Themes derived from data analysis included process of sense-making of ASD diagnosis, impact on overall family system and stressors fathers’ experience. Smaller subthemes arose from the larger themes that offer more understanding of fathers’ lived experiences.

Chapter 4

Themes From Current Study and Existing Literature

The present study explored the experience of fathers who have a child with autism spectrum disorder (ASD), which extends to other existing research, providing greater awareness for fathers who have a child with ASD. Fathers examined in the study all described unique ways in which they were impacted by having a child with ASD. Through understanding fathers' lived experiences, various clinical implications are offered to better serve this population. Additionally, future studies can consider strengths and limitations of the current methodology to aid in further understanding the experience of fathers as they raise a child with ASD.

Fathers' Process of Adjustment

The first theme derived from the experience of fathers involves the process of adjusting to their child's recent diagnosis of ASD. Fathers described how they made sense of their child's diagnosis. From their perspective, fathers shared what contributed to their adjustment of their child's diagnosis. Fathers included outlook, response to ASD, advocacy, supportive factors, and personal growth as contributing to their process of adjustment.

Fathers' outlooks on their child's diagnosis were shaped by faith, beliefs, and their overall perspective on life. Existing literature displays individuals with devout philosophies on life have fewer symptoms of depression and anxiety and cope better with stress (Rettner, 2015). As a result, fathers in the current study who held strong faith, beliefs, and philosophy on meaning of life were possibly more likely to have a more positive outlook on their child's diagnosis. Previous literature shows individuals who practiced faith beliefs or engaged in meditation had more activity in frontal-lobe areas, ultimately strengthening areas of the brain that equip individuals in being more calm and able to deal with various stressors (Rettner, 2015). A few fathers in the current research study described a more optimistic and accepting viewpoint of their child's ASD diagnosis which could be explained by religious or philosophical engagements they are immersed in.

A monumental moment that impacts fathers' response to ASD, according to Burrell et al. (2017), is when parents receive a formal diagnosis of ASD for their child. Research has demonstrated fathers who were not expecting their child's diagnosis often take more time to reach acceptance and manage their own expectations of the capabilities of their child (Hartmann, 2020). Fathers in the current study who knew their child was on the spectrum shared reaching acceptance more quickly perhaps because this diagnosis was something to which they were gradually exposed, as opposed to other fathers where this diagnosis was seen as a shock.

One primary supportive factor the fathers mentioned regarding sense making of their child's diagnosis was support they received from others. All fathers reported having a partner who assisted in caring for needs of the child. Fathers more satisfied with their social support system are less likely to feel overburdened as a parent (Camilleri, 2022). Fathers may feel less burdened when having social support due to decrease in feelings of isolation. The connection between social support acting as a supportive factor can be explained through various studies where social support is a barrier between stress, depression, and social isolation (Dunn et al., 2001; Falk et al., 2014).

Role of advocacy equips fathers toward sense-making of an ASD diagnosis. Four of six participants reported receiving an ASD diagnosis helped in the process of acceptance, which was the catalyst toward taking appropriate next steps. According to Burrell et al. (2017) and the current research participants, next steps after receiving an ASD diagnosis were getting connected with different services and resources. Fathers tend to take a role of being the problem solver (Falk et al., 2014). The desire fathers may feel to advocate on their child's behalf may be viewed, in their eyes, as finding a solution. Similarly, in the current research study, four of six participants mentioned they took the initiative to get their child tested for ASD, found different therapies, and advocated on their behalf at school. One father in current research study went to the extent of going to the school, refusing to leave until there was written proof his daughter would get the services she needed, after she was denied services due to a misunderstanding. Receiving a diagnosis of ASD can feel powerless to some fathers (Yi, 2018). To regain a sense of control, fathers may take it upon themselves to be an advocate for their child's needs, ensuring they get the care they need.

Family System

The second theme identified from analysis of data was impact on family system. According to Bronfenbrenner's ecological system, each complex multifaceted layer within the environment has a different impact on the individual (Paquette & Ryan, 2001). Changes or disruptions to one layer of an individual's environment has a direct impact on all other layers of an individual's ecological system (Paquette & Ryan, 2001). The immediate environment and interactions among the larger environment must be considered. Family systems theory reinforces Bronfenbrenner's ideology that when a major change occurs within the family system, all dynamics within the family shifts (Yi, 2018). Different ways the family system shifts are through marriages, parenting and parental role, relationship with child and expectations related to child with ASD. Another subtheme that provides greater context to the impact on family system is what a typical week looks like for fathers. Related to a typical week, fathers described their routines, the importance of adaptability, and lastly, their responsibilities.

Family systems are impacted by their child with ASD as a whole and within different relationships among family. Stressors within the family system have a direct impact on parents' marriages, causing partners to become more closed off and taking out their stress on one another (Grey, 2018). Some fathers shared that they had less date nights, their child coslept with the parents, and their world revolved around their child with ASD. The focus shifting from the marriage to their child with ASD can lead to a lack of attunement and distance, creating less opportunities to be vulnerable with one another. However, research displays stress may also be beneficial in a marriage depending on one's outlook (Grey, 2018). If stress is viewed as a way to navigate difficulties together, the relationship can be stronger.

Fathers in the current research study who noticed symptoms related to ASD or expected their child to have ASD appeared to have a stronger relationship with their child than others who were not expecting an ASD diagnosis. Previous literature overlaps with current findings, demonstrating fathers have a more difficult time connecting with their child in comparison to mothers, especially when they did not expect a diagnosis of ASD (Yi, 2017). These results could be explained through less time to grieve the loss of the expectations and dreams they held for their child (Hartmann, 2020). One participant in the current research study went into the adoption process knowing his daughter had some developmental disabilities and so 1 year later, when she received a formal ASD diagnosis, he vocalized being more attuned and more flexible to her needs. This was contrary to some other fathers in the research study who, prior to diagnosis, were unaware their child was on the spectrum and reported more behavioral problems and difficulty connecting with their child.

As fathers have expectations of what their relationship with their child may look like, these expectations exceed beyond parental relationship and include achieving some form of success in life (Grey, 2018). Fathers in the current research study who had higher education, expected the same for their child. Fathers who had children prior to their child with ASD had expectations their child would develop similar to their other children. The expectations fathers uphold for their child with ASD appear to be derived from previous experiences, such as life experiences of parents or their other children.

Ongoing Challenges and Stressors

The third theme identified from data collected was related to overall stressors fathers experienced. The subthemes that followed overall stressors of fathers included services received, finances, health issues, behavioral problems of the child, lack of social support, and stigma of ASD diagnosis. The themes derived from the current study were highly consistent with previous research on parenting.

One stressor the fathers mentioned was gaining the adequate services for their child. Gaining adequate services for their child requires extensive time trying to get their child on waitlists, working with different providers, and paying for additional tools to assist their child. The need for specialized accessories (e.g., diapers) and equipment (e.g., balance bike) for fathers in the current study was expressed as an ongoing stressor, particularly due to financial cost. Existing research shows although parents may have good insurance from their place of employment, additional tools that benefit their child would not be covered under insurance and can be a financial burden (Olley, 2005). Fathers may have a difficult decision of wanting to give their child everything to help them succeed but feel like they need to pick and choose what interventions to pursue based on their income.

As fathers are problem solving and considering appropriate next steps for their child, existing research and the new research study displays fathers lack adequate social support to keep them grounded. Previous research has documented the tendency of fathers to isolate themselves, feeling like there are not many who can relate to what they are going through (Hartmann, 2020). All fathers reported receiving some form of support whether it was from family, church, the community, or counseling. However, in everyday life, none of the fathers mentioned receiving support aside from their partner. In day-to-day life, fathers seemed to need support with assistance in caring for their child and conversations related to fathers' experiences of raising a child with ASD. All fathers in the current research study recognized not many people can relate to what they are going through, and existing research displays how isolating that experience can be.

Existing literature shows fathers tend to isolate when they feel the need to manage the expectations of family and the pressures feel excessive (Olley, 2005). Participants in the current research study shared not only having to manage children's expectations but also their spouses' expectations. Pressure to manage the other members in the family's expectations can be burdensome for fathers. Although participants in the study disclosed having support in caring for the needs of their child with ASD, participants did not address receiving emotional support from others in their community. Little information from participants about the emotional support from others could be a result of not believing information was relevant to mention in the study or not experiencing emotional support to report from others in their community.

Stigma is another challenge fathers reported experiencing when parenting a child with ASD, as they felt misunderstood and judged by others. Five participants in the study shared different experiences of being stared at by others at the store, having unsolicited comments by family members or declining invitations to go to events due to fear their child would act inappropriately. Existing research shows for some individuals who have a child on the spectrum, as a result of stigma, individuals will avoid going to certain events or engaging in activities where they may feel criticized or shamed by others (Hartmann, 2020). As a result, this makes their world smaller, inhibiting fathers from doing things they normally would have done otherwise.

Clinical Implications

One way fathers could receive support from the community is through gaining access to more resources that help provide funding for their children. For the father whose 8-year-old daughter was wheelchair bound and using diapers, he expressed financial difficulties of paying for various expenses. Several other fathers in the study expressed intentionality of taking advantage of resources that offered financial support but vocalized more resources being needed. Families who have two parents working full time may not be enough considering all the additional costs their child with ASD requires.

In consideration of already existing research in addition to the new research gathered, evidence supports for some fathers who parent a child with ASD, the experience can be isolating. Although existing and new research displays various services and supports such as therapies for parents and children and private organizations that assist in cost for therapy, these services and supports help individuals through a macro lens, little evidence displays support offered to fathers on a micro level. For instance, although there may larger resources and agencies that can offer families' and their child support, there appears to be little support for the individual needs of the fathers.

Existing research displays fathers in general, do not feel comfortable disclosing personal details about their life with others (Hartmann, 2020). However, research has shown peer support is dependent on the father, as some may want to compartmentalize different areas of their life, but this may not be the experience of everyone (Johnson, 2012). Desire to compartmentalize areas of one's life could be attributable to fathers with a child with ASD having worse psychological well-being than fathers of other developmental disabilities (Hartmann, 2020). In regard to compartmentalization, one of the participants in the current research study shared when he got home from work, he felt like he was "stepping on duty," indicating his role at work versus at home was widely different. However, if roles are compartmentalized, there may be difficulty in understanding the experience of fathers.

Therefore, fathers ought to have space to process things occurring in various aspects of their life through interpersonal relationships. One way transparency and vulnerability of fathers can be encouraged is through a decrease in stigma of ASD. Several fathers in the current research study shared feeling judged by their family. One father shared his in-laws blamed the parents for the child's behavioral problems, indicating they were the ones who "spoil her." Existing research displays when a child is displaying behavioral problems in a public setting, parents are often the victim to blame and judgement (Johnson, 2012). However, placing judgement on parents reinforces the mindset fathers may have of being unsupported by others, continuing the narrative father's ought to compartmentalize the various areas of their life.

One way to disrupt the narrative father's ought to compartmentalize various aspects of their life is through providing psychoeducation. Offering psychoeducation on symptomology, different parenting techniques and information regarding impact on parents who raise a child with ASD are just a few ways fathers may benefit from psychoeducation. Several fathers in the current study mentioned being unaware of the implications of their child's diagnosis on their life. Providing more opportunities for psychoeducation and resources may empower fathers to feel less isolated and more equipped as they parent a child on the spectrum.

Findings from the current research study can be applied in therapy through recognizing the areas in which fathers may have a difficult time, such as managing behavioral problems, impact on marriages, finances, and social isolation. This greater knowledge may guide mental health professionals in therapy to be intentional about asking about various aspects of one's life.

Another consideration of integration of these findings in therapy is cultural background. Five of the six participants identified as White, and one participant identified as Indian. Culture is one multifaceted layer that has an impact on individuals (Paquette & Ryan, 2001). Culture impacts the way individuals see the world around them.

Enculturation is the process of cultural values, beliefs, ideas, and patterns of behavior instilled into individuals; therefore, contributing to one's sense of meaning (American Psychological Association, 2022). One participant who identified as being from a cultural background other than White may have a unique experience in comparison to other participants. As a result, mental health professionals ought to consider all the different aspects of one's lived experience when working with individuals, including their cultural background.

Through the current research, it is evident there is a lack of resources and community support for those who parent a child with ASD. As a result, one way in which the community may advocate for these families is through equipping themselves with knowledge and identifying where the need is. For instance, some of the participants from the current study shared difficulties with finances. As a result, partnering with different organizations to assist in funding may alleviate some financial stress and create more opportunities for others to gain financial support. Additionally, decreasing stigma with mental disorders can make individuals more comfortable disclosing their hardships and seeking out help.

Strengths and Limitations

The strengths and limitations of the current research study are important to consider when understanding implications of the data. Being aware of these strengths and limitations inform how one may interpret results and the perspective in which the data collected is viewed. All fathers were heterosexual and married to someone of the opposite sex. Considering fathers were all in committed romantic relationships and shared similar sexual orientations, results would not be generalizable to those in same sex relationships, those who are parenting a child with ASD independently and those in other family structures. Another limitation of this study to consider was all participants were recruited from one applied behavioral analysis clinic. As a result, these results may not be as generalizable considering perspectives may be skewed based on geographical location of fathers. Due to the sample size being so small, with only six participants interviewed, there was a lack of generalizability of fathers' experiences.

When examining limitations of the study, it is also important to consider the strengths. One strength of the study was the even ratio of fathers who had boys and girls. Having three fathers who raised daughters and three fathers who raised sons provided more perspective on the experiences of raising different children on the spectrum. As a qualitative research study, the overall methodology was a strength. The methodology was a strength as the study allowed various perspectives and experiences to be heard. Having a semistructured interview allowed some main points to be addressed and then allowed space for fathers to add any additional information as they saw relevant.

Future Research

Analyzing the strengths and limitations of the recent study provided a framework of what can be done in future studies to increase reliability and validity. To increase generalizability and gain more insight into various perspectives, future studies should consider recruiting participants from various applied behavioral analysis clinics or other sources. The benefit of recruiting participants from different sources would be gaining the opportunity to hear different lived experiences. Another way to gain awareness of the lived experience of others in future research would be to focus on families with fewer resources, as the difficulties they endure may be vastly different than those in other socioeconomic backgrounds. Individuals with fewer resources may have limited access to treatments and less support, causing a very different lived experience than others who have more resources. As a result, gaining understanding of the experience of those with fewer resources offers a more well-rounded understanding of the lived experience of different individuals and ways to offer support.

Another consideration for the future would be to recruit fathers with various relationship statuses, including those who are single, married, casually dating, in committed relationships, and open relationships, to see how these factors may also play a role in fathers' lived experience. The current research study interviewed six fathers to gain insight into their perspective of what it is like to raise a child with ASD. To gain a broader understanding of ways in which fathers are impacted by having a child with ASD, a larger sample size would be helpful. A larger sample size would essentially mean more fathers' perspectives are considered and ultimately, more implications of the data would be available. A wider sample of ages of children with ASD would also be helpful as parents' experiences may vary significantly with children's age. Parents may encounter different stressors based on where their child is developmentally. Lastly, future studies that include a grounded theory methodology studying both mothers and fathers allow a wider understanding of parents' experiences in general. Through understanding the similarities and differences between mothers and fathers, quantitative measures could be developed as screening tools to monitor and better support parents.

Conclusion

Through studying the lived experience of fathers who have a child with ASD, research displays ways in which fathers may benefit from additional support. Fathers may benefit from additional financial support and greater awareness of the experience of raising a child with ASD. As fathers may feel isolated, misunderstood, and pressure to carry the family, there is importance in recognizing ways they may struggle and offer support as needed. Themes derived from the current research study coincide with already existing research, indicating themes collected were accurate to the experience of some fathers. Future studies ought to continue exploring the lived experience of fathers as they raise a child with ASD to find additional ways fathers who raise a child with ASD may be supported.

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Appendix A

EMAIL

LIVED EXPERIENCE OF FATHERS

Hello! My name is Jean Varghese and I am in my fourth year of graduate school at Northwest University, working toward my PsyD. For my dissertation, I am interested in studying the stressors fathers encounter as a result of having a child with autism. Every person has a unique life story and I desire to gain insight into their experience. If you are a father of a child aged 3–8 years old with autism, please contact me if you are interested in participating in a 40–60-minute interview and brief demographic questionnaire. The interview will be held via Microsoft Teams. Individuals who participate in this study will be entered in a raffle to win a $25 gift card to Amazon. Please don't hesitate to reach out if you have any questions!

Contact Information

Jean Varghese

[redacted]

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Dissertation Chair/Advisor

Dr. Leihua Edstrom

[redacted]

[redacted]

Appendix B

DEMOGRAPHIC QUESTIONNAIRE

The questionnaire protocol will entail the following questions:

1. What is your age?
2. What is your marital status?
3. What is your highest education completed?
4. What is your ethnic background?
5. How old is your child with autism?
6. How many children do you have?
7. At what age was your child diagnosed with autism?

Appendix C

INTERVIEW QUESTIONS

1. Describe what a typical week looks like for you parenting a child with ASD and the different activities that are involved.
2. Has anything changed about your family since your child was diagnosed? Such as relationships, expectations and roles within the family system.
3. Describe your relationship with your child with ASD.
4. There are various forms of parenting. Authoritarian parenting is viewed as disciplinarians where punishment is common, having high expectations with little flexibility. Then there is permissive parenting, where parents allow their children to do what they want, having little to no rules. Authoritative parenting is when parents are reasonable and nurturing, setting expectations that are clear. Describe your parenting style.
5. Autism spectrum disorder is understood in different ways by people. Has your cultural background or beliefs shaped how you view your child with ASD? If so, how has it shaped how you parent your child with ASD?
6. How is your health? Have you had any health problems occur since your child received their diagnosis?
7. What are all the different services your child receives? Have the different services impacted your family system financially? If so, please elaborate.
8. Have there been any stressors or challenges that have arose since your child was diagnosed with autism? If so, please explain.

Appendix D

CONSENT FORM

LIVED EXPERIENCE OF FATHERS

Northwest University

Jean Varghese

Project Description

The purpose of this study is to understand the lived experience of fathers who have a child with autism spectrum disorder. If you agree to participate in this study, you will take part in a 40–60-minute interview through Microsoft Teams. Your name and identifying information will not be mentioned during the interview. Any information, including identifying information that you do provide, will be kept confidential. All collected information, such as consent forms, demographic questionnaires and field notes will be kept in a secure online cloud storage. During the interview, you will be asked questions about your lived experience, specifically related to parenting a child who is on the spectrum, such as the different stressors you experience, any shifts in family dynamics, cultural considerations, health issues and finances. The interview will be video-recorded through Microsoft Teams and the researcher will be taking notes to better understand your responses.

Benefits and risks

There are minimal risks associated with participation. Some individuals may feel uncomfortable answering personal questions and are welcome to omit the answers to those questions. Individuals may feel distress, anxiety or other emotions when answering questions about their child or parenting. Some individuals may also worry that their responses to the questionnaire and interview will be able to link back to the participant. No identifying information, such as name, age or city of origin will be mentioned in the study.

If you would like to seek help in processing negative emotions as a result of this study, you are encouraged to find a counseling center to receive help. Psychology Today is an online platform where individuals can find therapists that fit their needs and can assist with connecting individuals to therapists in their area. This can be accessed through www.psychologytoday.com. Affordable Counseling is another organization that is located in Edmonds, WA and offers counseling services on a sliding scale, serving individuals with a variety of mental health needs. Affordable Counseling can be contacted through http://myaffordablecounseling.com or by calling 425.778.5544. Seattle Christian Counseling is a large organization that offers counseling services in a variety of locations, with the opportunity for online counseling as well. This can be accessed through https://seattlechristiancounseling.com.

The benefit of taking part in this study is the opportunity to participate in a research study. You will also have the opportunity to share your own lived experience during the interview. Participants who are willing to participate in the study, regardless of whether all questions on the interview or questionnaire are answered, will be able to enter a raffle to win a $25 gift card to Amazon.

Principal Investigator

The principal investigator is Jean Varghese. If you have any questions or concerns, please email xxxxx@northwestu.edu.

Voluntary Participation

Your participation in this project is voluntary and you are free to withdraw your consent and discontinue participation at any time without penalty. You will still have the opportunity to participate in the raffle.

Use of Data Collected

Results may be presented at professional conferences or in publications. No personally identifying information will be stored or disseminated with the results. The audio video recordings will be destroyed by December 31st 2021. The digital deidentified data will be kept in perpetuity specifically the transcripts, field notes and code book.

Confidentiality of Records

Your confidentiality will be maintained by placing only a code number, and no personally identifying information, in resulting data files. We will keep track of who participated in the experiment and this information will be confidential, but we will not be able to tell which participant produced which data file.

As this is via Qualtrics, please print this consent form if you would like a copy for your records.

Participant's Rights Information

If you have any questions concerning your rights as a research subject, you may contact the Chair of the Institutional Review Board, Dr. Cherri Seese at [redacted] for information or assistance.

Participant's Consent

The study has been described to me and I understand that my participation is voluntary and that I am free to withdraw my consent and discontinue my participation in the project at any time without penalty. I attest that I am at least 18 years of age. I also understand that the results of the study will be treated in strict confidence and reported as group data sets without personally identifying information, possibly in scholarly publications. I understand that if I have any questions or concerns about this experiment, I may pose them to Jean Varghese or Dr. Leihua Edstrom.

Jean Varghese
Doctoral Student in Counseling Psychology
College of Social and Behavioral Sciences
[redacted]

Dr. Leihua Edstrom
Dissertation Chair
College of Social and Behavioral Sciences
[redacted]

I have read and understand the above information and I consent to participate in this study by signing below.

____________________________ _________________________

Digital Signature Date