

FATHERS' EXPERIENCE WITH AUTISM SPECTRUM DISORDER

by

LINDA SUE FRYE

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Abstract

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Linda Sue Frye, PhD

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Supervising Professor: Donelle Barnes

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder that causes very mild to severe impairments in communication skills, social interactions, and unusual behaviors that interfere with the children's ability to function independently and interact appropriately with other people (American Psychiatric Association [APA], 2013). Children with ASD often appear normal (without physical deformities). The impairments are sources of economic burden, decreased emotional well-being, and decreased family cohesion. Some parents of children with ASD adjust, adapt, and become resilient when facing the multiple challenges of ASD, but others experience anxiety, depression, and poor mental health that can lead to decreased family cohesion and well-being.

Fathers have an important role in family cohesion, overall family well-being, and improved outcomes for children with developmental delays; yet very little research exists regarding fathers of children with ASD. The purpose of the study was to describe the experience of fathers of children with ASD, the depression or anxiety they may experience, and any resources needed to help them actively engage in their role as a father of a child with ASD.

ASD affects children in all socioeconomic and races, though not equally. A phenomenologic single case study was conducted with ten White fathers of children with a formal diagnosis of ASD (ASD: ICD-9 Code 299) who live in the same home as their children with ASD. White fathers were selected for the study because the ASD prevalence rate in White non-Hispanic children is 1 in 63, significantly higher than other races (Baio, 2014). Fathers were asked about their children with ASD, the effect of ASD

on the fathers' lives and lives of their family, challenges they faced as fathers of children with ASD, strengths they had to meet and cope with the challenges, their reaction to the diagnosis, how other people reacted or responded to their children, reaction to these people, advice they had for other fathers of children with ASD, their needs to help them in their role as fathers of children with ASD, and their sources of support.

Fathers in the study described their family life and making adjustments, their needs to meet the challenges of ASD, and feelings of grief and loss related to ASD. ASD became the center of family life requiring every member of the family to adjust and adapt to the challenges of ASD. The fathers described their needs including money, teamwork, honesty and information, get involved/take action, and time. The fathers expressed a variety of emotions, representing their grief and loss. Grief and loss after receiving the ASD diagnosis is similar to the grief and loss experienced with the death of a loved one. The stages of grief and loss for these fathers included denial and isolation, anger, bargaining, depression, and acceptance similar to the classic work of Kubler-Ross and Byock (2011). Movement through the stages of grief and loss is not linear, the stages may occur at any time, any order, and may be repeated at any time.

Learning about the fathers' experience with ASD can assist health care providers to address the fathers' needs and help them move through the stages of grief and loss to the acceptance stage where they can become resilient against the challenges they face related to ASD.

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Chapter 1

Introduction

The purpose of this chapter is to provide an overview of the literature regarding parenting a child with ASD. The focus of the study was the experience of fathers of children with ASD. The background, prevalence, and consequences of ASD will be presented. The significance of actively engaged fathers with children with developmental delays, an early warning sign for ASD, will be discussed. The Resiliency Model of Family Stress, Adjustment, and Adaptation will be presented as the theoretical model for this study. The study purpose, study question, assumptions, boundaries, and delimitations will also be presented.

Background

Prevalence and Impairments

ASD is a lifelong neurodevelopmental disorder that causes impairments in communication skills and social interactions, and unusual behaviors (APA, 2013). The impairments can range from very mild symptoms to severe impairments that interfere with the child's ability to function independently and interact appropriately with other people. Children with ASD often appear normal (without physical deformities); it is the impairments in social interaction, communication, and behavior abnormalities that set them apart from other children.

ASD affects 1 in 68 children in all socioeconomic and ethnic groups, though not in equal numbers (Baio, 2014; Centers for Disease Control and Prevention [CDC], 2014). The prevalence rate in 2010, the year for which the most recent data were available, was dramatically higher than the previous rate of 1 in 88 children in 2008 (Baio, 2014, CDC, 2014). The prevalence in White non-Hispanic children is 1 in 63, which is significantly higher than the rate of 1 in 81 Black non-Hispanic children and 1 in 93 Hispanic children

(Baio, 2014). ASD affects boys at a prevalence rate of 1 in 42 compared to 1 in 189 girls

(Baio, 2014). Boys are 4.5 times more likely to have ASD than girls.

Economic burden

Having children with ASD is a huge financial burden for the parents and society, including local school districts, government funded insurance programs, private insurance companies, and taxpayers. The general lifetime cost for an individual with ASD is approximately \$3.2 million for healthcare expenses, educational costs, therapies, support services, loss of income for the parents and child, and loss of tax revenue related to the loss of employment (CDC, 2011). In 2011, ASD expenses were \$11.5 billion, the equivalent of \$17,081 for every child with ASD. This amount is in addition to the annual expenditures for a typically developing child (Lavelle et al., 2014). As the prevalence of ASD continues to rise, the financial burden will also continue to rise.

Cost for education services.

Children under three years of age with disabilities and developmental delays, including ASD, are eligible to receive state and federal government funded early childhood intervention services (ECI) including therapy, education, and other services (Montes, Halterman, & Magyar, 2009; Texas Department of Assistive & Rehabilitative Services [DARS], 2013). When children reach age three, they are no longer eligible for ECI services and must transition to services provided by their local school district. The cost of special education for children with ASD can range from \$6,595 for children with mild ASD to \$10,421 annually for those with severe ASD, averaging \$8,610 per child (Lavelle et al., 2014). Physical, occupational, and speech therapies provided at school are an additional expense. Local school districts provide the funding for special education and therapies for children with ASD using school tax dollars paid by the taxpayers in the school district (Montes et al., 2009).

Cost for medical expenses.

Medical expenses for children with ASD averaged \$3020 per child in 2011, approximately 18% higher than the expenses for children without ASD (Lavelle et al., 2014). The higher medical expenses for children with ASD include prescription medications, physician office visits, emergency department visits, and non-physician office visits such as occupational, physical, and speech therapy (Lavelle et al., 2014). Emergency department visits contribute significantly to the higher cost of medical care for children with ASD. For example, children with moderate and severe forms of ASD had a higher number and severity of injuries requiring emergency care due to the children's higher risk for self-injurious behaviors and their lack of awareness of dangers in their surroundings (Cavalari & Romanczky, 2012). Children with moderate and severe forms of ASD were nine times more likely to visit the emergency department for psychiatric emergencies compared to children without ASD (Kalb, Stuart, Freedman, Zablotsky, & Vasa, 2012).

In 2003, private insurance companies paid approximately \$5,254 per child for ASD medical care, therapies, and related services (Wang, Mandell, Lawer, Cidav, & Leslie, 2013). Medicaid expenses for the same ASD services in the same year averaged \$22,653 per child. Children with ASD receiving Medicaid insurance coverage had a higher number of prescription medications, occupational and physical therapy visits, behavior and social skills therapy visits, and a higher number of other ASD specific expenses compared to children covered by private insurance (Wang et al., 2013). The cost for ASD related medical expenses covered by private insurance and Medicaid is distributed among the private insurance policy holders and taxpayers, forcing them to share the economic burden of ASD.

Cost to parents.

Most insurance companies place an annual or lifetime cap on funding for ASD services forcing parents to pay for the services, find other sources of funding, or stop the beneficial services when the cap has been reached (Hock, Timm, & Ramish, 2012; Lutz, Patterson, & Klein, 2012). In many families of children with ASD, one parent takes on two or three jobs to provide the income necessary to support the family and the cost of ASD care, while the other parent stops working to stay home and becomes the primary care giver (Hock et al., 2012; Lutz et al., 2012).

Approximately 43% of parents report financial problems related to their children's ASD and the cost of their therapies (Child and Adolescent Health Measurement Initiative [CAHMI], 2013). Sacrificing a career, working multiple jobs to provide an income for the family, paying for therapies and treatment, and having financial burden caused by having a child with ASD can lead to depression, anxiety, and decreased family function and cohesion.

Consequences

Cohesion

Family cohesion is the family members working together as a team to meet and overcome any challenges they face (Hock et al., 2012). Having children with ASD is a major source of conflict between parents that can reduce family cohesion. Parents frequently blame each other for their anger and frustration, for not carrying an equal share of the burden, for causing the ASD, and for a lack of understanding of the other parent's burden (Hock et al., 2012; Karst & Vaughn Van Hecke, 2012; Neely-Barnes, Hall, Roberts, & Graff, 2011). The emotional toll of having children with ASD can reduce family cohesion, marital stability, and overall well-being for the family.

One of the greatest obstacles for parents of children with ASD is the severity of the child's symptoms and associated behaviors (Hill-Chapman, Herzog, & Manduro,

2013). When the child is experiencing severe behavior outbursts, family cohesion can deteriorate, resulting in disintegration of the family (Hoogsteen & Woodgate, 2013).

Divorce Rates of Parents of Children with ASD

The divorce rate among parents of children with ASD is 23.5% compared to 13.8% in a matched representative sample of parents of children without ASD (Hartley et al., 2010). Divorce rates declined over time for parents of children without ASD, but as the children with ASD reached adolescence and early adulthood, the divorce rate remained high for parents of children with ASD even as the child became an adult (Hartley et al., 2010). Most parents look forward to an empty nest when their children are grown and independent. Parents of children with ASD face a lifetime of economic burden, career challenges, and taking on multiple roles to provide care for their children. The lifelong burden of ASD for the parents can lead to feelings of anger, blame, and frustration; to taking on multiple roles; and to the higher divorce rate (Hartley et al., 2010).

Mothers' Roles

Mothers usually take on the role of primary caregiver, providing constant care and supervision for children with ASD (Karst & Vaughn Van Hecke, 2012; Lee, 2009; Lutz et al., 2012). Mothers assume responsibility for children's daily needs including feeding, bathing, dressing, transportation to and from therapies, and reinforcing lessons learned at therapies, in addition to their other household and parental responsibilities to other family members (Myers, Mackintosh, Goin-Kochel, 2009). Mothers often sacrifice their career and other activities outside of the home to provide full-time care for the children with ASD (Harper, Dyches, Harper, Roper, & South, 2013; Myers et al., 2009).

Mothers also take on the role of teacher, teaching children with ASD the developmental skills naturally acquired by typically developing children. Mothers learn and reinforce the skills children with ASD learned during therapy sessions. Another role

for mothers is educating their families and the public about ASD (Hoogsteen & Woodgate, 2013). Mothers often become the primary caregiver and teacher, in addition to their other responsibilities including coordinating household tasks, caring for any other children, finding treatments for their children with ASD, locating payment sources for services, and being a wife and mother (Hock et al., 2012). The demands placed on the mother can become an overwhelming burden.

Fathers' Roles

Fathers often work overtime or take on a second or third job to provide the income for family needs and pay for therapies, insurance co-pays, and the loss of the mothers' income (MacDonald & Hastings, 2010). The extra workload causes fathers to miss opportunities to become actively involved in their children's treatment and caregiver activities (MacDonald & Hastings, 2010). Fathers face extraordinary challenges while trying to balance the extra workload, family responsibilities, and emotional support needed by the primary caregiver, which can become overwhelming for fathers (MacDonald & Hastings, 2010). The burden placed on the fathers can cause depression, anxiety, and decreased family cohesion, resulting in a negative outcome for the entire family.

Mental Health of Mothers and Fathers

The persistent burden of providing lifelong, intense, and sustained care for someone with ASD can have a negative effect on the emotional well-being of the caregiver and the entire family (Khanna et al., 2011). Persistent burden can lead to depression and anxiety in mothers and fathers of children with ASD, which can reduce family cohesion and the overall well-being for the entire family leading to additional challenges for the family.

Depression

In multiple studies, clinical depression was significant in mothers of children with ASD. Severity of the children's ASD and associated behaviors were positive predictors for the level of clinical depression in the mothers (r range .37 to .69, $p < .001$) in five studies with sample sizes ranging from 28 to 370 and one study with a sample size of 104 ($r = .61$, $p < .01$) (Barker et al., 2011; Beer, Ward, & Moar, 2013; Davis & Carter, 2008; Jones, Totsika, Hastings, & Petalas, 2013; Kelly, Garnett, Attwood, & Peterson, 2013; Phetrasuwan & Miles, 2009). Moderate to severe levels of clinical depression were reported in 14.8 % to 41.1% of the mothers in four studies with sample sizes ranging from 17 to 84 mothers (Benson & Karlof, 2009; Giallo, Wood, Jellett, & Porter, 2013; Lee, 2009; Meirschaut, Roeyers, & Warreyn, 2010). Researchers compared the rate of clinical depression in mothers within a week of their children's ASD diagnosis with the rate of depression in the same mothers 15 months after diagnosis (Taylor & Warren, 2012). Researchers found that 79% of mothers had significant clinical depression within one week of their children's ASD diagnosis, and 37% continued to experience clinical depression 15 months after the children received the ASD diagnosis (Taylor & Warren, 2012). Mild levels of depression were reported in 17 to 41.1% of fathers of children with ASD in two studies with sample sizes of 6 and 23 fathers (Benson & Karloff, 2009; Lee, 2009). Depression was significantly associated with the severity of children's ASD impairments and behaviors (r range from .37 to .44, $p < .001$) in three studies with sample sizes ranging from 54 to 135 (Davis & Carter, 2008; Hartley, Seltzer, Head, & Abbeduto, 2012; Jones et al., 2013).

Anxiety.

Anxiety was strongly associated with the severity of the children's behavior for mothers of children ASD in multiple studies (Barker et al., 2011; Davis & Carter, 2008;

Jones et al., 2013; Kelly et al., 2008). The more severe the children's ASD behavior and impairments, the higher the level of anxiety in the mothers in four studies with a sample ranges from 54 to 379 (r range .43 to .63, $p < .001$) (Barker et al., 2011; Davis & Carter, 2008; Jones et al., 2013; Kelly et al., 2008). Approximately 51.8% of mothers had severe anxiety in two studies with sample sizes of 28 and 104 mothers (Beer et al., 2013; Lee, 2009). Fathers experienced lower levels of anxiety than mothers. Mild anxiety was significantly correlated to the children's behavior in fathers of children with ASD (r range from .25 to .49, $p < .001$) in three studies with sample sizes ranging from 23 to 161 fathers (Davis & Carter, 2008; Jones et al., 2013, Lee, 2009).

When parents become overwhelmed, they are at risk for missing therapy sessions, non-compliance in reinforcing therapy lessons, not following through with homework assignments, and not monitoring the safety of the children (Rao & Beidel, 2009). These actions can have negative consequences for children with ASD. The result can be an increase in children's dangerous and inappropriate behaviors creating a vicious cycle for children and an increased burden for their caregivers. The constant burden for ASD caregivers is a significant predictor of their mental health (Bekhet, Johnson, & Zauszniewski, 2012; Khanna et al., 2011). Some parents of children with ASD adjust, adapt, and become resilient when facing the multiple challenges of ASD, but others experience anxiety, depression, and poor mental health that can lead to decreased family cohesion and well-being.

Gap in Knowledge

Single-parent homes are more common today than at any time in history. Among the 11.2 million children in the United States living in single-parent homes, approximately 76% are living with single-mothers, and 24% are living with single-fathers (Flippin & Crais, 2011; Livingston, 2013). Single-father homes have increased by 60% in

the past decade (Livingston, 2013). Fathers are the primary caregiver for approximately 24% of preschool age children (Flippin & Crais, 2011). Census numbers are not available on the number of children with ASD living in single-father homes or those with fathers as the primary caregiver. With the increasing number of single-father homes and the number of fathers who are primary caregivers for their preschool age children, it can be predicted that some children with ASD are being raised in single-father homes and have fathers as their primary caregiver.

Research About Fathers

Fathers, particularly actively engaged fathers, can improve family cohesion, family stability, and the well-being for every member of the family (Bagner, 2013). Actively engaged fathers were a strong predictor of developmental outcomes in children with developmental delays, an early sign of ASD. Children with developmental delays and actively engaged fathers had significant and sustained improvements in their emotional regulation, cognitive development, and language development (Bagner, 2013).

Family cohesion was significantly improved when fathers were actively engaged with their children. When fathers were actively engaged, mothers reported lower real and perceived levels of burden, improved mental health, and better overall quality of life compared to single mothers or mothers with non-engaged spouses in the study (Bagner, 2013). The decrease in burden and improved quality of life for the mothers also were associated with improved family cohesion and well-being for the entire family (Bagner, 2013). Actively engaged fathers had a more positive outlook about the children's future, provided emotional support and comfort to the mothers, had better family cohesion, and had improved well-being for the family (MacDonald & Hastings, 2010).

Fathers have an important role in family cohesion, overall family well-being, and improved outcomes for children with developmental delays (Bagner, 2013). It is

important to understand fathers' experiences with their children with ASD, the depression or anxiety they may experience including the source, and any resources needed to help them actively engage in their role as fathers of children with ASD. This knowledge may assist healthcare providers in the future to better support parents to help them adjust, adapt, and become resilient to the challenges of ASD.

Theoretical Framework

The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1988, 1993) was the theoretical model for this research study. The model was designed to assist health care professionals as they evaluate the family's needs and provide interventions to help the family avoid a crisis situation (Brody & Simmons, 2007; McCubbin & McCubbin, 1988, 1993). Some families faced with challenges adjust, adapt, and grow stronger to become resilient, but others facing the same challenges disintegrate. Health care providers can provide interventions at any time during the adjustment or adaptation phase of the model to help the family meet the goal of resilience.

Resiliency Model of Family Stress, Adjustment, and Adaptation Diagram

The graphic representation of the model in figure 1 illustrates the relationship between the stressor and pileup using one-directional arrows. The relationships between the concepts are represented with bi-directional arrows indicating how they are interconnected and form the propositions for the model (McCubbin & McCubbin, 1988, 1993).. In the adaptation phase, the two external elements are outside of the interactive circle to provide additional support to the family and help them achieve resiliency (McCubbin & McCubbin, 1988, 1993)..

The model has an adjustment phase, which occurs when the patient receives the diagnosis of an illness or medical condition. This phase focuses on the adjustments that

occur due to the diagnosis. Adaptation is the second phase of the model. It occurs as the family adapts to the long-term challenges of the illness or medical condition. Families who adjust and adapt become resilient.

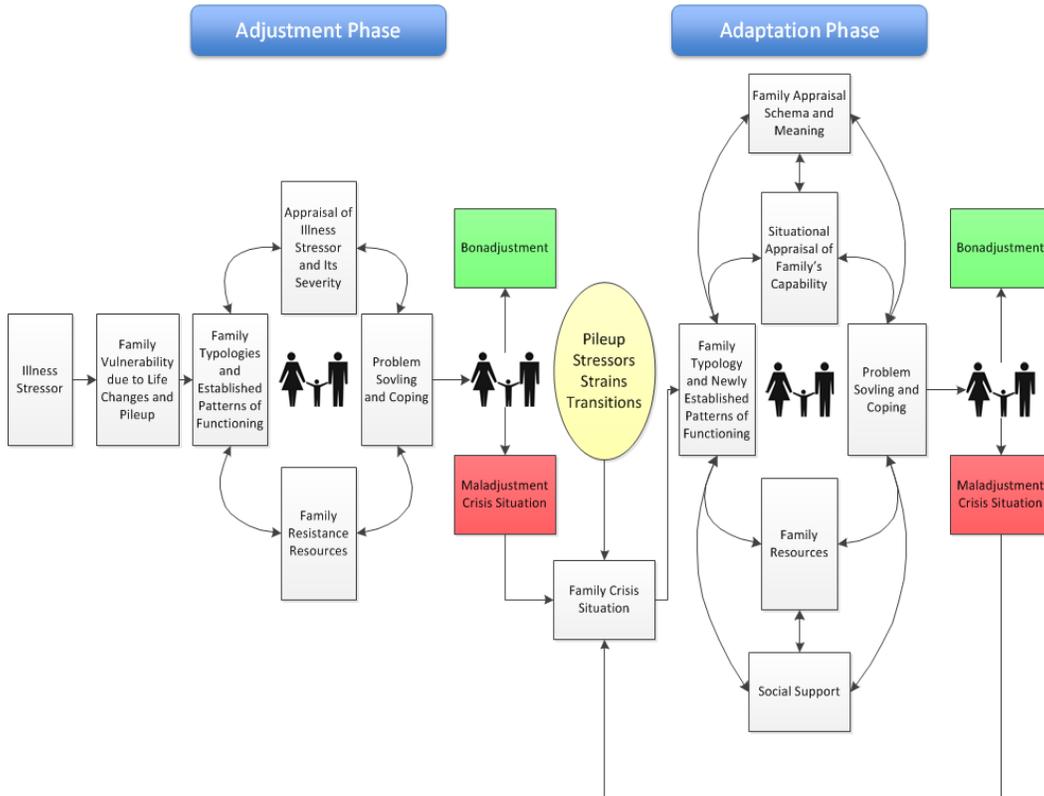


Figure 1 Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993)

Terminology, Propositions, and Characteristics of Resiliency

Understanding the terminology used in the model is critical to appropriately apply the model to the research study. Resilience, the desired outcome, is the ability to recover from the challenges caused by a stressor illness or medical condition (McCubbin & McCubbin, 1988, 1993). A stressor is an illness or medical condition that affects the patient and family. The severity of the stressor and its effect on the family members depends on how they perceive the challenges they face (McCubbin & McCubbin, 1988, 1993). Pileup refers to the accumulated demands placed on the individual or family

including any pre-existing demands and those resulting from the stressor. Demands can include financial concerns, altered health status, changes in work schedules, leaving the work force, reduced sleep, and caring for other sick family members among others. The stressor and pileup demands can leave the family vulnerable and unable to adjust to the challenges (McCubbin & McCubbin, 1988, 1993).

Typology is the family's typical functional routine (two parent home, working mother, stay at home father). Resistance resources are qualities the family members have in place to help them meet any challenges, such as good communication between the family members and a willingness to work together (McCubbin & McCubbin, 1988, 1993). Family appraisal is how the family members view the stressor and whether they have the ability to manage the challenges presented by the stressor and pileup demands. Problem-solving skills and coping strategies are the family members' way of managing the challenges they face from the stressor and pile up. Positive problem solving skills and coping mechanisms include finding available resources to assist them, talking about the problem, becoming informed about the stressor, and finding ways to relieve the pressure placed on the family (McCubbin & McCubbin, 1988, 1993). Negative problem solving skills and coping mechanisms include becoming angry, blaming each other, withdrawing, and other harmful behaviors that threaten to tear the family apart. Adjustment is the ability to overcome the challenges presented by the stressor and pileup. Bonadjustment is a positive adjustment, and maladjustment is a poor adjustment causing a crisis for the family (McCubbin & McCubbin, 1988, 1993).

Adaptation occurs when the family overcomes the on-going challenges created by the stressor, pileup, and long-term challenges of managing the stressor using the concepts, propositions, and external resources (McCubbin & McCubbin, 1988, 1993). Bonadaptation is a positive response to the stressor, and maladaptation is a negative

response resulting in crisis for the family. Resiliency is a dynamic process that occurs when the family adjusts, adapts, and achieves a balance between the stressor and a quality level of functioning in the family.

Concepts are abstract characteristics that provide meaning to a phenomenon by describing and naming it (Grove, Burns, & Gray, 2013). Five concepts interact to form the propositions in the adjustment phase of the model (McCubbin & McCubbin, 1988, 1993). The concepts are 1) pileup or demands, 2) family typologies (cohesion, adaptability, family hardiness, and routines), 3) family resistance resources, 4) family appraisal, and 5) the family's coping skills and problem solving strategies (McCubbin & McCubbin, 1988, 1993).

Propositions are abstract links demonstrating a relationship between concepts (Grove et al., 2013). The propositions include 1) the interaction between the stressor and pileup or demands that leave the family vulnerable to disintegration, 2) families who are cohesive and adaptable are able to meet the new and existing challenges, 3) families with economic stability, good communication, and flexibility are able to adjust to the challenges, 4) a positive appraisal of the stressor and the ability to manage the challenges allows the family to adjust, and 5) families with good coping skills and problem solving strategies are able to overcome the challenges (McCubbin & McCubbin, 1988, 1993).

The concepts in the adaptation phase of the model include family typologies and newly instituted patterns of functioning (caregiver versus working outside the home, new roles, and new routines), family resources (individual or group including knowledge about medical condition, physical and emotional health, and self-esteem), situational appraisal and family's capability (family's strength and ability to manage the challenges), problem solving, and coping skills (McCubbin & McCubbin, 1988, 1993). Family members

working together as a team focus on the needs of the entire family rather than their individual needs. The team or we focus of the family members focuses their appraisal of the challenge on the family, family schema, and meaning for the family working together, meeting the challenges, and providing support within the family to overcome the challenges. Social support is an external resource that provides support to the family and may include extended family members, friends, support groups, and community resources among others. Propositions for the adaptation phase of the model include the following statements. Families with a positive, newly established pattern of functioning use their resources, problem-solving methods, coping skills, and situational appraisal of the families' capability in addition to social support and their family focused appraisal, schema, and meaning of the condition to adapt (McCubbin & McCubbin, 1988, 1993). Families with weaknesses in any of the concepts have difficulty working together to meet the challenges of managing the stressor and pileup, which may lead to poor family cohesion and negative consequences for the entire family.

The nine characteristics of resiliency include a balance between the stressor and pileup, quality family functioning, good communication, a positive attitude and appraisal of the situation, flexibility, commitment to the entire family, effective coping skills, social support, and a good working relationship with members of the health care team (McCubbin & McCubbin, 1988; 1993). Achieving the balance between the stressor and pileup using the concepts in the adjustment and adaptation phases of the model helps the family achieve resiliency.

Adjustment Phase

The adjustment phase begins when a family member becomes ill or receives a diagnosis, such as ASD. The stressor, the pileup related to the challenges of the stressor, and the pre-existing pileup interact and place the family at risk of crisis

(McCubbin & McCubbin, 1988, 1993). The family members must use their resistance resources, problem-solving skills, coping strategies, appraisal of the stressor and its severity, and typology together to overcome the challenges caused by the diagnosis and pileup. The concepts work together to form the theoretical propositions for the adjustment phase of the model. Families with strengths in the concepts achieve the theoretical propositions resulting in adjustment to the challenges, while those who do not have strengths in these areas can disintegrate into crisis. Health care professionals can provide interventions during this phase to help the family adjust to the stressor and pileup to help the family overcome the challenges (McCubbin & McCubbin, 1988, 1993). The goal of the adjustment phase is using the resources, coping strategies, positive appraisal, and problem solving skills to manage the stressor and achieve a balance between the demands and quality family functioning (Brody & Simmons, 2007; McCubbin & McCubbin, 1988, 1993; Tway, Connolly, & Novak, 2007).

Adaptation Phase

Adaptation is the most important concept of the model (Brody & Simmons, 2007; McCubbin & McCubbin, 1988, 1993; Tway et al., 2007). Families may enter this phase in a state of crisis or the crisis may occur as the adjusted family faces the long-term demands caused by the stressor (Luther, Canham, & Creton, 2005). The long-term challenges may change resulting in different types of challenges and pileup including changes in family roles, financial burden, long-term therapy, special education, and so forth (McCubbin & McCubbin, 1988, 1993). The family's ability to adapt is determined by the interacting concepts including a new pattern of family functioning, family resources, appraisal of the situation and the ability to manage the challenges, problem solving strategies, and coping skills. Additional elements in the adaptation phase include how the family as a whole evaluates the stressor and their ability to overcome the challenges,

and external sources of social support. The goal of this phase is achieving a balance between the individual members, the family as a whole, the stressor, and the on-going challenges caused by the stressor (Brody & Simmons, 2007; McCubbin & McCubbin, 1988, 1993; Tway et al., 2007).

Propositions for the adaptation phase are positive qualities in the concepts working together to support the families as they face the ongoing challenges of the stressor and pileup. Families with good problem solving strategies, positive coping skills, social support, a positive schema, and ability to manage the challenges presented by the stressor and pileup become resilient (McCubbin & McCubbin, 1988, 1993). Families without these qualities do not become resilient and may disintegrate. Health care providers can provide interventions such as education about the stressor, therapies, respite care, condition management strategies, support groups, financial assistance, and financial support from various condition specific agencies, that may help the family meet the challenges and become resilient.

The adaptation phase of the model begins with the family facing the challenges related to the long-term management of the stressor and the challenges it causes for the family, as well as pre-existing or on-going pileup. The family enters the interactive circle of family typology with a new functional pattern, situational appraisal of the ability to manage the challenges, family resources, problem-solving strategies, and coping skills, supported by family appraisal schema, meaning, and social support as external sources of support (McCubbin & McCubbin, 1988, 1993). Quality in the relationship between the concepts, propositions, and adequate external support can help the families adapt and become resilient, while those families without strengths in these areas may not adapt resulting in crisis for the family.

Application of Model

This model applies to families of children with ASD. The diagnosis can be devastating to families, especially when combined with challenges and impairments related to ASD and other pre-existing pileup. The diagnosis can change the family's typical pattern of function, and roles, as one parent becomes the primary caregiver, and the other parent works to provide for the family's needs. The family members must use their resistance resources, which include good communication, flexibility, hardiness, and stability, plus their problem-solving strategies, coping style, appraisal of the ASD, and the effect it will have on their lives to adjust to the challenges.

As the family members adjust to the diagnosis of ASD, they are faced with the long-term challenges of parenting a child with ASD. ASD is a lifelong condition that can cause an emotional and economic burden to the family caused by the treatment, therapies, special education, and role changes for the parents, in addition to the challenges associated with the child's impairments in communication, social interactions, and unusual behavior. Families with adequate resources become resilient, and those without adequate resources and balance can deteriorate. Health care providers can provide interventions at any point in the model to help the family in its goal of achieving resiliency. ASD challenges can change throughout the children's lives, causing resilient families to face new challenges. The model is applicable to these families to assist health care providers to identify and provide the support necessary to help them regain their resilience.

Purpose of Research

The purpose of this study was to describe the experience of fathers of children with ASD, the depression or anxiety they may experience, and any resources needed to help them actively engage in their role as a father of a child with ASD.

Study Question

The study question is what is the lived experience of the fathers of children with ASD?

Assumptions

Children with developmental delays, an early warning sign for ASD, had improvements in behavior, cognitive, and language skills when their fathers were actively engaged with the children and their therapy sessions compared with children with single mothers and non-actively engaged fathers (Bagner, 2013). Developmental delays are early warning signs for ASD; therefore, it was assumed that the fathers' role with children with ASD would be similar to the role in children with developmental delays. It was also assumed that fathers of children with ASD would be willing to talk about their experience and able to articulate their feelings about their role and any burden they experience.

Delimitations

The study described the experience of White fathers of children with ASD because White children have higher prevalence rates of ASD compared to other ethnic groups (Baio, 2014). The study not include information about diagnosing ASD, ASD causes, increasing ASD prevalence, racial distribution of ASD, benefits of early ASD intervention, ASD services, ASD comorbidities, the experience of mothers, and so forth. The study focused on the experience of White fathers of children with a formal diagnosis of ICD 9 Code 299 ASD (Buck, 2012).

Chapter Summary

This chapter included an overview of the background, prevalence, and consequences of ASD. The research evidence about actively engaged fathers with children with developmental delays, an early warning sign for ASD was presented. The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin,

1988, 1993) was presented as the theoretical model for this study. The study purpose, study question, assumptions, boundaries, and delimitations were presented. The knowledge gained from this study may assist healthcare providers in the future to gain a better understanding of the experiences of fathers of children with ASD to provide the support needed to help fathers actively engage with their children with ASD.

Chapter 2

Review of Literature

This chapter will include an overview of the literature of parenting children with ASD. The population of interest for the study is fathers of children with ASD. Mothers are usually the primary caregiver for most children with ASD; however, more fathers are taking on the caregiver role, and little information exists about their experience as fathers of children with ASD. The purpose of this research is to describe the experience of fathers of children with ASD, the depression or anxiety they may experience including the source, and any resources needed to help them actively engage in their role as a father of a child with ASD.

This chapter includes a discussion of the cost of ASD to society, emotional burden for the family, financial burden on the family, mental health effect of ASD on the mothers and fathers, family cohesion, and the outcome for children with developmental delays and actively engaged fathers. A discussion of the existing scientific knowledge of the effects of ASD on the parents, cohesion issues for the family, and benefits for children with actively engaged fathers was included in the chapter. The gap in the current knowledge and a link to the current study are presented.

Autism Spectrum Disorder

ASD is a pervasive neurodevelopmental disorder characterized by impairments in communication skills, social interactions, and unusual behaviors (APA, 2013). The impairments can range from very mild symptoms to severe impairments that interfere with the child's ability to function independently and interact appropriately with other people. Approximately 50% of children with ASD have impairments present in their first year of life and 80% during the second year of life, yet almost half of all children with ASD reach school age before receiving the diagnosis (CDC, 2014). Children with ASD often

appear normal (without physical deformities); it is their lack of social interaction, communication, and behavior abnormalities that set them apart from other children (APA, 2013; CDC, 2014).

ASD affects children in all socioeconomic and ethnic groups, though not in equal numbers. The current prevalence rate in 2010, which are the most recent data available, was 14.7 per 1000 children (1 in 68) between the ages of 2 and 17 years of age (Baio, 2014; CDC, 2014). This is a dramatic increase from 2008, when the prevalence rate for the same population was 11.3 per 1000 children (1 in 88) (Baio, 2014; CDC, 2014). The racial prevalence rates for ASD per 1000 children are 15.8 (1 in 63) for White non-Hispanic, 12.3 (1 in 81) for Black non-Hispanic, and 10.8 (1 in 93) for Hispanic (Baio, 2014). ASD is more prevalent in White children compared to Black and Hispanic children. ASD affects 1 in 42 boys compared to 1 in 189 girls; a ratio of 4.5 boys to 1 girl (Baio, 2014, CDC, 2014).

ASD is a lifelong condition, which affects the child, their caregivers, families, teachers, and the community (Karst & Vaughn Van Hecke, 2012). Approximately 85% of individuals with ASD will never have the ability to live on their own because they require lifelong care or assistance (Karst & Vaughn Van Hecke, 2012). This is a daunting challenge to most parents who dream of their children growing up, becoming independent, moving out, and having a family of their own. Some parents of children with ASD adjust, adapt, and become resilient to the challenges they face, but other families become overwhelmed and have difficulty facing the challenges associated with ASD. ASD causes financial, social, and emotional obstacles for society and the families.

Economic Burden of ASD to Society

The general lifetime cost for an individual with ASD is approximately \$3.2 million in the form of healthcare expenses, educational costs, loss of income for the parents and

child, loss of tax revenue, therapies, and support services (CDC, 2014). The cost for individuals with ASD is ten times higher than the lifetime cost for individuals without ASD. Annual medical expenses for someone with ASD are approximately \$4,110 to \$6,200, which is 4.1 to 6.2 times higher than the average cost for individuals without ASD (CDC, 2014).

In 2011, the amount of money spent on ASD was \$11.5 billion, which is \$17,081 for every child with ASD (Lavelle et al., 2014). This amount is in addition to the annual expenditures for a typically developing child. The additional expenses were for ASD specific health care, education services, and the time the caregiver spent coordinating the child's ASD services and therapies (Lavelle et al., 2014). As the prevalence of ASD continues to rise, the financial burden to society will also continue to rise.

Cost for Medical Expenses

Medical expenses for children with ASD ranged from \$1,017 to \$4,259 (\$3,020 average) in 2011 (Lavelle et al., 2014). Health care expenses were 18% higher than for children without ASD. The higher costs included prescription medications, physician office visits, emergency department visits, and non-physician office visits such as occupational, physical, and speech therapy (Lavelle et al., 2014).

Emergency department visits contribute significantly to the higher cost of medical care for children with ASD (Cavalari & Romanczky, 2012). Children with moderate and severe ASD impairments and behaviors are at higher risk for injury due to their self-injury behaviors and lack of awareness of dangers in their surroundings. These behaviors contributed significantly to a higher number and severity of injuries requiring emergency department care (Cavalari & Romanczky, 2012). Children with more severe forms of ASD were nine times more likely to visit the emergency department for psychiatric emergencies compared to children without ASD (Kalb et al., 2012).

Cost to Private Insurance Companies and Medicaid

Private insurance companies divide the cost of health care expenses including ASD care among all of their policyholders (Wang et al., 2013). Individuals who are healthy share in the cost of those with health problems. Employers who provide private insurance to their employees share the cost among the employees in a variety of ways. Some employers cut back on the number of employees receiving insurance benefits to offset the cost, others decrease the hours employees work to avoid providing health insurance, and some employers pass the higher cost along to the employees in the form of higher premiums for the insurance (Bouder, Spielman, & Mandell, 2009). The result is a reduction in the workforce or a decrease in wages to pay for the premiums.

Private insurance companies paid approximately \$5,254 per child for ASD therapies and related expenses in 2003 (Wang et al., 2013). Medicaid expenses for children receiving the same ASD services were \$22,653 per child in 2003 (Wang et al., 2013). Medicaid expenses per child with ASD were more than four times higher than those with private insurance.

Children with ASD receiving Medicaid coverage had a higher number of prescription medications, occupational and physical therapy visits, behavior and social skills therapy visits, and other ASD specific expenses compared to children covered by private insurance (Wang et al., 2013). The state and federal governments use taxpayer dollars to fund Medicaid. As the incidence of ASD continues to rise, the cost for ASD care will also continue to rise. Taxpayers will continue to carry the economic burden in the form of higher taxes.

Cost for Education Services

Children under three years of age with disabilities and developmental delays, including ASD, are eligible to receive free early childhood intervention services (ECI)

including therapy, education, and other services (DARS, 2013; Montes et al., 2009). Early intervention services teach the families how to work with their children to improve their developmental delays, behavior problems, communication, feeding concerns, safety, sleeping, and other issues, as needed. ECI services are individualized and provided in the family's home. The state and federal governments pay for ECI services using taxpayer dollars (CDC, 2011; DARS, 2013; Giallo et al., 2013; Montes et al., 2009).

When a child reaches age three, he/she is no longer eligible for ECI services and must transition to services provided by the child's school district (DARS, 2013). Special education services range from \$6,595 for children with mild ASD to \$10,421 for children with severe ASD, averaging \$8,610 per child per year (Lavelle et al., 2014). Physical, occupational, and speech therapies provided at school are an additional cost per child to the school district. Local school districts provide special education and therapies for children with ASD using school tax dollars paid by the taxpayers in the school district (Montes et al., 2009).

Children with ASD create a financial burden for the entire community in the form of higher health care expenses, higher insurance premiums, higher costs of education, and a higher tax burden. Signs and symptoms of ASD can improve with special education, medication, and therapies, but it does not resolve. It is a lifelong condition that places a lifetime of burden on society and the families.

Financial Burden on the Family

Cost of ASD Insurance and Therapies

Private insurance, Medicaid, ECI, and the local school districts provide many of the services for children with ASD; however, the parents still face an economic burden for ASD. Primary among the financial burdens are costs and concerns about insurance coverage for beneficial treatment and therapies. According to the Texas Insurance Code

(TIC) § 1355.015, medical coverage is provided for all recognized ASD treatment for children with a formal ASD diagnosis (National Conference of State Legislatures [NCSL], 2012). This mandate only guarantees coverage until the child reaches 10 years of age (C. Reyna, personal communication, March 21, 2012). Some insurance providers will continue providing coverage until the child reaches 18 or 21 years of age, but others exclude children from additional ASD benefits when they reach the age of 10 years (C. Reyna, personal communication, March 21, 2012). Parents must find other sources of payment for non-covered services and therapies.

The Affordable Care Act (ACA) improved the insurance benefits for some people with ASD by including coverage for pre-existing conditions such as ASD, payment for behavioral health treatment, and coverage on the parent's insurance policy until the child reaches 26 years of age (U. S. Department of Health & Human Services [HHS], 2013); however, the coverage for people with ASD varies from state to state based on the individual state's insurance regulations. Only 26 states and the District of Columbia include coverage for behavioral therapy in their insurance regulations (HHS, 2013). Many of the ACA providers place a cap on the dollar amount they will pay for behavioral therapy and other behavioral services for ASD (HHS, 2013). Another concern for parents is the wide variance in the cost of ACA policy premiums and deductible amounts between the various ACA insurance providers. Many people are confused about the actual coverage and out of pocket expenses for their health services resulting in anxiety for the parents.

Deductible amounts, limitations for services, total out of pocket expenses, and covered services vary between private insurance companies (HHS, 2013). Parents spend a considerable amount of time finding information about their coverage and deductibles. Some insurance provided through employers changes from year to year

forcing parents to learn about provisions with the new provider. Some people faced changes in their insurance providers when the ACA went into effect (HHS, 2013). The changes in insurance providers, health care providers, coverage benefits, and confusion about the annual out of pocket expenses are additional sources of financial concern and anxiety for parents of children with ASD (CAHMI, 2013).

Local school districts provide speech, physical, and occupational therapy to some students with ASD (Montes et al., 2009). When the school district is not able to provide the therapies, the parents take on the task of finding therapy providers, arranging therapy session around school hours, and finding funding for any additional services (Montes et al., 2009).

Applied Behavior Analysis (ABA) is an intensive behavior modification therapy designed to increase the children's positive behaviors while decreasing negative ones (Shimabukuro, Grosse, & Rice, 2008). The cost for ABA therapy is \$40,000 to \$60,000 per year (CDC 2011; Shimabukuro et al., 2008). Some insurance providers pay for ABA therapy, some provide ABA until a dollar cap is reached, and some providers do not pay for ABA (HHS, 2013; Montes et al., 2009, Shimabukuro et al., 2008; TIC, 2012). The additional cost of ABA therapy adds to the financial burden the parents of children with ASD already face.

Career Challenges for Parents of Children with ASD

Coordinating care for the child with ASD, transporting him/her to therapy three to five times per week, working with insurance providers, locating funding for services, and providing almost constant care and supervision for children with ASD force many parents to cut back on their work schedule or stop working (Hock et al., 2012; Lutz et al., 2012). Parents often sacrifice career opportunities out of fear that any career change may force insurance changes which may not provide any coverage for the child and his/her

therapies (CAHMI, 2013; Hock et al., 2012; Lutz et al., 2012; Nealy, O'Hare, Powers, & Swick, 2012). In many families of children with ASD, one parent takes on two or three jobs to provide the income necessary to support the family and the cost of ASD care while the other parent becomes the primary care giver (Hock et al., 2012; Lutz et al., 2012).

Approximately 43% of parents report financial problems related to their child's ASD and cost of his/her therapies (CAHMI, 2013). Sacrificing a career, working multiple jobs to provide an income, paying for therapies and treatment, and the financial burden caused by having a child with ASD can lead to depression, anxiety, and decreased family function and cohesion.

Emotional Burden on the Family

The persistent burden of providing lifelong, intense, and sustained care for someone with ASD can have a negative effect on the financial and emotional well-being of the caregiver and the entire family (Barker et al., 2011; Benson & Karlof, 2009; Hoffman et al., 2008; Hoogsteen & Woodgate, 2013; Khanna et al., 2011; Lee, Harrington, Louie, & Newschaffer, 2008; Neely-Barnes et al., 2011.; Phetrasuwan & Miles, 2009; Zablotzky, Bradshaw, & Stuart, 2013). Some children with mild forms of ASD improve with intensive therapy and treatment, but children with moderate and severe levels of ASD require long-term treatment, constant supervision, and lifelong care by their parent(s) (Jang, Dixon, Tarbox, Granpeesheh, 2011). Some parents of children with ASD become resilient when facing the multiple challenges of ASD, but others experience anxiety, depression, and poor mental health (Bekhet et al., 2012).

Mental Health of Parents

Mental health is a concern for everyone when facing a lifelong medical condition (Sommer, 2013). Parents of children with ASD who feel overwhelmed often experience

depression and anxiety. When parents become overwhelmed, there is a risk of missing therapy sessions, non-compliance in reinforcing therapy lessons, not following through with homework assignments, and not monitoring the safety of the children (Rao & Beidel, 2009). These actions can have a negative effect on children with ASD. The result can be an increase in children's dangerous and inappropriate behaviors, creating a vicious cycle for the children and increased burden for the caregiver. The constant burden for ASD caregivers is a significant predictor of their mental health (Bekhet et al., 2012; Khanna et al, 2011).

Depression in Mothers of Children with ASD

Mothers of children with ASD cite failure, loss, grief, anger, blame, disappointment, and sacrifice as factors contributing to their depression (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008; Ryan, 2010). Many mothers believe that their children's lack of social interaction meant the children were rejecting them, and they were a failure as a parent (Cassidy et al., 2008; Ryan, 2010). Mothers believed that people blamed them for being a poor parent when the children with ASD displayed their ASD behaviors in public. Approximately 75% of mothers of children with ASD avoid social settings and limit people coming to their home to avoid people judging them as a parent (Karst & Vaughn Van Hecke, 2012; Rao & Beidel, 2009; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011; Zablotsky et al., 2013). Rejection by their children, feelings of failure as a parent, and isolation significantly contribute to depression in mothers of children with ASD (Karst & Vaughn Van Hecke, 2012; Rao & Beidel, 2009; Schaaf et al., 2011; Woodgate, Ateah, & Secco, 2008; Zablotsky et al., 2013).

Clinical depression was significant in mothers of children with ASD. Severity of the children's ASD and associated behaviors were positive predictors for the level of clinical depression in the mothers (r range from .37 to .69, $p < .001$) in five studies with

sample sizes ranging from 28 to 370 and one study with a sample size of 104 (r range = .61, $p < .01$) (Barker et al., 2011; Beer et al., 2013; Davis & Carter, 2008; Jones et al., 2013; Kelly et al., 2013; Phetrasuwan & Miles, 2009). Moderate to severe levels of clinical depression were reported in 14.8 % to 41.1% of the mothers in four studies with sample sizes ranging from 17 to 84 mothers (Benson & Karlof, 2009; Giallo et al., 2013; Lee, 2009; Meirschaut et al., 2010). Researchers compared the rate of clinical depression in mothers within a week of their children's ASD diagnosis with the rate of depression in the same mothers 15 months after diagnosis (Taylor & Warren, 2012). Approximately 79% of the mothers had significant clinical depression at diagnosis, and 37% continued to experience significant clinical depression 15 months later (Taylor & Warren, 2012). The percentage of mothers with significant clinical depression decreased, but more than one in three mothers continued to experience clinical depression.

Depression in mothers of children with ASD was related to the severity of their children's symptoms and behavior, social isolation, fatigue, overwhelming burden of care, financial burden, and lack of support from the spouse (Barker et al., 2011; Beer et al., 2013; Benson & Karlof, 2009; Davis & Carter, 2008; Giallo et al., 2013; Jones et al., 2013; Kelly et al., 2008; Lee et al., 2008; Meirschaut et al., 2010; Phetrasuwan & Miles, 2009). Mothers reported lower levels of depression and improved family cohesion when fathers were a source of support who shared the caregiver burden (Barker et al., 2011; Beer et al., 2013; Benson & Karlof, 2009; Davis & Carter, 2008; Giallo et al., 2013; Jones et al., 2013; Kelly et al., 2008; Lee, 2008; Meirschaut et al., 2010; Phetrasuwan & Miles, 2009).

Clinical depression was also reported in one qualitative study of 10 mothers of children with ASD (Hock et al., 2012). These mothers reported that their depression was

related to their lack of sleep, constant care for the child, and no time away from their children to focus on themselves. They also reported feelings of loneliness, anger, guilt, denial, and isolation as significant contributors to their depression. Some of these mothers blamed the fathers for causing the ASD and not being there to support them in their role as caregiver to the child. Many of the mothers were angry with the fathers because they did not want to talk about their feelings, mothers did not receive emotional support from the fathers, and the fathers were never home. The lack of emotional support from the fathers was a major source of depression and poor emotional well-being for these mothers. Depression negatively affected the mothers' ability to face the demands placed on them by their children's ASD, treatments, therapies, and the needs of the other members of their families. The result was a poor overall well-being for the family and a decrease in family cohesion (Hock et al., 2012).

Anxiety in Mothers of Children with ASD

Mothers of children with ASD cite a significant relationship between anxiety and feelings of failure as a parent, loss of a normal child and life, grief, anger, blame, disappointment, and sacrifice (Karst & Vaughn Van Hecke, 2012; Rao & Beidel, 2009; Schaaf et al., 2011; Zablotsky et al., 2013). Social isolation, feelings of rejection from the child, and lack of support from the fathers are other factors that significantly contribute to anxiety in mothers of children with ASD (Karst & Vaughn Van Hecke, 2012; Rao & Beidel, 2009; Schaaf et al., 2011; Zablotsky et al., 2013). Mothers of children with ASD reported higher levels of anxiety than clinical depression related to their children's ASD behaviors.

Anxiety was strongly associated with the severity of the children's ASD behaviors for mothers of children with ASD. The more severe the children's behavior and impairments, the higher the level of anxiety in the mothers in four studies with a sample

size range from 54 to 379 mothers (r range .43 to .63, $p < .001$) (Barker et al., 2011; Davis & Carter, 2008; Jones et al., 2013; Kelly et al., 2008). Approximately 51.8% of mothers had severe anxiety in two studies with samples of 28 and 104 mothers (Beer et al., 2013; Lee, 2009). The anxiety was related to the severity of the children's impairment, severity of the children's behavior, social isolation, maternal fatigue, and the burden of constant care for the children with ASD (Barker et al., 2011; Beer et al., 2013; Davis & Carter, 2008; Giallo et al., 2013; Jones et al., 2013; Kelly et al., 2008; Lee, 2009). Anxiety was lower in mothers who believed they had support from their partner and believed they had the ability to adjust and adapt to the demands placed on them by the ASD (Barker et al., 2011; Beer et al., 2013; Davis & Carter, 2008; Giallo et al., 2013; Jones et al., 2013; Kelly et al., 2008; Lee, 2009).

Researchers conducting a qualitative study reported that the mothers' anxiety was related to the overwhelming demands they experience caring for their children with ASD, never having time to relax, lack of support from their spouse, lack of sleep, isolation, and the severity of the children's ASD impairments and behaviors (Hock et al., 2012). Mothers felt that they were doing everything on their own and could not handle any more, including the needs of other family members. Many of the mothers wanted their spouse to give them emotional support and share in the caregiver burden. Mothers who received support from their spouse had lower levels of anxiety, and those who did not have support had significantly higher levels of anxiety (Hock et al., 2012). Anxiety in the mothers of children with ASD can reduce family cohesion and the overall well-being of the family.

Depression in Fathers of children with ASD

Fathers of children with ASD experience depression related to the severity of the ASD impairments and behaviors of their children. Approximately 17 % to 41.1% of

fathers of children with ASD reported mild levels of depression in two studies with samples of 6 and 23 fathers (Benson & Karlof, 2009; Lee, 2009). Depression in the fathers was significantly associated (r range .37 to .44, $p < .001$) with the severity of the children's ASD impairments and behavior in three studies with a sample size range from 54 to 135 fathers (Davis & Carter, 2008; Hartley et al., 2012; Jones et al., 2013). Fathers reported that their depression was related to the severity of their children's ASD impairments, concerns for their children's safety, the severity of their children's ASD behaviors, and depression in the mothers (Benson & Karlof, 2009; Davis & Carter, 2008; Hartley et al., 2012; Jones et al., 2013; Lee, 2009). Fathers of children with ASD experience mild levels of depression, but mothers experience significant clinical depression.

Anxiety in Fathers of Children with ASD

Fathers of children with ASD experience lower levels of anxiety than the mothers. Concerns about their children's safety, severity of their children's ASD behavior, their children's social-emotional impairments, and anxiety in the mothers were associated with mild anxiety in fathers (Davis & Carter, 2008; Jones et al., 2013; Lee, 2009). Mild anxiety had a significant correlation (r range .25 to .49, $p < .001$) with the children's behavior for fathers of children with ASD in three studies with a sample size range from 23 to 161 fathers (Davis & Carter, 2008; Jones et al., 2013; Lee, 2009).

Depression and anxiety in mothers and fathers of children with ASD can reduce the overall well-being of the family and family cohesion. Family cohesion is essential for a well-functioning family. Cohesive families have the ability to adjust and adapt to the challenges of parenting children with ASD while balancing the additional roles placed on them (Altiere & van Kluge, 2009).

Cohesion and Divorce Rates for Parents of Children with ASD

Cohesion

All families have strengths that bring them together and weaknesses that threaten to pull them apart. Cohesion occurs when families identify their strengths and develop a plan to help them overcome the challenges they face (Hill-Chapman et al., 2013; Hock et al., 2012). Social support and adequate resources contribute to cohesion in families, particularly when they face overwhelming challenges such as ASD. Cohesive families with social support, adequate resources, a positive outlook, strong coping mechanisms, and a willingness to work together are able to adjust, adapt, and become resilient against their challenges (Altiere & van Kluge, 2009).

Cohesion occurs when parents work together and talk openly about what they are experiencing rather than blaming each other for their situation (Hock et al., 2009). Willingness to talk and find a common ground improves cohesion, decreases anxiety and depression, and improves overall well-being. One of the greatest obstacles for parents of children with ASD is the severity of the children's ASD symptoms and behaviors (Hill-Chapman et al., 2013). When the children are experiencing severe ASD behavior outbursts, family cohesion can deteriorate and threaten the family structure. Parents who work together, provide emotional support to their partner, and communicate openly about their feelings and needs have less depression, less anxiety, and higher levels of cohesion (Hill-Chapman et al., 2013).

Mothers who did not receive support from their spouses had lower levels of family cohesion, lower sense of well-being, and negative outcomes for their children with ASD (Lickenbrock, Ekas, & Whitman, 2011). When maternal depression and anxiety were elevated, many fathers spent less time at home and avoided talking with the mothers (MacDonald & Hastings, 2010). Avoiding the problem and each other made the

problem worse for both parents. Family conflict was worse when parents did not openly communicate, support one another, and work together to balance their needs and face the challenges of parenting children with ASD (Hoogsteen & Woodgate, 2013). Family conflict and poor family cohesion have a negative effect on the well-being of the entire family.

Divorce Rates of Parents of Children with ASD

Having children with ASD is a major source of conflict between parents. Parents blame each other for their anger and frustration, for not carrying an equal share of the burden, for causing the ASD, and for lack of understanding of the other parent's burden (Hock et al., 2012; Karst & Vaughn Van Hecke, 2012; Neely-Barnes et al., 2011). The emotional toll of having children with ASD can reduce family cohesion and marital stability.

The divorce rate among parents of children with ASD is 23.5% compared to the rate of 13.8% in a matched representative sample of parents of children without ASD (Hartley et al., 2010). Divorce rates for parents of children without ASD declined as the children reached adolescence into early adulthood; however, the divorce rate remained high for parents of children with ASD even as the children became adults (Hartley et al., 2010). Most parents look forward to an empty nest when their children are grown and independent. Parents of children with ASD face economic burden, career challenges, and multiple roles as the caregiver for their children with ASD. The lifelong burden of ASD for the parents leads to anger, blame, and frustration, which contribute to the higher divorce rate (Hartley et al., 2010).

Family Function and Roles for Parents of Children with ASD

Mothers' Roles

Mothers usually take on the role of primary caregiver, providing constant care

and supervision for their children with ASD (Karst & Vaughn Van Hecke, 2012; Lee, 2009, Lutz et al., 2012). Mothers assume responsibility for the children's daily needs, including feeding, bathing, dressing, transportation to and from therapies, and reinforcing lessons learned at therapies, in addition to their other household and parental responsibilities to other family members (Myers et al., 2009). Mothers often give up their career to provide the full-time care for their children with ASD. The full-time caregiving responsibility also forces many mothers to sacrifice most other activities outside of the home (Harper et al., 2013; Myers et al., 2009).

Many children with ASD have challenging behaviors including temper tantrums, aggressive outbursts, self-injury, property destruction, nighttime wandering, and escaping from the home (Jang et al., 2011). These socially unacceptable and potentially dangerous behaviors cause concerns for the safety of the children and other members of the family, adding to the caregiver burden (Giallo et al., 2013; Hoffman et al., 2008). Many of the mothers of children with ASD report high levels of fatigue due to safety concerns for their children with ASD, constant attention given to their children, and poor sleep habits in the children with ASD (Giallo et al., 2013; Hoffman et al., 2008).

Mothers take on multiple roles as the caregiver for their children with ASD, including the role of teacher (Hock et al., 2012; Hoogsteen & Woodgate, 2013). Mothers must teach their children the developmental skills acquired naturally by typically developing children. They must also learn and reinforce the skills learned during therapies with the children and educate their family and the public about ASD (Hoogsteen & Woodgate, 2013). Mothers are also responsible for coordinating household tasks, caring for any other children, finding treatments for the children with ASD, locating payment sources for services, and being a wife and mother (Hock et al., 2012). Mothers take on all of these roles in addition to the demands as the primary caregiver for their

children with ASD.

Fathers' Roles

Fathers often work overtime or a second or third job to provide the income for the family's needs including therapies, insurance co-pays, and the loss of the mother's income (MacDonald & Hastings, 2010). The extra workload causes fathers to miss opportunities to become actively involved in their children's treatment and caregiver activities. Fathers face extraordinary challenges while trying to balance the extra workload, family responsibilities, and providing emotional support to the primary caregiver, which can become overwhelming for fathers (MacDonald & Hastings, 2010). The result for the fathers is depression, anxiety, decreased family cohesion, and a negative outcome for the entire family, but fathers and their experience receive little attention in current ASD research.

Research About Fathers

Single parent homes are more common today than at any time in history. Approximately 8.6 million or 76% of children are living in single parent homes with single-mothers, and 2.6 million or 24% are living in single-father homes (Flippin & Crais, 2011; Livingston, 2013). Single-father homes have increased by 60%, a nine-fold increase, in the past decade (Livingston, 2013).

Fathers are the primary caregiver for approximately 24% of preschool age children (Flippin & Crais, 2011). Census numbers are not available on the number of children with ASD living in single father homes or those with fathers as the primary caregiver. With the increasing number of single father homes and the number of fathers who are primary caregivers for their preschool age children, it is reasonable to predict that some children with ASD are being raised in single father homes and have fathers as their primary caregiver.

Outcomes for Developmentally Delayed Children

Fathers, particularly actively engaged fathers, can improve family cohesion, family stability, and the well-being for every member of the family (Bagner, 2013).

Actively engaged fathers were a strong predictor of developmental outcomes in children with developmental delays, an early sign of ASD. Children with developmental delays who had actively engaged fathers had significant improvements in their emotional regulation, cognitive development, and language development (Bagner, 2013).

Children with developmental delays who had actively engaged fathers had significantly lower reports of behavior problems and better developmental outcomes compared to children with single mothers and non-engaged fathers (Bagner, 2013). Children with actively engaged fathers had a lower therapy dropout rate (15%) compared to the dropout rates for children with single mothers (70%) or non-engaged fathers (33%) (Bagner, 2013). Attending therapy was critical for the children to receive the benefits of the therapy session to improve their behavior, cognitive, and language skills. The level of compliance for children with actively engaged fathers improved by 90% compared to 52% improvement for the children of single mothers, and 74% improvement with non-engaged fathers (Bagner, 2013).

When fathers were actively engaged, mothers reported lower real and perceived levels of burden, improved mental health, and better overall quality of life than the single mothers or mothers with non-engaged spouses (Bagner, 2013). The decrease in burden and improved quality of life for the mothers were associated with improved family cohesion and well-being for the entire family.

Fathers of children with developmental and intellectual disabilities who were actively engaged in their children's treatment reported a more positive outlook about the children's future, provided emotional support and comfort to the mothers, had better

family cohesion, and had improved well-being for the family (MacDonald & Hastings, 2010). Actively engaged fathers viewed their marriage as their main source of support, but mothers reported multiple sources of support outside of the family. Many fathers had difficulty finding support outside of the home and believed that other men did not understand what the fathers were experiencing (MacDonald & Hastings, 2010). Fathers wanted to talk to other men going through the same experience, but they did not know where to find them (MacDonald & Hastings, 2010). Fathers who found external sources of support had higher levels of engagement with their children and improved family cohesion (MacDonald & Hastings, 2010).

Children with developmental delays and actively engaged fathers had improvements in their behavior, cognitive, and language problems when compared to a similar population of children with absent and non-engaged fathers (Bagner, 2013). Children with actively engaged fathers continued to have sustained improvements for a minimum of six months after the conclusion of their therapy sessions. Developmental delays are a warning sign for ASD; therefore, it can be anticipated that similar results might exist in children with ASD.

Gap In Literature

Children with developmental delays had improved outcomes when they had actively engaged fathers compared to similar populations with absent and non-engaged fathers (Bagner, 2013). Improvement in the children's behavior and developmental skills significantly improved family cohesion and well-being. More children are living in homes with single-fathers, and more fathers are taking on the caregiver role for their children with ASD, yet very little research exists regarding fathers, their role as primary caregiver, and their experience as fathers of children with ASD.

The current study used a phenomenological case study approach to describe the

experience of fathers of children with ASD. The purpose of the research was to use the fathers' voices to describe their experience as fathers of children with ASD, the depression or anxiety they may experience including the source, and any resources needed to help them actively engage in their role as fathers of children with ASD. This knowledge may assist healthcare providers in the future to better support parents of children with ASD.

Chapter Summary

This chapter included a discussion of the cost of ASD to society, emotional burden for the family, financial burden on the family, mental health effect of ASD on the mothers and fathers, family cohesion, and the outcome for children with developmental delays and actively engaged fathers. Existing knowledge of the effects of ASD on the parents, cohesion issues for the family, and benefits for children with actively engaged fathers was presented. The gap in the knowledge was given with a link to the current study.

Chapter 3

Methods and Procedures

This chapter includes an explanation of the phenomenological case study method, which was used to describe the experience of fathers of children with ASD. The chapter provides an overview of phenomenology as the philosophical approach and case study as the method for the study. Sample selection methods, study setting, data collection, and data analysis are discussed. Ethical considerations and rigor are also addressed in this chapter.

Research Method

The primary investigator (P.I.) conducted a phenomenological case study to describe the experience of fathers of children with ASD, their level of engagement in their child's care, anxiety or depression they have and its source, and sources of support for the fathers. Qualitative research uses participants' words to provide rich, in-depth detail to describe the meaning and experience of the phenomenon (Munhall, 2012). Using participants' words to describe their lived experience with the phenomenon expands the knowledge, understanding, and insight about the meaning and experience of the phenomenon that other research methods cannot do (Baxter & Jack, 2008; Creswell, Hanson, Plano Clark, & Morales, 2007; Munhall, 2012; Yin, 2003b). The researcher takes on the role of a reporter in the field or natural setting, observing, recording, interpreting, and reporting the detailed picture of the phenomenon, setting, and meaning to the participants (Stake, 1995, 2006).

Phenomenology was the research approach used for this descriptive case study. Phenomenology is used when the aim of the study is hearing, understanding, and accurately telling the story of the research participants to gain a better understanding of the phenomenon (Munhall, 2012). It is conducted in the natural setting because the

phenomenon and the setting cannot be separated (Bultas, 2012; Hancock & Algozzine, 2011). A goal of the phenomenological approach is to improve clinical practice using the information obtained in the study to address any needs or concerns of the participants (Creswell, 2014; Hancock & Algozzine, 2011; Munhall, 2012). The researcher described the experience of fathers of children with ASD; the depression or anxiety they experienced, including the source; and any resources needed to help them actively engage in their role as fathers of children with ASD.

Case studies are an appropriate research method to use when the phenomenon is so deeply intertwined with the participant's life that it is impossible to separate them (Yin, 2003a, 2003b). Case studies are also an appropriate research method when very little information exists about the phenomenon (Hentz, 2012). This method was appropriate for this study because very little information exists about the experience of fathers of children with ASD.

The first step in case study research is identifying the case for the study (Yin, 2003a, 2003b). The case for this study was White fathers of children with a formal diagnosis of ASD (ASD: ICD-9 Code 299) who live in the same home as their children with ASD (Buck, 2012). This step determined the limits of the study to the specific population of interest, White fathers who were living in the same home as their children diagnosed with ASD. The next step was determining if the study would include single or multiple cases. Single cases use one participant or a group of participants. Multiple cases have more than one case, such as fathers of children with ASD who have a comorbid condition such as cognitive impairment or conduct disorder. The fathers have experience with having children with ASD, but the cases are different due to the comorbid conditions of the children. The data from these participants are analyzed as multiple cases in a research study (Baxter & Jack, 2008; Yin, 2003a, 2003b). The current study

used a single case study design with ten participants whose data were analyzed together as a single case. The single case study design was used, because the ten White fathers lived in the same home as their children who had a formal diagnosis of ASD (ICD-9 Code 299; Buck, 2012) and no mental health co-morbidities. The shared characteristics of the ten fathers in the study met the criteria single case study design with multiple participants analyzed as a single case. Using multiple participants as members of a single case provides the opportunity to find similarities in the participants' experience or contrasting information (Baxter & Jack, 2008; Yin, 2003a, 2003b). The data collected from the group were analyzed together as a single case.

The phenomenological approach combined with the case study method provided a voice to the fathers of children with ASD to describe their experience with their children with ASD. The information gained in the study will improve the health care providers' knowledge about the fathers' experience with ASD from their perspective, learn how it affected them, and identify what needs they had to help them become successful in their role as fathers of children with ASD. Identifying the resources fathers need to become actively engaged with their children can improve clinical practice and the overall outcome for children with ASD and their families.

Sample

The sample consisted of White fathers of children with a formal diagnosis of ASD (ASD; ICD-9 Code 299; Buck, 2012). ASD affects more White children than any other race, so this study was limited to White fathers (Baio, 2014). Additional inclusion criteria were that the fathers spoke English, were at least 18 years old, had a child with a formal diagnosis of ASD (ICD-9 Code 299), and lived in the same home as their children with ASD. Exclusion criteria were that the children could not have co-morbid conditions such as cognitive impairment, conduct disorder, or any other co-morbid conditions, because

those cases would have different characteristics that would change the experience of the phenomenon for the fathers. All fathers who met the sample criteria and agreed to participate in the research study were included in the study, reducing bias.

Recruitment

Participants were recruited using purposive and snowball sampling methods. Purposive sampling means selecting research participants because they meet the sample criteria, and they have a deep understanding of the phenomenon (Gliner, Morgan, & Leech, 2009). Snowball sampling uses word of mouth recruitment by the research participants or others who are familiar with the research study and its purpose (Gliner et al., 2009). All research participants were required to meet the sample criteria to be included in the study.

Recruitment occurred concurrently with data collection and analysis until the entire sample was obtained. Sampling occurred using a letter of introduction that included information about the study and contact information for the P.I. (See Appendix A). The letters of introduction were distributed to fathers of children with ASD by an independent music therapist who worked with children with ASD. If the fathers were interested in participating in the research study, they contacted the P.I. via email to determine if they met the sample criteria and establish a meeting time and location. Snowball sampling occurred by word of mouth using the fathers participating in the study and other individuals who were aware of the research study and its purpose.

Sample size

This study used a single case study design with fathers of children with ASD analyzed as one case obtaining as much information as possible about the fathers' experience with ASD. Single case studies with multiple participants should use a minimum of four and a maximum of ten participants (Stake, 2006; Yin 2003b). The

minimum number provides enough information to gain a clear understanding of the phenomenon and its context, and the maximum number limits the amount of information to prevent it from becoming confusing and losing the meaning (Stake, 2006).

Recruitment ended when ten White fathers of children living in the same home with a their children who had a formal ASD diagnosis, and no MH comorbidities completed their interviews.

Saturation was an important consideration for determining the final number of participants for the sample size. Saturation is the point during data collection and analysis when no new information is expected to occur from any additional interviews (Brod, Tessler, & Christensen, 2009; Hentz, 2012). An expandable saturation grid was used during data analysis to track the themes and codes in the data determining if saturation was reached (See Appendix B).

Setting

Interviews were conducted in participants' homes or similar setting of comfort selected by the participants. Using the home setting provided a level of comfort for the research participants and minimized any disruption to their schedule. The home setting also helped to protect the participants' privacy and confidentiality. Arrangements were made to meet with any participants who did not wish to meet at their home. Those interviews were conducted in another location to maximize privacy for the research participants, such as a study room at a local library. Interviews were scheduled at a time selected by participants to minimize disruption of their schedule.

Data Collection Methods

Interviews were conducted using a combination of open-ended and probing questions. Interviews are one of the most important sources of data for case studies and should include ten to twenty questions (Stake, 1995). Open-ended questions were used

to obtain in-depth responses from the participants to learn as much information about the experience with the phenomenon. The interview questions were designed to allow the interviews to flow like a conversation between the P.I. and the participants. The questions were used to guide the conversation. The interview setting and design encouraged the fathers to talk openly about their experience with the phenomenon and its deep connection with their lives (Creswell et al., 2007; Hentz, 2012; Yin, 2003b).

The interviews used a demographic sheet (See Appendix C) and eighteen open-ended questions in a one-time face-to-face interview format (See Appendix D). The demographic data provided information about the research participants. Follow-up or probing questions, not included on the interview schedule, were asked to provide clarification and more detail about participants' responses. Interview questions were grouped to obtain information about the children with ASD, the effect of ASD on the fathers' lives and lives of their family, challenges they faced as fathers of children with ASD, and the strengths they had to meet and cope with the challenges. Additional questions were used to learn about the fathers' reaction to the diagnosis, how other people reacted or responded to their children, and the fathers' reaction to these people. The final questions were asked to learn what advice the fathers had for other fathers of children with ASD, any needs the fathers had to help them in their role as fathers of children with ASD, and their sources of support.

Data collection also included direct observation and field notes. These methods included notes taken during the interviews regarding the setting, comfort level of participants, and all non-verbal communication that helped provide additional context for the interviews (Yin, 2003b). Conducting the interview in participants' homes provided the opportunity for direct observation of the phenomenon in the natural setting with the participants.

The interviews, field notes, and direct observation of the participants in their natural setting were important data sources that provided vital pieces of information about the phenomenon and participants. The goal of the P.I. was to use the pieces of information like pieces of a puzzle to build the picture and report the real-life experience of participants with the phenomenon. The result was an increase in knowledge and a deeper understanding of the meaning of the experience for the participants (Baxter & Jack, 2008).

Research Protocol

Research protocols included the rules established for the study, as well as the tools the P.I. used for data collection and analysis (Yin, 2003b). Following the protocol established for the study helped to limit the study to its aim and purpose while preventing it from losing focus (Yin, 2003b). The protocol for this study included the inclusion and exclusion criteria, sample size, research setting, demographic data, interview questions, data collection, and data analysis. All information about the study including the raw data and analysis were maintained in a database on a password protected, encrypted computer.

The database included all the raw data for the study and provided an audit trail to improve the rigor of the study. The database provided organization and documentation for the study by maintaining all records for the study in one location (Baxter & Jack, 2008; Yin, 2003b). All verbal data were collected by the P.I. using audio recordings of the interviews following the questions on the interview sheet. Observations and field notes were recorded using paper and pencil before, during, and after the interviews by making notations on the participants' interview forms. The field notes, audio recordings, and observations helped to insure the completeness, accuracy, and consistency of the data collection process. The raw data included in the database included the word-for-word

transcripts of the interviews, demographic sheets, field notes including documentation of the interview setting, non-verbal expressions of the participants, description of the settings, and any additional information critical to the interview process or data collection method (Yin, 2003b).

Ethical Considerations

Approval was obtained from the University of Texas at Arlington (UTA) Institutional Review Board (IRB) prior to recruitment. The P.I. implemented informed consent procedures for all potential participants expressing a willingness to participate in the study. Written consent was obtained for each participant in the study. Participants were given an informed consent to read explaining the purpose of the study, the participant's role, and the risks and benefits of participating. Participation in the study was voluntary, and participants were instructed that they could stop participating at any time without penalty. Contact information for the P.I. and faculty advisor were included on the informed consent. If the fathers agreed to participation in the study, their written consent was obtained on the consent form. The informed consent format was provided and approved by the UTA IRB office (See Appendix E).

No physical harm or risk for harm was anticipated for the participants. There is a small risk of emotional discomfort for the fathers participating in the study. Participants were instructed to notify the P.I. immediately if they experienced any emotional discomfort. The participants were informed that they could stop the interview at any time without any negative consequences. There were no direct benefits of the study, potential benefits of the study included the opportunity for the fathers to talk openly about their experience with their children with ASD, identify their strengths, and identify any resources required to help them in their role as fathers of children with ASD.

The audio recordings, field notes, demographic data sheets, interview sheets,

and transcriptions were maintained in a locked safe in the P.I.'s home until completion of the data analysis. All of the information will be transferred and stored in the Center for Nursing Research (CNR) at the P.I.'s educational institution, University of Texas at Arlington College of Nursing (UTA CON) upon completion of the dissertation process. Transcripts and codes from the transcriptions were entered into a password protected and encrypted external hard drive and stored in a locked safe in the P.I.'s home. Access to the transcriptions and codes were password protected with access limited to the P.I. and members of the dissertation committee who are trained in human subjects' protection by UTA. The disseminated data included only aggregated data to prevent identification of any individual research study participant. The data will be maintained in a locked, secure location for five years before being shredded or destroyed.

No participant in the research study received compensation for participation. Participation in the study was voluntary, and participants were permitted withdraw at any time during data collection.

Data Analysis

Descriptive statistics for demographic information

Descriptive statistics were used to describe participants' demographic information (See Appedix C). The information was not used to make any inferences, comparisons, or associations about the participants or the information obtained in the study (Gliner et al, 2009).

Qualitative data preparation and analysis

Data collection and analysis occurred simultaneously. The P.I. transcribed the audio recordings of the interviews word for word within 24 hours of the interview. This improved the accuracy of the transcription (Creswell et al, 2007). The transcriptions were reviewed while listening to the play back of the audio recording to verify the accuracy of

the transcription.

Data collection and analysis occurred simultaneously to identify common themes present, identify any rival themes, and determine if any information was not present that required alterations to the interview sheet (Creswell, 2014; Creswell et al., 2007; Hentz, 2012; Yin, 2003b). Data analysis included reviewing the transcripts, field notes, and documents to identify all themes or codes (Creswell et al., 2007; Hentz, 2012; Saldana, 2013; Yin, 2003a, 2003b).

Interviews were conducted, transcribed, and analyzed following the research protocol. Data analysis was conducted using line by line coding of each transcript by the P.I. An expandable saturation grid was used to track the codes (See Appendix B). The first column on the saturation grid was used for the codes, and quotes from the participant supporting the code were written in the second column. Theoretical ideas or insights about the data or codes were recorded using memos (Grove et al., 2013). Writing memos helped the researcher transition from the information present in the participants' statements to determine the concepts, themes, or patterns present in the data (Grove et al., 2013). Pattern matching allowed the researcher to identify the common themes using the statements the participants used to describe their experience theme (Baxter & Jack, 2008; Yin, 2003b). Data analysis was conducted using emotion and in vivo coding methods. Emotion coding uses the participants' responses to the interview questions to identify expressed or perceived emotions (Saldana, 2013). In vivo coding gives a deep, rich quality to the participants' experience using their words to describe or explain their experience with the phenomenon (Saldana, 2013).

Additional coding to identify codes and themes in the data was done using Atlas.ti 7.5 software (Muhr, 2014). Atlas.ti 7.5 was also used to organize the interviews, quantify the codes present in the data, organize the codes into themes, maintain a

codebook, and provide an audit trail for the study. Quantifying the codes present in the data demonstrated how many times each code was used by the fathers during their interviews.

Rigor

Rigor was used to determine the quality of the research (Guba, 1981; Krefting, 1991). Rigor was addressed at every step during this research study. Qualitative research uses credibility, applicability, consistency, and neutrality to evaluate the quality and rigor of the research (Gibbert, Ruigrock, & Wicki, 2008; Krefting, 1991; Yin, 2003b).

Credibility or truth-value means that the research findings accurately describe the experience of the fathers of children with ASD (Guba, 1981; Krefting, 1991). It was addressed during research design, data collection, and data analysis (Gibbert et al., 2008; Krefting, 1991; Yin, 2003b). The research design for the study, phenomenological case study method, was an appropriate research design to use because little information exists about the phenomenon, the experience of fathers of children with ASD. Data collection and analysis occurred simultaneously using accurately transcribed interviews identifying and reporting common and rival themes present in the data. Additional methods to improve credibility included spending an adequate amount of time with the fathers listening and observing them, using field notes to record the setting and non-verbal information, and maintaining consistency between the data and its interpretation.

Applicability or transferability meant the results of the study were applicable to different participants or settings (Guba, 1981; Krefting, 1991). This was addressed during the research design by following the inclusion and exclusion criteria, sample size, setting, and data collection methods. Selecting participants that met the sample criteria limited the study to participants with experience with the specific phenomenon of interest. Using multiple fathers from different locations improved the ability to apply the results to

fathers in different locations of the country. Transferability was improved during research design by using purposeful sampling to obtain a sample that met the criteria and collecting in-depth descriptive data about the phenomenon.

Consistency or dependability meant the study could be repeated and provide similar results (Guba, 1981; Krefting, 1991). The study followed the prescribed research protocol and included appropriate data collection methods and data analysis (Yin, 2003b). The questions on the interview sheet were asked of fathers in a variety of locations and produced similar results. A research database contained all of the research study information providing an audit trail that can be used to replicate the study.

Neutrality means that the findings are the result of the phenomenon rather than researcher bias or other causes (Guba, 1981; Krefting, 1991). Researcher bias was controlled by following the interview sheet, making audio recordings, accurately transcribing the interviews, conducting line by line coding of the data, using the ATLAS.ti 7.5 (Muir, 2014) software coding package, and accurately reporting all of the data obtained from the study.

Triangulation is one method to improve rigor in qualitative research. It involved using different research approaches to examine and analyze the phenomenon of interest (Hancock & Algozzine, 2011; McBrien, 2008; Yin, 2003a, 2003b). Two methods of triangulation were used during this study, methodological and investigator triangulation. Methodological triangulation used multiple sources of evidence such as interviews, observation, and field notes to provide a complete picture of the research participants and their experience with the phenomenon (Stake, 1995). The P.I. used each of these methods to obtain data during this study. Investigator triangulation was done using the ATLAS.ti 7.5 (Muir, 2014) software and investigator conducting line by line coding to identify codes and themes present in the data.

Adherence to the details of truth-value, applicability, consistency, and neutrality during every step of the qualitative research study improved the rigor for this study. The P.I. adhered to the standards and provided an audit trail to improve the rigor and quality of the study.

Chapter Summary

A phenomenological case study was conducted using semi-structured interviews and participant observation to describe the experience of ten, White fathers of children with ASD. The chapter included an overview of phenomenology as the philosophical approach and case study as the method for the study. Sample selection methods, study setting, data collection, data analysis, and ethical considerations were addressed. The research protocol was included to insure that the study remained focused on the research goal throughout the research process. Rigor was established to insure the trustworthiness of the study and the results. The final product for the study used participants' words to provide rich, in-depth details about the fathers' experience with their child with ASD.

Chapter 4

Findings

This chapter presents the findings of this phenomenological qualitative case study of fathers' experience with autism. Sample characteristics, data analysis, codes grouped by themes, participant quotes supporting the findings, and chapter summary are included in the chapter.

Sample Characteristics

Convenience and snowball sampling were used to obtain a sample of ten White fathers of children diagnosed with ASD. Demographic information for the sample was divided into characteristics for the fathers and the children.

Fathers' Characteristics

Participants ranged in age from 29 to 62 years (mean 41.4 years, SD = 10.5). Each participant had one child with a formal diagnosis of ASD. All of the fathers were the birth fathers for their children, and all lived in intact homes with both the mother and father of the child with ASD. Two of the fathers shared primary caregiver responsibility for their children, and eight reported the children's mothers as the primary caregiver. The 20% of fathers identified as a primary caregiver in the sample is similar to fathers identified as the primary caregiver for preschool age children in the general population (approximately 24%; Flippin & Crais, 2011). Four fathers became aware of developmental concerns during the first year of their children's lives, an additional three fathers became aware of between ages two and three years, and three fathers became aware of developmental concerns by age four years.

Children's Characteristics

Three of the children were diagnosed with attention deficit hyperactivity disorder (ADHD) in addition to ASD. The number of children in the family ranged from one to four

children (mean 2.4 children). Of the ten children with ASD in the sample, eight were males, and two were female. The sample ratio of male/female children with ASD (4:1) is similar to the incidence of ASD in the general population: 4.5:1 male to female (Baio, 2014). In the study, the children’s age at ASD diagnosis ranged from two years to seven years (mean 4.25 years). The time since the children were diagnosed with ASD ranged from 1.5 years to 11 years (mean 5.6 years). See Table 1 for additional demographic data.

Table 1 Sample Demographics

Characteristic	Description	Result
Paternal Education	Finished High School/GED	2
	Some College	2
	Completed College	6
Employment Status	Unemployed/Disabled	1
	Employed Full Time	8
	Working Overtime	1
Child’s Age at Diagnosis with ASD	2 years	1
	3 – 3.5 years	3
	4 – 4.5 years	2
	6 years	2
	7 years	2

Data obtained from the fathers’ interviews met the criteria for a single case with multiple participants as defined for the study. The case was defined as White fathers of children with a formal diagnosis of ASD (ASD: ICD-9 Code 299) who live in the same home as their children with ASD. The data were analyzed as a single case with three major themes.

Themes

All of the fathers in the study stated that his was the first time anyone asked them to talk about autism, their experience, what it means to them, their needs, and their sources of support. They said that it felt good to talk about ASD and put into words their thoughts and feelings never before expressed verbally. A few of the fathers became very

emotional during the interview, feeling pain and sadness. The fathers experiencing pain and sadness, along with all of the fathers in the study, openly talked about their overwhelming and unconditional love for their children.

The next section will include the three major themes of family life: making adjustments, a father's needs, and grief and loss. Quotes are provided supporting the themes.

Theme One: Family Life: Making Adjustments

Once the children received their ASD diagnosis, the families were forced to make changes to their daily lives to meet the immediate challenges of the ASD diagnosis. As the family members adjusted to the diagnosis, families adapted their lives to meet the long-term challenges associated with ASD. The challenges included finding funding for therapies and treatments not covered by insurance, meeting with teachers to formulate the education plans for the children, transporting the children to therapies often held five days per week, reinforcing lessons learned at therapies, and making career sacrifices to become the children's caregivers. ASD became the center of family life requiring every member of the family, mothers, fathers, and siblings to adjust and adapt to the challenges of ASD.

"I took a full-time job working week-ends and my wife worked during the week...we decided that would be best for our family."

"My wife stayed home all the time...it was a full-time job to get her to therapies, ABA, and other appointments. Now that she is older we can relax a bit, but one of us always has to be on call in case something happens at school and we have to pick her up."

"Everything is a challenge with autism. We had to take him for the diagnosis, then figure out where he could do his therapies and who would pay for them. There were

constant meetings at school to get his IEP in place and make sure he was getting what he needed. It was a full-time job plus you never knew when something would cause a meltdown. Those were the worst times, they still are.”

“Time heals all wounds and that is how it is with his autism. Autism is just a word, it’s how you react to it and what you do about it that makes a difference.”

Siblings were forced to make adjustments because of their sibling with ASD. The siblings gave up their dreams of having fun as a family and doing things together such as going to the movies, going to Six Flags, having friends spend time in their home with them, and attending other special occasions children dream of doing. Siblings also took on the role of protector for the sibling with ASD.

“You have no idea what it is like to look your kids in the eye and tell them we can’t go on vacation or the movies or to a lot of other places.”

“It has been hard for the other kids (siblings). They love their brother, but we can’t take them a lot of places that families like to go because of the noise, stimulation, and expense.”

“The boys (siblings) are great with their sister, but it has not been easy for them. They are not allowed to have friends over to the house because of her and her autism.”

“He (son with ASD) is not her (sister) responsibility. She thinks it is and she is fantastic with him. She spends so much time with him and is so protective of him.”

Family members were forced to make adjustments in their lives due to the immediate challenges related to the ASD diagnosis and they had to adapt their lives to the long-term challenges associated with the lifelong care and burden caused by ASD. All of the changes in the family members’ lives to overcome the challenges of ASD led to the next theme, a father’s needs.

Theme Two: A Father's Needs

Fathers stated needs including money, teamwork, honesty and information, get involved/take action, and time. These items became the codes in the theme, a father's needs. Each code in the theme represents specific needs of the fathers and families.

Money

While fathers expressed a need for money to support their families and pay for high cost of ASD therapies, all of the fathers believed the cost was worth it if their children benefited in any way. Some of the fathers discussed spending between \$500,000 and \$750,000 for a variety of ASD services not covered by their insurance. Expenses related to ASD included developmental specialists, diagnostic evaluations, travel to ASD specialty centers, private tutors, communication specialists, iPads and other electronic communication devices, and ABA therapy. Many of the additional services and therapies provided valuable benefits for the children. Fathers of children with ASD will do almost anything to help their children. Some of the fathers spoke about people who said they would help their children and their ASD symptoms and behaviors, when all those people wanted was the money, and they did not help the children at all. For example, chelation therapy to remove heavy metals from the children's blood, chemical supplements to restore normal brain function, restrictive diets designed to remove gluten and casein from the children's diets, and light therapy designed to reprogram the brains of children with ASD to eliminate their communication, socialization, and behavioral impairments. Fathers stated that these treatments were expensive and did not benefit their children with ASD.

Some of the fathers worked extra hours, sacrificing time with their families to earn the income necessary to pay for services and support the families. One father described how not having insurance and the money to pay for the diagnostic evaluation

for his child delayed the diagnosis until the child was school age when the evaluation was done by the school. The fathers who owned their own businesses spent much of the profits from their businesses on ASD services rather than relaxing, enjoying, and rewarding their successes. The sacrifices to provide the income to support the family and pay for additional ASD services left the fathers feeling depressed, guilty, and angry because each wanted to be with his family rather than working and focusing on money.

“If I could go back and change something, I would start with money. (It) feels like it always comes back to money. If we had money, we could afford to take him to a specialist. I put money before my son.”

“It is so expensive, it makes it hard to make ends meet sometimes, but he is worth it even if the only thing that happens in return is him making eye contact or smiling at us.”

“We have spent about half a million dollars trying to find help for him. A lot of it was wasted, but the money spent that has helped him has been well worth it.”

“We have spent hundreds of thousands of dollars to find a cure for him, but we know there isn’t one. So, we have spent over half a million dollars chasing every possible treatment, medicine, and therapy that promised to make life better. I wouldn’t say it was all wasted, but a lot of it was.”

Teamwork

Teamwork helped the families face the challenges of ASD together. Parents and families working together were essential to sustain the relationship between the husbands and wives. All of the fathers in the study were actively engaged with their children with ASD. They had a clear goal, the best possible future for their children. Their marriages were a source of strength, they had a partner working with them, loving, and supporting them through the difficult times they faced due to their children’s ASD.

Their unity helped strengthen their families against the challenges of ASD. It was important for them to have time as a couple to keep their marital relationship strong.

“We stick together and do things as a family. That is how we cope – being a team.”

“Men need to work together with their wives, and figure out the best way to handle it and whatever it brings down the road.”

“Work together and enjoy the time together. That may be the best day of your life because you never know what the future will bring. Work together because if you don't it can tear everyone apart.”

“We need to work together as a team because when we do that helps all of us. Knowing that we are in this together and working together to figure it out helps; it took us a while and some yelling for all of us to get on the same page.”

Fathers also described the importance of working with the health care providers, teachers, and therapists as essential elements to improve the outcome for their children. When the team worked together toward a common goal, the fathers' believed the outcome for their children improved. Fathers wanted an action plan to follow for their children including therapies, treatments, communication techniques, education, engagement activities, and any other available options to help their children.

“I would tell other dads to push for what they need, and if it doesn't happen make some noise and make them do something for your kid.”

“I would tell dads to take the time off to go to the appointments with the doctors and specialists. They need to know and understand what is going on and push for what they need.”

“Don’t take no for an answer or wait until the next visit to discuss your concerns. I would tell them to ask questions and hold the doctors’ and specialists’ feet to the fire. That needs to happen. Work together to help your child.”

Honesty and Information

The fathers wanted honesty and openness from the health care providers, therapists, and teachers. They had an expectation of the health care providers, listening to them, addressing their concerns, possessing knowledge about ASD, and finding the appropriate treatment and therapies for their children. Their expectations were often met with disappointment because the health care providers, therapists, and teachers did not listen to them, did not address their concerns, and/or told them to wait until the next visit to see if any improvements occurred. Fathers believed that the health care providers, therapists, and teachers were not honest with them or did not have their children’s best outcome as the goal.

“I do get upset with people who are not honest and open with me. I expect people like the doctors and therapists, and his teachers to be honest with me.”

“I’d rather they say ‘I don’t know’ than treat us like dirt. I respect honest people.”

“It still hurts to think about all the time we wasted and how everyone was so quick to blame us rather than try to help her.”

“My biggest challenge is knowing what to do for him. It is better now that he is in school, but I still have times when I am not sure they are doing the right thing or if he is just another kid with autism that is put in their autism box rather than doing what is best for him. But, I am happy they are doing something. It took us a long time to get him diagnosed and started in therapy. I was so mad. We kept telling them something was wrong, but they told us we had to wait until he was older. Then nobody who worked with kids like him took our insurance or they were a long way away. It made me furious.”

Fathers also wanted a central location to find honest and beneficial information about ASD, including information from other parents with the same or similar experiences with their children with ASD. Health care providers, therapists, and teachers frequently had information about ASD and some types of therapies, but the information was limited and often did not apply to their children. Fathers turned to the internet to learn more about the available therapies and treatment options. A plethora of information is available on the internet, however some of the options can cause harm or have no effect, and can be extremely expensive. A central location for the information requested by the fathers does not currently exist.

“(We) need good information or a way to find the best information from people who have actually experienced the care or treatment. You know, people who tell you the truth rather than the slick salesman who tells you what they are paid to tell you.”

“I wish there was a way to meet or talk to other parents who have been through this. What have they done with puberty and all of the challenges of having a girl with autism? It would be helpful to have some place to turn for answers or support that would help”

Getting Involved/Taking Action

All fathers in the study said that they would advise any father who is concerned about their child’s development and possibility of ASD to get involved and take action. Getting involved was described as being present at medical appointments, listening to the information, and asking questions about their concerns. Taking action meant pushing for a developmental evaluation or referral to a specialist rather than waiting until the next office visit.

“I would tell dads to take the time off to go to the appointments with the doctors and specialists. They need to know and understand what is going on and push for what

they need. Dads need to be there to hear the news together and work on a plan together.”

“If you think there is something that is not right with your child, don’t wait to find out. I am not sure things would be different if we pushed for answers sooner, but now we know we should not have waited until he was in second grade.”

“Don’t take no for an answer or wait until the next visit to discuss your concerns. We were told to wait several times. Don’t wait. I would also tell them to ask questions and hold the doctors and specialists feet to the fire – not that it helps very much.”

“Before we knew it was autism, everyone thought he was a bad kid with terrible behavior and we were awful parents who didn’t care. We tried to show them. We knew it was more than bad behavior, but no one listened. Things are different since they told us he was autistic.”

Time

Time was the least frequent code in the needs theme. Fathers described their desire to have more time to work with their children with ASD and more time with their other family members, especially their other children. None of the fathers wanted time alone to care for their needs or any form of self-care. They all wanted to do what they could to ensure their wives had time away from their children to attend to their own needs.

“I miss having the time with my wife and us being a family. It is hard to describe.”

“My wife needs a break, but it is better when he is in school. That gives her some time for herself.”

“I do things like watch her so my wife can go get a manicure or something like that. She deserves a break because for her it is 24/7. I at least get out to go to work.”

“You have to take advantage of any time together you can have.”

The lifelong burden ASD causes for the parents can lead to feelings of anger, blame, and frustration related each family member adjusting to the diagnosis and adapting to the long term care of the children with ASD. While describing family life: making adjustments and a father's needs, the fathers expressed a variety of emotions, which are combined into theme three, grief and loss.

Theme Three: Grief and Loss

Fathers of children with ASD have lost their ideal child, their dreams of what their child would become, resulting in emotional grief. Instead of looking forward to their children getting an education, a job, a spouse, and someday children of their own, these fathers must accept a child who will need a caregiver for his/her entire life. The stages of grief and loss for these fathers include denial and isolation, anger, bargaining, depression, and acceptance' similar to the classic work of Kubler-Ross and Byock (2011). Grief and loss are common when experiencing a death; however, the same stages can be experienced when facing a loss, chronic illness, or medical condition including ASD. Movement through the stages of grief and loss is not linear; the stages may occur at any time, any order, and may be repeated at any time. Each stage of grief and loss is presented as a code with sample quotes to support its inclusion in the theme of grief and loss. The stages of grief and loss include denial/isolation, anger, bargaining, depression, and acceptance (Kubler-Ross & Byock, 2011).

Denial/isolation

The first stage of grief and loss is denial and/or isolation (Kubler-Ross & Byock, 2011). Fathers of children with ASD may have difficulty accepting the diagnosis, realizing the lifelong nature of the condition, and how different their future will be from the one they planned and dreamed of. This can lead to feelings of denial and isolation.

Fathers talked about their losses including the loss of a normal child, loss of a typical family, loss of additional children, and the uncertain future for their family. All of the fathers described their concerns, fear, and worry about a variety of current and future issues such as puberty, their children's future if the fathers weren't present, money, their children with ASD never becoming independent, and poor treatment by others including extended family, friends, medical professionals, and other people. Several fathers spoke openly about their isolation and rejection by their extended family members, friends, and the avoidance of public places because of their children's ASD.

Codes included in the denial/isolation category were loss, not a monster, isolation, and worry/fear. Losses included having a normal child, being a typical family, having more children, dreaming of a bright future for them and their children, having hope, having faith, losing themselves, and losing support from extended family members. Fathers described their need to isolate and protect their children from the responses and reactions of extended family members and other people. Freak and monster were used to describe how extended family members and other people reacted to their children with ASD and their behaviors, rather than understanding they were just children with ASD.

"I thought by now I would be slowing down and planning for a fun and exciting future, but that isn't going to happen. He will be with us for the rest of our lives."

"She doesn't smile, she just stares off into space. The problem is, knowing what it is also lets us know that it will never go away and there isn't a pill to calm her down or fix it. That isn't going to happen. We avoid going places and no one wanted to come to visit because of her."

"They (other family members) didn't want us around because of him. They need to see he is just a little boy, not the monster they said he was"

“We were shunned by our families. We moved away – they didn’t want to be around us anyway, so we moved away from them so nobody has to feel bad about not spending time together. It was better for everyone.”

The fathers’ feelings of loss, not a monster, isolation, and worry/fear were challenges for the fathers. Their need to isolate and protect their children from extended family members and the public, along with hearing their children with ASD described as freaks and monsters forced the fathers to become isolated. Feelings of denial and isolation can be overwhelming to the fathers and lead to another stage of grief and loss, anger (Kubler-Ross & Byock, 2011; Sommer, 2013).

Anger

Anger resulted from the fathers’ expressions of frustration, lack of understanding, blame, helplessness, and abandonment. None of the fathers that stated they were angry with their children. Their anger was directed toward themselves, members of the health care team, teachers, extended family members, and other people. They were angry with themselves, because they did not attend medical appointments, push for a diagnosis, and were not able to fix their children’s ASD. They were angry with members of the health care team for not listening to their concerns, identifying ASD earlier, initiating therapies, and having knowledge about funding sources, valid therapies, support programs, and options to help their children as they reach adolescence. Their anger was also directed at the teachers who treated all children with ASD the same, rather than identifying their strengths and working to improve their weaknesses. The final source of anger was extended family members and other people who responded with negative comments about parenting, and calling the children monsters who needed discipline rather than understanding that the children had ASD and needed their understanding.

“We didn’t have insurance and couldn’t afford to take him to a specialist and figure out what was wrong. It was too expensive and we didn’t know there were other places to go for help. I blame myself.”

“I blame myself for his autism. I wonder if it was caused by something that I was exposed to at work or all the medicine I had to take. My other kids are fine, so why did he get this? It had to be me, I feel so guilty about it.”

“Not all people with autism are the same. When he went to school and they put him in a class and expected all of the kids in there to be the same and learn the same way. They acted like every kid with autism is the same and that isn’t true. They weren’t interested in finding the best way for him to learn or figuring out how smart he is. They just put him in that class and did the same thing for everyone who was in there.”

“People look at him like he is a freak. They just don’t understand, most of the time I wish they did, they wouldn’t stop and stare if they were in my shoes – they would know what it is like, but they don’t they are just ignorant.”

Fathers expressed their feelings of frustration, lack of understanding, blame, helplessness, and abandonment as feelings of anger. Their anger was directed toward themselves, members of the health care team, teachers, extended family members, and other people. Anger in the fathers as they were experiencing grief and loss resulted in bargaining as a way to negotiate a resolution to their anger and loss (Kubler-Ross & Byock, 2011; Sommer, 2013).

Bargaining

Bargaining occurs when those experiencing grief and loss try to make a deal to lessen their feelings of grief and loss (Kubler-Ross & Byock, 2011; Sommer, 2013). Fathers try bargaining with God as a method to resolve their feelings. Examples of bargaining include an increase or decrease in hope and/or faith, as well as doing

everything possible to find solutions and answers to their crisis. Some of the fathers in the study relied heavily on their faith and hope to help them meet the challenges of ASD, and other fathers turned away from their faith and lost hope.

“Faith gives you hope and hope gives you strength. I did not come to this easily, but I find if I rely on my faith, I can face any challenge placed before me.”

“You have to have hope, that with time, therapies, and schooling your child will learn how to communicate.”

“If I didn’t have hope that tomorrow will be a new and better day, and the faith that if it is not then the next day will be. I would be in bad shape. But my hope and faith get me through. They have been with me through the good times and the bad. They brought me through the bad times and kept me humble in the good times.”

“I used to be a very religious man, but not anymore . I don’t believe the sins of the father are taken out on the children or anything like that, but I don’t understand why this happened to me. I did everything I was supposed to do and now it is very hard to understand why this happened. So, one of the many negative things is the change in my faith.”

People experiencing grief and loss may turn to bargaining in an attempt to make a deal to resolve or erase the challenges they face (Kubler-Ross & Byock, 2011; Sommer, 2013). When bargaining is not effective, it can intensify their feelings of depression associated with their grief and loss.

Depression

Anyone experiencing grief, loss, anger, isolation, frustration, abandonment, questioning of their faith, and a loss of hope is at risk for depression. Self-described depression in the fathers was frequently associated with their feelings of guilt. They described their failures as not being able to fix their children, being ignored when they

told the health care providers about their concerns, being abandoned by their extended families, not having the resources to meet the needs of their children and families, and feelings of hopelessness.

“I feel so lost, feel like nothing will ever be right again. Autism has ruined everything.”

“Autism brought sadness into our lives. It is not fair to have another child and have them be like our son or have to miss out on things because of him. It has been very hard on us emotionally. We feel like we lost so much even though he is here with us, autism took our son away.”

“I hate to think about the future. I have to take it one day at a time because that is all that I can handle. One day at a time is as good as it gets.”

“I don’t know what we would do if we had other kids. I guess we would manage, but it would be hard. Autism forced us to make a lot of changes. It is not something you sit down and think about because it would drive you crazy.”

Depression is a common finding in people experiencing grief and loss related to death or a diagnosis such as ASD. Working through the depression may result in the acceptance necessary to take positive steps to address the challenges they face.

Acceptance

Acceptance involves adjusting and adapting to the loss of a loved one or the diagnosis and treatment of medical conditions including ASD (Kubler-Ross & Byock, 2011; Sommer, 2013). Acceptance is a necessary step for families to help them become resilient against the challenges of ASD. The fathers may continue to experience the other stages of grief and loss throughout their lives with their children with ASD, however, acceptance can help them move forward and take action. They come to the realization that blame, anger, and self-pity prevents them from accepting the situation, finding the

best help available, facing the challenges head on, loving the child unconditionally, experiencing the joy their children bring to their lives, and using their love to face the challenges.

“It is what it is and getting mad, blaming others, and feeling sorry for yourself keeps you from accepting it and finding the best help for your child.”

“This is the road we were given and we need to stick with it. I have faith that no matter what challenges we face, we will meet it head on and providence will help us make it happen.”

“You can get angry, deny it, and blame everyone for your troubles or you can say this is what we face now, how do we handle it so it doesn’t handle us?”

“Accept it and figure out what you are going to do about it.”

Fathers of children with ASD face challenges as they adjust to the diagnosis and adapt to long-term care their children require related to ASD. The fathers move through the stages of grief and loss including denial/isolation, anger, bargaining, depression, and acceptance. Acceptance encourages fathers toward overcoming the negative emotions, taking steps toward finding the best treatment, care, and available resources to help their children, and becoming resilient to the challenges of ASD. Adjusting and adapting to the challenges of ASD leads the fathers to acceptance. Acceptance helps the fathers become resilient to the challenges they face due to ASD.

Rigor

Rigor was used to determine the quality of the study. Rigor for the study was addressed using credibility, applicability, consistency, and neutrality as described in chapter 3 (Gibbert et al., 2008; Krefting, 1991; Yin, 2003b). Methodological and investigator triangulation were used to strengthen the findings using line-by-line coding by the P.I. and ATLAS.ti 7.5 software coding package (Muhr, 2014), and accurately

reporting all data obtained from the study. An expandable saturation grid and ATLAS.ti 7.5 were used to sort the data, provide frequency tables for the codes, and maintain an audit trail for the study.

Fathers' comments about their needs including money, teamwork, honest information, get involved/take action, and time were described and the frequency the codes were present in the data were recorded. The results are presented in Table 2. The theme grief and loss was supported by defining the stages of grief and loss, identifying the codes included in the stages, including codes contained within each stage of grief and loss, and documenting the frequency the codes were used by the fathers in the data. The stage of grief and loss, code, and frequency the codes are used in the data are presented in Tables 3.

Table 2 A Father's Needs

Code	Description	Frequency
Money	Never enough, delayed diagnosis, wasted	19
Teamwork	Family, Providers	14
Honesty/Information	Best source, honest	14
Get involved/Take action	Be present, don't wait	7
Time	Never enough	3
Total Frequency		57

Table 3 Grief and Loss

Stage	Code	Frequency
Denial/isolation	Loss	23
	Worry/Fear/Concern	13
	Alone/Isolation	6
	Not a monster	2
	Code Total	44
Anger	Frustration	24
	Don't Understand	12
	Mad	9
	Blame	8
	Can't Fix It	6
	Trial & Error	3
	Code Total	62
Bargaining	Hope/Faith:	10
	Won't Accept No	1
	Code Total	11
Depression	Guilt	16
	Code Total	16
Acceptance	Acceptance/Resolve	24
	Love	11
	Protection	7
	Commitment	1
	Code Total	43
Total Frequency		176

Chapter Summary

This chapter included the findings of the study to describe the fathers' experience with autism. The chapter included the sample demographics including characteristics of the fathers and their children with ASD, study procedure, themes including family life: making adjustments, a father's needs, and grief and loss with supporting quotes, and rigor.

Chapter 5

Discussion

This chapter links the study findings to previous research on the experience of parenting children with ASD. The chapter also includes a discussion of the applicability of the theory framework, implications for clinical nursing practice, recommendations for future research, study limitations, and conclusion.

Major Themes

The presence of ASD in children presents a wide range of challenges for the parents (APA, 2013). Although the children often appear normal (without physical deformities), impairments in their social interactions, communication skills, and unusual behaviors set them apart from other children without ASD and often result in a variety of responses from their parents (APA, 2013; CDC, 2014). Previous studies focused on mothers of children with ASD, so the themes in this study will be compared to previous studies of mothers of children with ASD. The themes for fathers can be interpreted similarly to those of mothers of children with ASD.

Approximately 50% of children with ASD have impairments present in their first year of life and 80% during the second year of life, yet almost half of all children with ASD reach school age before receiving the diagnosis (CDC, 2014). Findings in the study sample are similar to the national averages for the age when parents are concerned about their children's development and possible ASD symptoms. Four fathers in the current study were concerned about their children's development since birth, and all were concerned about their children's development by the age of four years. Children of four fathers in the study received their diagnosis after reaching school age. The sample ratio of 4 out of 10 children with ASD receiving their diagnosis after reaching school age is similar to previous studies of 5 out of 10 children receiving their diagnosis after reaching

school age (CDC, 2014). Mothers in previous studies reported that the delay in diagnosis until school age caused feelings of anger and frustration with their health care providers and teachers for not listening to and addressing their concerns about their children (Bultas, 2012; Cassidy et al., 2008; Flippin & Crais, 2011; Montes et al., 2009). Findings in the current study are consistent with findings in previous studies.

Family Life: Making Adjustments

The economic effect of ASD and changes in typical family function can be overwhelming to families of children with ASD (Hock et al., 2012; Lavelle et al., 2014; Lutz et al., 2012; Shimabukaro et al., 2008). Researchers in previous studies reported that mothers typically gave up their career to take on the caregiver role, and fathers worked to provide the income necessary to support the family and the cost of ASD (Hock et al., 2012; Lutz et al., 2012; MacDonald & Hastings, 2010). Fathers in the current study reported similar adjustments to their family structure and function. Fathers adjusted their work schedules to have time at home with their children with ASD and worked overtime at their jobs to increase income to support their families and pay for ASD services.

Researchers in previous studies reported that the lifelong burden of ASD for the parents can lead to feelings of anger, blame, and frustration; to taking on multiple roles; and to a higher divorce rate (Hartley et al., 2010; Hoogsteen & Woodthgate, 2013; Myers et al., 2009). Fathers in the current study made any adjustment necessary to help their family adjust to the challenges of ASD. One father moved his family to another state, because their extended families shunned them and their child with ASD. Another father described how his and his wife's families rejected his child, so they took their daughter without ASD to spend time with their respective families while the other parent stayed home with the child with ASD. Fathers were willing to make the adjustments necessary to meet the challenges caused by ASD. In previous studies, the divorce rate for parents

of children with ASD remained elevated even as the children became adolescents and adults (Hartley et al., 2010). In this study, fathers stated they would do whatever it took to keep their marriage intact. Although the fathers made adjustments, they expressed overwhelming needs to help them face the challenges.

A Father's Needs

Money, teamwork, honesty, pertinent information, a central location for valid information, and time were the needs identified by the fathers. The need for money stated by fathers in the study supports the findings of previous researchers regarding the financial burden for families of children with ASD (Hock et al., 2012; Lutz et al., 2012; Nealy et al., 2012). Researchers in previous studies reported financial burden, blaming each other for their anger and frustration, not carrying an equal share of the burden, causing the ASD, and a lack of understanding of the other parent's burden as sources of decreased cohesion between parents in previous studies (Hock et al., 2012; Karst & Vaughn Van Hecke, 2012; Neely-Barnes et al., 2011). The current study does not support those findings. Fathers in this study described that the need for teamwork with their wives improved their cohesion. The current findings are consistent with previous researcher findings that families who worked together had better coping skills and improved resiliency against the challenges they faced (Altiere & van Kluge, 2009; Bagner, 2013; Bultas, 2012; Cassidy et al., 2008; Hock et al., 2012; Lee et al., 2008).

Fathers in the study expected the same teamwork approach while working with the health care providers, therapists, and teachers, yet they were often disappointed because the professionals did not listen to and address their concerns about their children or they treated all of the children the same regardless of their abilities. Findings in this study are consistent with previous researcher findings of anger and frustration felt by mothers toward their health care providers and teachers for not listening to,

addressing their concerns, and being honest with them about their children and ASD (Bultas, 2012; Cassidy et al., 2008; Flippin & Crais, 2011; Montes et al., 2009).

Fathers in the study wanted more time to spend with their wives, their children with ASD, and their other children. Mothers in previous studies reported the overwhelming burden of full time caregiving for their children with ASD, lack of sleep, taking the children to appointments and treatments, and no time away from the child to focus on themselves as significant contributors to feelings of anxiety and depression (Hock et al., 2012; Harper et al., 2013; Myers et al., 2009). Mothers in previous studies wanted time away from their responsibilities and time alone in contrast to fathers in the current study. The overwhelming burden faced by mothers in previous studies contributed significantly to feelings of depression associated with grief and loss. Fathers in the current study also experienced grief and loss.

Grief and Loss

One father described ASD as a death sentence because he lost everything, a normal child, a typical family, a future, and hopes and dreams of a future with the child becoming independent. The loss he described was similar to the death of a loved one. Intense emotions associated with parenting children with ASD create lifelong challenges for the parents, including social isolation, risk for anxiety and depression, physical health concerns, loss of career, and financial concerns that can result in feelings of grief and loss similar to those experienced with the death of a loved one. People facing a chronic illness or medical condition, including ASD, can experience the stages of grief and loss described by Kubler-Ross and Byock (2011) even though their loved one is still alive (Sommer, 2013).

The death or loss for fathers of children with ASD is related to the loss of the perfect child, a normal family life, a normal relationship with their children with ASD, and

future plans and dreams for the children with ASD and their families. Researchers in previous studies reported that mothers of children with ASD experienced feelings associated with grief and loss as they faced the challenges of ASD (Barker et al., 2011; Beer et al., 2013; Benson & Karlof, 2009; Davis & Carter, 2008; Giallo et al., 2013; Jones et al., 2013; Kelly et al., 2008; Lee et al., 2008; Meirschaut et al., 2010; Phetrasuwan & Miles, 2009). Findings of fathers in the current study support the previous findings.

Denial/Isolation

Fathers in the current study openly discussed their isolation and the negative effect on their family. One father talked about moving away from extended family because they did not accept his child with ASD; another talked about keeping his child away from extended family because of how they treated him, and others talked about spending time with their children with ASD away from the general public to protect them. The finding of isolation in fathers is similar to the social isolation of mothers in previous research studies (Barker et al., 2011; Beer et al., 2013; Benson & Karlof, 2009; Davis & Carter, 2008; Giallo et al., 2013; Jones et al., 2013; Kelly et al., 2008; Lee et al., 2008; Meirschaut et al., 2010; Phetrasuwan & Miles, 2009). Isolation and rejection by their extended family members and friends and the avoidance of public places because of their children's ASD led to feelings of anger for the fathers.

Anger

Fathers in the study were angry with extended family members, friends, other people, their health care providers, teachers, and the school system. These findings support the findings of previous researchers of mothers of children with ASD, who reported that mothers were angry with the same groups of people for similar reasons (Hock et al., 2012; Karst & Vaughn Van Hecke, 2012; Neely-Barnes et al., 2011).

Frustration and anger in the mothers in previous studies was also directed to the fathers,

resulting in a negative effect on family cohesion, marital stability, and overall well-being for the family. Findings in the current study do not support these previous research findings. Fathers in the current study were not angry with their wives and did not allow their anger and frustration to have a negative effect on their family cohesion, marital stability, and well-being of their family. Fathers in the study worked to control their feelings of anger and frustration and often kept them bottled inside with their other feelings of grief and loss, placing the fathers at risk for depression.

Depression

Researchers previously reported significant levels of clinical depression in mothers and mild levels of depression in fathers of children with ASD associated with the severity of the children's ASD impairments and behaviors (Barker et al., 2011; Beer et al., 2013; Davis & Carter, 2008; Jones et al., 2013; Kelly et al., 2013; Phetrasuwan & Miles, 2009). In the current study, although fathers did not talk about feelings of depression, they spoke about feelings of guilt and failure because they were not able to fix their children's ASD, were ignored by the medical providers about their concerns, were abandoned by their families, and did not have the resources to meet the needs of their children with ASD and families. The fathers' feelings of hopelessness were related to their guilt and failure rather than the severity of their children's ASD impairments and behaviors. Guilt, failure, and isolation can cause symptoms of depression. Findings in the fathers for their sources of their depression do not support previous research findings. Fathers described anger as an obstacle to helping their families meet and defeat the challenges they face due to their children's ASD.

Acceptance

Fathers have a unique role in the family dynamic. Having a positive attitude toward their experience with ASD, medical providers, teachers, and others can improve

the outcomes for the child and family (Flippin & Crais, 2010). Findings from fathers in the study supported the previous research study findings. Fathers described how accepting the diagnosis helped them meet their needs and improved the current outcome for their families. The fathers who made negative statements about ASD and openly expressed continued anger and frustration were the same fathers who talked about their needs not being met and their overwhelming loss caused by ASD. These findings support previous research findings and provide implications for nurses to help the fathers and their families adjust, adapt, and become resilient to the challenges of ASD.

Findings in the study support using The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1988, 1993) with families who have children with ASD. The framework was designed to assist health care providers to evaluate the families' needs and provide interventions to help families become resilient against the challenges of ASD (Brody & Simmons, 2007; McCubbin & McCubbin, 1988, 1993). Health care providers can use the model to identify weaknesses in the family members including lack of knowledge about ASD, various treatments and therapies, and special education then provide the information to assist the families. Health care providers can identify sources of social and economic support to benefit those families who need additional support. They can also provide counseling or information about counseling for those families who need assistance with their coping skills and problem solving skills. Addressing the needs and weaknesses of the family members of children with ASD can help them adjust, adapt, and become resilient to the challenges of ASD.

Implications for Nursing

Nurses are in a unique position to listen to the fathers of children with ASD, address their needs, provide beneficial interventions, advocate for the fathers and their children, and include fathers in future ASD research. Nurses have opportunities in the

clinical and research settings to help fathers and families of children with ASD adjust, adapt, and become resilient to the challenges of ASD.

Nurses in Clinical Settings

Nurses often have more contact with families than other health care providers as the parents seek answers to their questions and concerns about their children's development. Nurses in the clinical setting typically spend more time with the children and their families and become the eyes and ears for the other members of the health care team. This places nurses in the unique position to provide accurate and detailed information to the health care team and address the parents' concerns. Nurses can advocate for parents when there is a delay in the diagnosis, treatment, and other needs of children with ASD. Nurses can provide options to insure fathers are included in the discussion about their children's developmental concerns, ASD, and diagnostic and treatment options. Nurses can work with families to schedule appointments when the fathers are available to attend the appointment. If that is not an option, nurses can contact the fathers by phone or other methods to answer their questions and address their needs.

Parents rely on the nursing staff to be a source of information about available ASD resources. Nurses in the clinical setting can maintain information about ASD, diagnostic options, therapies, treatment centers, education requirements, respite care, ASD funding sources, resources to find additional information, and support groups for parents and siblings in their region. Providing this information to parents gives them a place to start looking for help for their children rather than sending the parents off to find the information on their own and from questionable sources. Information was one of the needs stated by a majority of fathers in the study. Nurses in the clinical setting who take

the time to compile this type of information and make it available for the parents can help the parents overcome some of the challenges of ASD.

Nurses in Research Settings

Nurse researchers can use qualitative, quantitative, and mixed methods to determine the needs of families facing ASD and evaluate interventions implemented during their adjustment and/or adaptation phases to determine their effectiveness. Future qualitative studies using ethnography can describe the experience of fathers of children with ASD of various races or cultures. Race and culture may change the experience of fathers of children with ASD. Ethnography can describe the experience using cultural perception, values, and beliefs of the experience of fathers of children with ASD (Grove et al., 2013). Phenomenological studies could explore the experience of fathers of children with ASD in a variety of father roles. Examples of fathers' roles for future studies include fathers of younger children with ASD, stepfathers living in a home with children with ASD, birth fathers sharing custody of children with ASD, birth fathers with limited or no visitation with their children with ASD, and adoptive fathers living with children with ASD. Grounded theory studies could examine the experience of fathers of children with ASD and the processes fathers use to manage the challenges. The grounded theory method can provide a better understanding of the experience, guiding nursing interventions and developing a new theory for the experience of fathers of children with ASD (Grove et al., 2013).

Including fathers with a wider demographic base may provide deeper insight into the fathers' experience with ASD. Comparing the experience of fathers of sons versus daughters with ASD may help provide a focus for specific interventions for fathers of daughters and those of sons. A larger sample size may increase the knowledge about the experience of fathers of children with ASD.

Future studies using a correlational design could examine the relationship between different variables to describe, predict relationships between variables, or test the relationships using a theoretical model (Grove et al, 2013). Descriptive correlational studies could examine the relationships of variables such as depression, resiliency, and anxiety, with the socioeconomic status of fathers of children with ASD, educational levels of fathers of children with ASD, and rural versus urban settings of fathers of children with ASD. Correlational studies can describe and/or predict the relationship between the variables to help researchers design interventions for the fathers of children with ASD.

Intervention studies can be used to determine the effectiveness of nursing interventions for fathers of children with ASD (Grove et al., 2013). Current findings identified fathers' needs including money, information, and teamwork. Nursing interventions addressing the needs of the fathers of children with ASD could be assessed using experimental, quasi-experimental, or comparative experimental designs (Grove et al., 2013). Addressing the fathers' needs and determining the effectiveness of the interventions can improve the resiliency and long-term outcomes for the fathers, children with ASD, and their families.

Study Limitations

The study has several limitations including the small sample size. Limiting the sample size to ten fathers and using convenience and snowball sampling may not have captured the rich, in-depth detail of the experiences of fathers of children with ASD that may be possible with a larger sample size or different sampling method. The small sample size was consistent with the maximum number recommended for case study design (Stake, 2006; Yin 2003b).

The children of the fathers in the study were all attending school and several were receiving additional music therapy. Fathers of children not attending school and

receiving therapies may have a different experience with ASD than the current study population.

Other limitations for the study include limiting the population to White fathers and fathers of children living in the home with the children with ASD. Fathers of different races may have a different experience than White fathers of children with ASD. The experience may be different for stepfathers living in a home with children with ASD, birth fathers sharing custody of children with ASD, birth fathers with limited or no visitation with their children with ASD, and adoptive fathers living with children with ASD. Including children with ASD and mental health comorbidities may also change the experience for the fathers of children with ASD. All of the variants in the social and living arrangements, and comorbidities for the children with ASD may alter the experience of fathers of children with ASD.

Conclusions

The phenomenological case study method was an appropriate research design for the study because little information exists about the experience of fathers of children with ASD. All of the participants stated that this was the first time they talked about their experience with ASD and how it affected their lives. Using their words to describe their experience provided insight and a better understanding of their experience as fathers of children with ASD.

The ten fathers in the study all described their family life and making adjustments caused by ASD, their needs to meet the challenges of ASD, and their feelings of grief and loss as they adjusted and adapted to ASD. Learning about their experience can assist health care providers to address their needs and help them move through the stages of grief and loss to the acceptance stage where they can become resilient against the challenges they face related to ASD.

This chapter presented a comparison of this data to previous studies, and the ways in which the findings support the theory framework. Study limitations, implications for nursing practice, and recommendations for future nursing research were also provided.

Appendix A

Letter of Introduction for Primary Investigator and Research Study

Dear Sir,

My name is Linda Frye and I am a nurse. I am in a doctoral program (PhD) in the College of Nursing at the University of Texas at Arlington. I am conducting a study about the experience of fathers of children with autism spectrum disorder. I am curious about the challenges and rewards of caring for your child and the support you receive or need, but do not receive from others. The information from this study may help nurses better support families who have a child with ASD.

Participation in the study will include a one-time face-to-face interview that should last approximately one hour. Interviews will be conducted at a time and place that is convenient for you. If you would be interested in participating in the study, please contact me so I can answer any questions you may have and schedule a time to meet. Please email me at linda.frye@mavs.uta.edu.

Thank You,

Linda Frye RN, MSN, CPNP Candidate for PhD Degree
College of Nursing at the University of Texas at Arlington

Appendix B
Coding Saturation Grid

	1	2	3	4	5	6
1						
2						
3						
4						
5						
6						
7						

..

Appendix C
Demographic Questionnaire

1. How old are you?

2. Paternal Education
 - A. Some high school
 - B. Finished high school
 - C. Some college
 - D. Completed college
 - D. Advanced degree

3. Employment status
 - A. Unemployed
 - C. Employed part time
 - B. Employed full time
 - D. Works more than one job

4. Does your child have any other diagnosis in addition to autism spectrum disorder?
 - A. Yes
 - B. NoIf yes, what is/are they? _____

5. How many children do you have? _____

6. How many have autism spectrum disorder? _____

7. Gender of child(ren) diagnosed with autism spectrum disorder
 - A. Male
 - B. Female

8. How old was your child when diagnosed with autism spectrum disorder? ____

9. How old was your child when you first became concerned about his/her development? _

10. Who is the primary caregiver for the child? _____

Appendix D
Interview Questionnaire

1. Tell me about your child(ren) with autism spectrum disorder?
2. How has your child(ren)'s autism spectrum disorder affected your life and the life of your family?
3. Has anything in your life changed since your child(ren) received the diagnosis?
4. What are the challenges you face as the father of a child with ASD?
5. What are your strengths as a person?
6. What are the challenges your family face with a child with ASD?
7. What are your strengths as a family?
8. What do you need as a father and/or family to assist you with your child with ASD?
9. What activities do you do for fun or relaxation?
10. What activities does your family do for fun or relaxation?
11. How much time do you spend with your child on a daily basis?
12. What activities do you do with your child?
13. How do people react or respond to your child with ASD?
14. How do you respond to their reaction and how does it make you feel?
15. How do you cope with the challenges of ASD / are there any specific coping mechanisms you use?
16. What advice do you have for other fathers of children with autism spectrum disorder?
17. Where do you receive the information you have or learned about ASD?
18. Do you have any social support, such as a support group or any other source of support?

Appendix E
Informed Consent

Informed Consent

PRINCIPAL INVESTIGATOR

Linda Frye RN, MSN, CPNP Candidate for PhD Degree

College of Nursing at the University of Texas at Arlington

Contact information:

Cell Phone: 678-488-9615

Email address: linda.frye@mavs.uta.edu

FACULTY ADVISOR

Donelle Barnes PhD, RN, CNE Dissertation Committee Chair

College of Nursing at the University of Texas at Arlington

Contact information:

411 S. Nedderman Drive, Box 19407, Arlington, Texas 76019-0407

Phone: 817-272-0108

Email: donelle@uta.edu

TITLE OF PROJECT

Experience of Fathers of Children with Autism Spectrum Disorder (ASD)

INTRODUCTION

You are being asked to participate in a research study about your experience as the father of a child with autism spectrum disorder (autism or ASD). Your participation is voluntary. You may refuse to participate or stop participating at any time during the research study. Please ask questions at any time if there is anything you do not understand about the consent, research study, or other questions related to the research study.

PURPOSE

The purpose of this research study is to describe the experience of fathers of children with ASD, the depression or anxiety they may experience, and any resources needed to help them actively engage in their role as a father of a child with ASD.

DURATION

Participation in this study will last up to 60 minutes.

NUMBER OF PARTICIPANTS

The number of anticipated participants in this research study is 15.

PROCEDURES

The procedures which will involve you as a research participant include:

1. An interview with the primary investigator (P.I.), Linda Frye
2. The interview will be audio recorded. After the interview, the tape will be transcribed, which means it will be typed exactly as it was recorded, word-for-word, by the researcher. The audio recording and transcription will not be used for any future

research purposes not described here. The audio recording and transcription will be stored in a locked and secured location for five years and then the recording and transcription will be destroyed.

3. During the interview, the P.I. will also take hand written notes about the interview setting or any other non-verbal information. The hand written notes will be stored in a locked and secured location with the audio recording and transcript and destroyed in five years.

POSSIBLE BENEFITS

The benefits of the study include the opportunity for the fathers to talk openly about their experience with their child with ASD, identify their strength, and identify any resources required to help them in their role as the father of a child with ASD.

POSSIBLE RISKS/DISCOMFORTS

No physical harm or risk for harm is anticipated. Should you experience any emotional discomfort, please inform the researcher immediately. You have the right to stop participating in the study at any time without consequence.

COMPENSATION

No compensation will be given for participating in this research study.

ALTERNATIVE PROCEDURES

There are no alternative procedures offered for this study. However, you can elect not to participate in the study or quit at any time at no consequence.

VOLUNTARY PARTICIPATION

Participation in this research study is voluntary. You have the right to refuse to participate in any or all study procedures or quit at any time without consequence.

CONFIDENTIALITY

Every attempt will be made to see that your study results are kept confidential. A copy of this consent form and all data collected including the audio tapes, transcripts, and notes from this study will be stored in the Center for Nursing Research at the University of Texas at Arlington college of Nursing for at least three (3) years after the end of the study.

The results of the study may be published and/or presented at meetings. You will not be named as a research participant. Additional research studies could develop from the information you have provided, but your information will not be linked to you in anyway; it will remain anonymous.

Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA Institutional Review Board (IRB), and personnel particular to this

research have access to the study records. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above. The IRB at UTA has reviewed and approved this study and the information within this consent form. If in the unlikely event it becomes necessary for the Institutional Review Board to review your research records, the University of Texas at Arlington will protect the confidentiality of those records to the extent permitted by law.

CONTACT FOR QUESTIONS

Questions about this research study may be directed to

Donelle Barnes PhD, RN, CNE Committee Chair

College of Nursing at the University of Texas at Arlington

Contact information:

411 S. Nedderman Drive, Box 19407, Arlington, Texas 76019-0407

Phone: 817-272-0108

Email: donelle@uta.edu

Any questions you may have about your rights as a research participant or a research-related injury may be directed to the Office of Research Administration; Regulatory Services at 817-272-2105 or regulatoryservices@uta.edu.

As a representative of this study, I have explained the purpose, the procedures, the benefits, and the risks that are involved in this research study:

Signature and printed name of principal investigator or person obtaining consent

Date

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Biographical Information

Linda Frye received her diploma in nursing from Conemaugh Valley Memorial Hospital School of Nursing. She earned her Bachelor of Science in Nursing from Marymount College of Kansas and her Master of Science in Nursing with a Concentration in Child Health/Practitioner at Georgia State University. Linda is an active member of the National Association of Pediatric Nurse Practitioners (NAPNAP) and the Special Interest Group in Developmental, Behavioral, and Mental Health. She is also a member of the Society for Developmental and Behavioral Pediatrics.

Linda's career path has varied from pediatric to adult patients in clinic and hospital settings. Her focus on children with developmental delays and autism spectrum disorder (ASD) began after meeting with autism specialists in Atlanta and touring their facility. Linda became a member of the developmental diagnostic team working to diagnose and determine treatment plans for children with developmental delays and ASD. ASD is becoming increasingly prevalent resulting in economic and emotional burdens for society and the families. Families of children with ASD need an advocate to identify their needs, provide interventions to help overcome the challenges related to ASD, and investigate the effectiveness of the interventions.

Linda plans to expand her program of research as a full-time faculty member, encouraging the students to listen to the needs of the patients, become their advocates, and include all of the family members in the discussion. Health care providers at every level need to understand the importance of listening, including, and advocating for the patients in their care. Children with ASD and their families will continue to be the focus of Linda's program of research including interventions to help this vulnerable population and their families as they adjust, adapt, and become resilient to the challenges associated with ASD.