

Effects on the Enduring Marriage of Parenting a Young Adult with Autism Spectrum Disorder

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Department of Community Care and Counseling, Liberty University

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Education

School of Behavioral Sciences

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Abstract

The purpose of this transcendental phenomenological study is to understand the challenges facing couples who have been married for more than 18 years, and whose autistic child is now a young adult. It seeks to describe how the couples have overcome their trials. In addition, this study will investigate the dimensions along which the couple and the family are affected by the autistic family member. Parents raising a child with autism spectrum disorder (ASD) have a higher propensity than parents of neurotypical children to report worry, anxiety, stress, and depression, burdened as they are with the behavioral and social challenges of the child. These negative emotions can cause a disruption to the family system and the marital relationship. The theory guiding this study is Olson's circumplex model of marital and family systems, as it incorporates the family's unity, the family's flexibility in times of change, and the functionality of the communication of the marital and family systems. The shared experience of raising a child with ASD takes a different toll on each partner but can lead to the same physical and mental health problems for the mother and father. The impact of managing a child with autism propagates into anxiety and stress, which leads to depression when parents are depleted of coping skills and sources of support. The never-ending adjustments that need to be made as the child becomes a young adult increase the tension experienced by the parents, which continues to jeopardize the marriage. Faith-based coping skills can positively affect the parenting and marital experience.

Keywords: autism spectrum disorder (ASD), faith, enduring marriage, parenting, social support, stress

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Dedication

Above all, I dedicate this work to my Heavenly Father, who equipped me with knowledge, strength, and fortitude on this academic pursuit. My mere words could never express my gratitude for His guidance and faithfulness to me, not only on this journey, but on my life's journey as well.

To my dear daughter, Hunter, who taught me how life is meant to be lived with regard and respect for everyone. She has the purest soul of anyone I have ever met, and my daily goal is to emulate her heart. My cherished husband, Henry, thank you for encouraging me throughout this doctoral program and instilling patience and perseverance when I struggled under what felt like insurmountable challenges. Thank you, also, for being my partner in our enduring marriage, for going through all the moments of hope and despair, and for growing with me each step of the way. We are truly blessed and richer for the experiences. To Barb, my dear friend and confidant. I am a better person because of our friendship, and I needed your stability and belief in me throughout this dissertation process. Your encouragement bolstered me continuously.

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I gratefully acknowledge the eight couples who participated in this study and were willing to share their experiences as husband and wife in long-term marriages as they journey along parenting a young adult with autism. Their willingness to expose tender and difficult moments allowed me to present the results of this study, which will be instrumental to mental health professionals and others who seek to understand the onward challenges and rewards known to couples in enduring marriages who continue to parent their autistic young adults. To Dr. K. Don Small and Dr. Joseph Torres, I am grateful for your tutelage. Lastly, I thank Penny Evans, who came alongside me in God's perfect timing and offered the necessary support I needed when I felt like I was simply limping along an arduous path. I am grateful to have been your colleague over these last months. Blessings!

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List of Abbreviations

Activities of Daily Living (ADL)

Autism Spectrum Conditions (ASC)

Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder and Typical Cognitive Ability (ASD-CA)

Autism Spectrum Disorder and Intellectual Disability (ASD-ID)

Autism Transition Research Project (ATRP)

Centers for Disease Control and Prevention (CDC)

Computer Assisted Qualitative Data Analysis (CAQDAS)

Daily Living Skills (DLS)

Developmental Disability (DD)

Differentiation of Self (DoS)

Emotion Focused Therapy (EFT)

Executive Functioning (EF)

Intellectual Disability (ID)

Mental Health Conditions (MHC)

Quality of Life (QoL)

Stress, Aging and Emotions Study (SAGE)

CHAPTER ONE: INTRODUCTION

Overview

The purpose of this transcendental phenomenological study is to understand the impact on long-term marriages for a couple who are parenting a young adult with autism spectrum disorder (ASD), given the cumulative effect of the lack of internal and external resources and the ongoing adjustments that need to be made for the young adult who remains in their care post-high school and beyond. ASD is a developmental disability that results in social inadequacies in communication and interactions and affects about 1.5 million children between the ages of 3–17 (Dietz et al., 2020). Previous research has been conducted regarding the challenges of raising a child with ASD, a lifelong developmental disability with varying levels of impact, and the significant issues for parents, including increased stress levels, mental and physical ailments, alienation from social supports, financial duress, and marital/family discontentment (Ghanouni & Hood, 2021; Hayes & Watson, 2012; He et al., 2022). While ASD is a lifelong disability for the child, parents experience the effects of raising a child with ASD for their lifetime as well (Cachia et al., 2015). Limited research exists about the ongoing stress that occurs after the child turns 18 years of age and the unending challenges, conflicted marital relations, financial burdens, and limited sources of support that these parents will still have to endure. ASD may affect as many as one in 45 adults between the ages of 18 and 84, and some of these adults may require significant support throughout their lifetime (Dietz et al., 2020). Current literature was reviewed to gain an understanding of the trials that parents of children with ASD have experienced, as well as the role that religiosity or spirituality, and the sustainability of hope play in helping to bolster marriages that have withstood decades of stress, only to find that the stress will continue as their young adult may not be able to become fully independent.

This study was designed to understand the participants' lived experiences and the coping strategies they used to sustain their marriage. The study intended to provide insight into the challenges facing parents of young adult children with ASD and to share information on how these demands impact the marriage. The awareness gained from this study may enable parents to recognize these conflicts as growth opportunities. It might provide all stakeholders with the knowledge that will help to improve the well-being of the marriage and, subsequently, the families with an autistic family member. This chapter describes the background of the problem and the purpose of the study, outlines research questions, describes the theoretical framework for the study, and provides relevant definitions.

Background

A developmental disability that causes differences in the brain (Center for Disease Control and Prevention ([CDC] 2023), ASD can be considered an invisible disability given that the autistic person may not appear to be disabled (Corcoran et al., 2015). Ferenc et al. (2023) identified autism spectrum conditions (ASC) as complicated and incongruent conditions that span a broad range of outcomes, whether the developmental course of the autistic individual or their response to interventions. The CDC (2023) advised that people who are diagnosed with ASD have varying strengths and challenges, which lead to unique treatment plans. When transitioning from high school and becoming a young adult, services that might be available for the autistic person range from helping with health and activities of daily living while also facilitating social support for lower functioning individuals, or, for higher functioning individuals, assistance with continuing education, employment training, and finding housing (CDC, 2023). The complexities of an ASC diagnosis and the subsequent lack of clear direction for moving forward compound the challenges of an already frustrating situation for parents

(Ferenc et al., 2023).

Numerous studies have been conducted that have affirmed the stress, anxiety, worry, and depression that are experienced by parents who are raising a child with ASD (Cachia et al., 2015; Chan et al., 2018; Herrema et al., 2017b). These studies identify the difficulties faced by parents and family members as they navigate the challenges of having a child with ASD and that mothers, as the primary caregivers, are more likely to be depressed, which spills over negatively into the marriage (Di Renzo et al., 2021). The stress from raising a child with ASD affects the dynamics within the family, and the stress experienced individually and between the marital partners can lead to marital discord, dissatisfaction, dissolution, and divorce (Schiltz & Van Hecke, 2020).

While many marriages succumb to the pressure, some marriages can sustain themselves through the years of distress leading up to when the child becomes a young adult (Sim, Cordier et al., 2019). Research has shown that some couples remain together due to the shared understanding of the stressors associated with raising a child with ASD and the financial stability of the union (Freedman et al., 2011) as well as the lack of social support available to them outside of their marriage (Marsack & Perry, 2017). Other couples can rise above the challenges as they recognize the need to prioritize their marriage and seek to improve their communication with one another, improving the marital relationship (Sim, Cordier et al., 2019).

The long-term married couple who has survived the childhood of the autistic child may find that their stress is exacerbated as their child becomes a young adult, which brings with it a new host of stressors. While other children matriculate to college and leave the family home, the young adult with ASD may remain behind. This situation places the couple on another level of isolation as they watch other families celebrate the successes of their increasingly independent

adult children. The parents may have expected to be financially responsible for the young adult through the college years; however, the expenses continue, given the young adult's inability to become independent (Oti-Boadi et al., 2019). The fortunate couples who can support their young adult in a program outside of the home will still experience stress, anxiety, worry, and potentially depression as they remain concerned about their young adult and the financial obligations that alter their retirement plans. Couples who cannot give financial assistance for some level of independence for their young adult will find themselves with a third person in their marriage.

Stress is known to negatively affect marital satisfaction, and the stress of raising children with ASD can have consequential results as it spills over into a couple's marriage (Hartley et al., 2018). The strain on the marriage continues from adolescence into young adulthood, given the need to help the autistic child transition from secondary school to finding employment or seeking long-term solutions for care (Cheak-Zamora et al., 2015; Chen et al., 2018). Having weathered the storm of raising their child with ASD, the long-term married couple finds yet another storm in their path. A tsunami of young adults with ASD (Parsi & Elster, 2012) who are unable to become independent is threatening marriages, financially and emotionally. The risk of divorce remains high when children with autism reach adolescence and adulthood, given the ongoing stressors and new challenges of helping young adults with their post-secondary transition and ultimately recognizing that they may not be able to become empty nesters (Bluth et al., 2013; Hartley et al., 2018). Still, long-term marriages can survive and thrive while experiencing new and unexpected struggles. This study seeks to fill the gap in the literature and to determine how these couples can remain bonded in their marriages, whether simply a financial and practical decision or because of the sacred vow that they made to one another long ago, the meaning-making that they will expand upon as they enter a new phase of raising a young adult with ASD,

and their faith in the glory of God, as expressed in Jeremiah 29:11, “‘For I know the plans I have for you,’ declares the Lord, ‘plans to prosper you and not to harm you, plans to give you hope and a future’” (*Holy Bible, New International Version*, 2015).

Situation to Self

Phenomenological research requires that the researcher abandon their understanding of the experience and resultant preconceived notions to avoid permitting biases that would taint the research. This study was conceptualized from my own experience of parenting a daughter on the autism spectrum and the challenges it presented in my marriage. My husband and I were blessed with one child. Upon her diagnosis at 6 years of age, my immediate and sustained goal was to provide her with every opportunity and to leave no stone unturned so that she would have the tools necessary to graduate high school and matriculate to college. We imagined that she would become an adult and have her own family. Our marriage became a roller coaster, cresting the peak when our efforts seemed to be paying off, only to find ourselves speeding downhill when she could not achieve or master the necessary skills. We would feel derailed as we witnessed her peers becoming more and more successful through their elementary, middle, and high school years. Additionally, our hearts would break as she was overlooked and excluded by her classmates, which led us to become isolated as we became her social circle. This isolation became unhealthy for our marriage and the parenting of our daughter.

Overprotective parenting occurs when parents, who may have the best intentions fueled by wanting to keep their child safe and healthy, interfere with their child’s growth by stepping into problem-solving when they were not asked to do so (Van Petegem et al., 2021). Further, Van Petegem et al. noted that overprotective parenting is a behavioral representation of triangulation wherein the child aligns with one parent against the other. Camisasca et al. (2019)

explained that previous studies have noted the negative effect of triangulation on the relationship between the parents and the child (Camisasca et al., 2019). I understood that this phenomenon was occurring in our home and referred to our family as an “isosceles triangle,” as the two long sides of the triangle represented the two who were “against” the smaller side of the triangle. The people on the different sides of the triangle switched constantly as my husband and I drew our daughter into the conflict that was occurring in our marriage due to the stress of raising a child with ASD.

The family dynamics in our household, coupled with the grief that I was experiencing for my daughter and the damage to my marriage, led my husband and me through some dark and turbulent days. My husband began traveling for work, leaving me with even more obligations to tend to our daughter’s needs and my growing isolation. I began to wonder why God would allow moments where there were glimmers of hope for an independent future for our daughter, only to find myself in the depths of discouragement as I recognized that she was not achieving the milestones that were necessary for independence. Van Petegem et al. (2021) noted that overprotective parenting can result in disordered eating, which proved to be true in our family as our teenage daughter was diagnosed with binge eating disorder (BED). Our family was privately spiraling out of control, and my husband and I had the dreaded conversation about whether we would want to remain married. We have worked diligently on our marriage and our family, and with the help and strength of our God, whom we trust, we have overcome the large hurdles even as the small irritants continue.

While much research has been conducted on the challenges of raising a child with autism spectrum disorder, scarce has been written about the next phase of life when the child becomes a young adult. I pondered to what extent other families experienced the same marital challenges

my husband and I faced as our daughter grew from adolescence to young adulthood. The adhesive that held our marriage together was the three-cord strand (*Holy Bible, New International Version*, 2015, Ephesians 4:12) created when we took our vows in the presence of God. I contemplated whether other couples had the experience of surviving the peaks and valleys of their child's youth only to discover that the challenges continued as the child became a young adult and what impact these struggles had on their marriage. This study will be achieved without bias and will seek to gain insight into the lived experiences of the participants as they transitioned from raising a child to parenting a young adult with ASD.

Problem Statement

In 2000, one in 150 children who were 8 years of age were diagnosed with autism, and by 2018, the number of 8-year-old children diagnosed with autism rose to one in 44 (Maenner et al., 2023). Maenner et al. (2023) found that the upward trend continued and that in 2020, one in 36 children aged 8 years were diagnosed with ASD. Those children from two decades ago have become young adults, and a very large population of soon-to-be young adults with autism is following closely in their footsteps. The spectrum of the autism condition causes individuals to vary greatly in the level of clinical support that they need and in their functional presentation, creating significant differences in the cost of their care and treatment (Buescher et al., 2014). The societal economic burden of ASD is approximately \$268 billion annually, which substantially surpasses the economic burden of stroke and hypertension. If the growth trajectory of ASD continues, it will exceed the costs associated with diabetes or ADHD (Leigh & Du, 2015). Indirect costs to families with an ASD member include family members' loss of productivity given lower hours of employment, decreased income, and altered household obligations; direct costs—aside from medical costs—include home health care and accommodations for the autistic

family member (Cakir et al., 2020). Caregivers of children with ASD have indicated issues with access to care and the quality of the care as compared to children with developmental disabilities (DD) or other mental health conditions (MHC) (Vohra et al., 2013). Additionally, as compared to other special needs groups, caregivers of children with ASD are more likely to state that they have inadequate insurance coverage, economic burden, employment issues, and that they experience time-related pressure (Vohra et al., 2013).

Parents of autistic young adults struggle financially, as organized programs can be prohibitively expensive, and while more options are becoming available, they are often few and far between. The cost to the couple's relationship could be even more significant, given their marriage's newfound strains and relentless tension. Couples who expected that their young adult would be able to either attend college or enter the workforce are dismayed that their young adult struggles to accomplish either. Regardless of the level of severity on the autism spectrum, parents hope for their young adult to be gainfully employed, whether the young adult would achieve financial independence or, for lower functioning ASD young adults, would enjoy a meaningful daily work experience (Anderson et al., 2020). Young adults with autism spectrum disorder with typical cognitive ability (ASD-CA) may not be eligible for assistance or may be past the limit of the age of transition for services (Anderson et al., 2020). Given the lack of mitigation of the obstacles that a young adult with ASD might face in the workplace, parents might be dismayed as their young adult continues to experience the challenges associated with ASD (Anderson et al., 2020).

Few studies address the continued frustration, fatigue, anxiety, stress, depression, and marital discord that accompany this time of life when parents who had planned for their retirement suddenly find their futures to be far different than what they expected. The lack of

resources for this population of young adults creates unbounded distress for the long-term married couple who are seemingly faced with providing levels of support for their autistic young adult for which they had not planned. To guide stakeholders (i.e., mental health care providers) and long-term married couples parenting a young adult with autism, I conducted my research to gain an understanding of the challenges that these couples endured as they recognized that their young adult would continue to need their support and sought to understand the coping strategies that have contributed to the success of their marriage.

Purpose Statement

The purpose of this transcendental phenomenological study was to understand the lived experiences of the long-term married couple parenting a young adult with mild to moderate ASD, the ramifications on their marriage, and the factors that contributed to sustaining their marital union. The DSM-V-TR identifies three levels of severity of ASD, with level one indicating that the ASD individual would benefit from support to aid in their obvious impairments in social communication, and level three, at the other end of the spectrum, requiring substantial support given severe impairments (APA, 2022). Long-term married couples parenting a young adult with ASD who would benefit from support but whose symptoms are not severe enough to require level three support were chosen to participate in this study. A lack of available research that addresses this population prompted this study, especially as more and more couples are on the horizon that will reach this milestone with their autistic young adult. The theory guiding this study is Olson's circumplex model of marital and family systems (Olson, 2000). This study explores the family system and the interactions that take place between the marital couple and their young adult with ASD. Olson's circumplex model of marital and family systems supported the understanding of the changes and dynamics of the family and the couple that take

place over time (Olson et al., 2019) as they transition from raising a child with autism and who are now parenting a young adult with autism even as the couple had expectations of moving on to their next phase of life.

Significance of the Study

This study is significant in that it fills the gap in the literature about the ongoing challenges faced by long-term married couples as their autistic child becomes a young adult, which introduces a host of new and unforeseen challenges in their child's life as well as continued strain on their marriage. The transition for young adults with autism is a challenging time for parents and their young adults as access to support programs is not readily available, which contributes to stress and anxiety in this next phase of life (Cheak-Zamora et al., 2019). The parents express a desire for a break in caregiving for their youth, given the overwhelm of continued responsibility, while the autistic young adult is also feeling overwhelmed as they are experiencing new challenges that accompany the responsibilities of young adulthood (Cheak-Zamora et al., 2019). Communication in the family can suffer as the young adult shuts down to avoid conversation about their fears, and parents also avoid communication with their young adult who is attempting to express their struggles with becoming an adult (Cheak-Zamora et al., 2019). A study by Griffith et al. (2012), which was specific to Asperger's syndrome (higher functioning individuals with ASD), found that these parents of young adults with autism were concerned about their young adults' future care as they anticipate remaining a primary source of support, which led to tremendous strain on the parents. Parents worry about their autistic young adults and are caught between feelings of hope and fear as they accept the uncertainty of the future (Chen et al., 2018).

Long-term marriages are vulnerable to the ongoing challenges that are experienced when

parenting an autistic young adult. This study is focused specifically on marriages that have remained intact throughout the life of their young adult with autism. The study seeks to extend the current literature as it pertains to stress, anxiety, worry, depression, and marital strife for this population of married persons, as well as to provide clarity as to how these couples were able to overcome the adversity in their marriages and remain together.

Empirically

Conducting a study of the lived experiences of long-term married couples with young adult children with autism is significant given the levels of stress, worry, mental health issues, and marital discord experienced by these couples (Bonis, 2016). Additionally, the population of young adults with autism spectrum disorders is on the rise (Maenner et al., 2023). Therefore, many more marriages will be affected as they face the decision of how to incorporate a third person into their retirement years and the potential need to adjust their financial future as they contemplate available resources for caring for their young adult with ASD (Romney et al., 2020). In addition to coming to terms with their own aging, parents who expect to become empty nesters are fearful and are tasked with searching for available support programs, future living options, and caregiving for their child (Marsack-Topolewski & Graves, 2019).

This study builds on previous research relating to the stress and challenges experienced by parents of children with autism spectrum disorder (González-Herrera et al., 2021; Kütük et al., 2021; McStay et al., 2014b) and focuses on the next stage in their child's lifespan. Some married parents of children with ASD are at risk of not maintaining their marital union due to exhausted emotional resources and the resultant inability to resolve conflict effectively. In contrast, others can survive and thrive as they exhibit heightened sensitivity to one another in their couple interactions (Hartley et al., 2017). This study will add to the literature as it explores

how long-term married couples can supersede the stressors that they have dealt with for decades and discover how their marriages can grow amid the chaos and reimagined futures. This new area of study builds on the body of knowledge that currently exists and will inform stakeholders, including mental health care providers, parents, and family members of young adults with autism, of the personal accounts of the effect that a young adult with autism has on long-term marriages.

Theoretically

General systems theory is a unique worldview, or *Weltanschauung*, of individuals as they relate to and understand others (Von Bertalanffy, 1950, as cited in Cridland et al., 2013). A family is a compilation of several subsystems that influence the entire system (Persram et al., 2019). These subsystems might involve the relationships between parent-child, siblings, marital partners, and parent-parent (Persram et al., 2019). Research has been conducted that examines the effect of an autistic child's behaviors on the parents' mental health due to concerns about the future of the child, economic challenges, and marital distress (Chan et al., 2018). The circumplex model of marital and family systems is systems-focused and identifies three dimensions that help to recognize balanced and unbalanced systems: cohesion and flexibility, which are curvilinear dimensions, and the linear dimension of communication, which helps families and couples facilitate movement along the other two dimensions (Olson, 2000; Olson et al., 2019). The model recognizes that families are dynamic and will move in different directions amidst varying family life cycle stages (Olson, 2000). This study will seek to expose the family system functioning and the changes that occur throughout the marriage as the couple moves from raising a child with autism to parenting a young adult with ASD.

Practically

This study provided the opportunity for long-term married couples to discuss the obstacles that impede the years after their autistic child becomes a young adult. The information gathered may be typical of couples who have endured the initial challenges when raising a child with ASD and have discovered that they must continue to use coping skills to protect their long-term marriage and potentially create new coping skills as they enter territory yet to be explored as their young adult with ASD remains under their care. This study will provide parents of young adults with ASD, their families, friends, and other stakeholders (such as mental health providers) an opportunity to understand the lived experiences of hope and despair for long-term married couples with a young adult with mild to moderate ASD. The results of this study will provide insight into the coping mechanisms of the long-term married couple as they endure ongoing anxiety and stress, the effect that a young adult with ASD has on the family system, and the potential for strengthening the marriage as the couple uses faith and meaning-making given that their future unexpectedly involves a third person in their union. This information will permit a glimpse into the ongoing social isolation, fatigue, and burnout while also allowing an understanding of the role of commitment to the marital vow that long-term married couples have chosen to honor.

Research Questions

According to Goldschmidt and Matthews (2022), research questions are the essential and initial starting point of a successful research project. Articulation in developing the research questions is necessary not only to acquire unambiguous answers but also to identify other aspects of research by gaining the perspective of the phenomenon (Goldschmidt & Matthews, 2022).

This transcendental phenomenological study will explore the lived experiences of parents who have been married for more than 18 years and who are parenting a young adult with mild to

moderate autism. The research questions were conceptualized to identify the lived experiences of a long-term married couple with an autistic young adult and the impact this has had on their marriage, their relationship with their young adult, and each of the partners as individuals. Insight was also sought to identify coping skills and areas that led to their enduring commitment to the marriage. Thoughtful attention was paid to choosing participants for this research study who would be relevant representatives of the identified audience (Goldschmidt & Matthews, 2022).

Central Research Question

I wanted to capture the lived experiences of couples in an enduring marriage who were in the phase of life of parenting a young adult with ASD by utilizing this central research question: How do long-term married couples describe their experiences of moving past the challenges of raising a child with ASD only to enter the new realm of challenges of parenting a young adult with ASD with mild to moderate symptoms that require some support? Research indicates that raising a child with autism is incredibly challenging and that the spillover of the stress associated with raising a child with ASD affects the parents and the marital union (Hartley et al., 2018). Parents of young adults with autism continue to be involved in their child's life (Benson, 2019), and this active participation does not permit increased intentionality in bringing the marriage to the forefront (Hartley et al., 2018).

Research Sub-Questions

The following additional research questions were formulated to understand the toll on the long-term marriage of parenting a young adult with ASD while also gleaning how spirituality, hope, and ongoing discouragement affect the marital union.

SQ1: How do long-term married couples describe areas of their marriage that are stressed when parenting a young adult with autism?

SQ2: How do long-term married couples describe the role of religiosity in sustaining their marriage through the difficulties of parenting a young adult with autism?

SQ3: How do long-term married couples describe the effects of hope and discouragement in marital discord or marital satisfaction, especially as they relate to concerns about the future of your young adult with autism?

Definitions

The following terms were used in this study:

1. *Activities of Daily Living (ADL)* – basic needs that include feeding, hygiene, work, and household management (Marsack-Topolewski, 2022).
2. *Adaptive Behavior/Adaptive Function* –the skills necessary to function and live independently in the world (McQuaid et al., 2021; Paul et al., 2004).
3. *Autism Spectrum Disorder (ASD)* – a neurodevelopmental disability that affects verbal and non-verbal communication, behavior, social interaction, and educational abilities that require a range of support depending on severity and may or may not be accompanied by an intellectual disability (APA, 2022).
4. *circumplex model of Marital and Family Systems* – a system-focused model that observes three family and marital systems dimensions including cohesion, flexibility, and communication (Olson, 2000).
5. *Daily Living Skills (DLS)* – daily skills related to hygiene, home maintenance, cooking, and managing finances (Duncan & Bishop, 2013).

6. *Developmental Disability (DD)* – a group of conditions typically seen across the lifespan and include physical, learning, or behavioral impairments that impact activities of daily living (Centers for Disease Control and Prevention, 2022).
7. *Enduring marriage* – a long-term marriage of at least 20 years (Masumoto et al., 2021) to more than 40 years (Mullins, 2016; Rosowsky et al., 2012).
8. *Executive Function (EF)* – the ability to organize thoughts, establish and execute a plan, and follow the plan through to completion (Jurado & Rosselli, 2007; Wisner-Carlson et al., 2020).
9. *General Systems Theory* – viewing systems in their entirety and the relations between the systems (Bertalanffy, 1969; Tadros, 2019;).
10. *Intellectual Disability (ID)* – a heterogenous developmental disorder that includes intellectual and adaptive functioning deficits and ranges from mild to profound (APA, 2022).
11. *Meaning Making* – a core of human existence is seeking meaning through meeting existential needs, including values and purpose (Sørensen et al., 2015).
12. *Mild intellectual disability* – in adults, difficulties with abstract thinking, executive functioning, and impairment of functional use of academic skills and require some support with activities of daily living (APA, 2022).
13. *Religiosity* – participation in church functions such as attending services, prayer, and Bible study, which offer comfort in times of distress (Parker et al., 2011)
14. *Spillover* – the negative impact that one family subsystem brings to another family subsystem, given tension and adversity (Hickey, Nix & Hartley, 2019).

15. *Spirituality* – faith that provides patience, strength, and a belief that God is intimately involved in one’s daily life (Parker et al., 2011).
16. *Triangulation* – using a third party to ease the tension in a relationship (Bowen, 1976, as cited in Willis et al., 2020).
17. *Young Adult* – early adulthood, which spans from 18 to 40 years of age (Berk, 2010).

Chapter One Summary

The astronomical demands on a couple with an autistic child require them to adjust their personal lives, the function of the family, and their devotion to the marital relationship. The initial trauma of learning of the diagnosis leads to crises along the development of the lifespan of the child as the parents seek to provide support for their child through interventions and acceptance of a life that will be demanding and complicated. The lack of time, energy, and resources, challenging behaviors by the child, and the potential for siblings of the autistic child to act out compound the stress that parents experience. Mothers, as the typical primary caregiver, are particularly vulnerable to the stress of raising the child and are susceptible to anxiety, stress, and depression. Fathers are affected by the level of impact that ASD has on their children, their increased financial burdens, and the depression of their wives. The marriage can be a victim of parental stress as both partners are depleted and suffering psychological distress and emotional pain.

The challenges of raising a child with autism continue through the years into young adulthood. The partners in a long-term marriage must remain committed to one another and express respect for each other even amid relinquishing dreams for the futures of themselves and their young adult. Autism affects all races and socioeconomic groups, and consideration should

be given so that all populations receive the support that they need. A spiritual foundation based on faith in God can contribute to hope for a meaningful future.

CHAPTER TWO: LITERATURE REVIEW

Overview

This literature review explores the current literature as it relates to the challenges of raising a child with ASD. The review begins with the theoretical framework for the study and continues with a general description of ASD and the transition to emerging adulthood for autistic youth. The focus of the literature review continues by exploring the effects that the autistic family member has on the parents and the family, including stress and other negative emotions that can either upset the balance of the marital and family systems or strengthen the union and the family by moving beyond growth edges and identifying areas of meaning-making. Previous studies that discuss parental stress for both mothers and fathers, as well as marital conflict and marital satisfaction, were explored. Finally, the review focuses on literature from the perspective of religiosity and spirituality, which contribute to the couple's ability to withstand volatility in their relationship given that their challenges of raising a child with ASD continue as they parent their young adult with autism.

This literature review is grounded on prior research that was conducted about raising a child with autism and exposed a gap in the literature on the experiences of couples in an enduring marriage who are parenting their young adult with ASD. This study identifies the need to investigate the ongoing issues presented to long-term married couples who have entered the next phase of their child with ASD becoming a young adult. Eight couples in an enduring marriage who have entered the phase of parenting a young adult with ASD are the participants in this study.

Theoretical Framework

Identifying the theoretical framework in the research study is critical as it serves as the

foundation and anchors the reason for the study, problem statement, purpose, significance, and research questions (Grant & Osanloo, 2014). Identifying a theory directs the study, and the theory serves as a research strategy (CohenMiller & Pate, 2019). The theory guiding this literature review is Olson's circumplex model of marital and family systems. Olson et al. (1988) explained that prior to 1985, many theorists had focused on general systems theory (GST) regarding family dynamics and that the circumplex model of marital and family systems incorporated family cohesion, adaptability, and communication as the dimensions on which to focus. This theory provides the structure for gaining an understanding of the perspectives and lived experiences of the long-term couple with a young adult with ASD.

Circumplex Model of Marital and Family Systems

The circumplex model of marital and family systems is a 5 x 5 model that differentiates balanced from unbalanced families along five levels of cohesion and flexibility (Olson et al., 2019). The circumplex model recognizes that balanced couples and families are happier, engage in more positive communication, and can change their levels of cohesion and flexibility when faced with stressful situations (Olson et al., 2019).

The circumplex model is founded on basic systems theory concepts and assists in understanding the couple and family systems (Olson et al., 2019). Cohesion is the emotional bonding between the couple and the family and helps identify the balance of separateness and togetherness, including variables such as boundaries, emotional bonding, and decision-making (Olson et al., 2019). Four levels of cohesion are identified: disengaged, separated, connected, and enmeshed, with disengaged being at one extreme (limited attachment) and enmeshed at the other extreme (not enough independence) (Olson et al., 1988). Flexibility refers to how well systems can balance stability with change and includes concepts such as discipline, role relationships, and

rules of the relationships (Olson et al., 2019). This dimension is described as having two extremes: chaotic (extremely high levels of flexibility) or rigid (extremely low levels of flexibility) (Olson et al., 2019). The dimensions of cohesion and flexibility help to determine the functioning of the family and identify families that are out of balance if they fall at the extremes of the dimensions (Carr & Kellas, 2017).

Communication is the third dimension in the circumplex model. It is considered to facilitate movement in the levels of cohesion and flexibility to aid in dealing with demands on the system (Olson et al., 2019). Communication includes listening (empathy and active listening) and speaking skills (speaking only for oneself and not for others), as well as self-disclosure and respect (Olson et al., 2019). Good communication skills afford the couple and the family to voice more explicitly the type of relationship that they would like to have along the cohesion and flexibility dimensions (Olson et al., 2000). When families can effectively communicate thoughts, feelings, and problem-solving ideas, the dimension of communication permits a means to cope with adversity (Carr & Kellas, 2017; Olson et al., 2000). A balanced family system is considered to have good communication; conversely, an unbalanced family system suffers from poor communication (Olson et al., 2000).

This theoretical framework was the basis for the design of this phenomenological study. It enabled an understanding of the lived experience of couples in long-term marriages who were parenting a young adult with autism. Additionally, the circumplex model guided the researcher in creating questions and conducting semi-structured interviews. Applying the circumplex model helped the researcher clearly comprehend factors that contribute to the functioning of a balanced and cohesive family.

Related Literature

The adverse effects on parents of raising a child with autism spectrum disorder have been well-researched, resulting in studies that explain the stress, anxiety, depression, marital conflict, and life dissatisfaction as the diagnosis usurps the family and upsets the balance. This was validated by an extensive meta-analysis of 132 articles by Bonis (2016). One study that Bonis reviewed was conducted by Ramisch et al. (2013), which acknowledged the difficulties in marital relationships for parents of children with ASD and suggested in-home emotionally focused therapy (EFT) for three couples over 10 weeks. This qualitative study sought to understand whether EFT would strengthen the participants' marriages, and the results indicate that EFT was a beneficial modality for the participants, especially since the intervention was done in their homes. The participants indicated that they would not have gone to a clinic for the therapy, citing busy schedules and social stigma (Ramisch et al., 2013). The authors acknowledged that they did not get through the 10 sessions as planned. However, they purported that EFT helped the couples identify negative patterns of interaction and state that much more research needs to be conducted on marital interventions for parents of children with ASD (Ramisch et al., 2013).

A limitation of the study was the small population of three couples. Falk et al. (2014) was another study in the Bonis meta-analysis that affirmed the considerable research that has been conducted on the stress, anxiety, and depression that are experienced by parents of children with autism. This quantitative study recruited mothers and fathers separately (not parenting dyads) and included 250 mothers and 229 fathers. One glaring shortcoming of this study was that the dynamic dependency of coupled mothers' and fathers' emotions, stressors, and responses was not evaluated. Given the publication date of the Bonis study, one of the criticisms of the meta-analysis is its relative overreliance on antiquated studies done before 2013.

Additionally, the meta-analysis reviewed studies that were conducted on parents of children with ASD and did not study marital couples who were parenting young adults with autism. Iadarola et al. (2017) queried the stress experienced by underrepresented parents of children with ASD, including those who self-identified as belonging to a racial or ethnic minority, received government assistance other than Medicaid, or lived in a rural area. This qualitative study was conducted to learn about the experiences of people not typically included in research. The results indicated that the 17 parents of children with ASD who participated in the study expressed that their lives were impacted by the disruption to family life (including self-sacrifice), community/familial misunderstanding of ASD symptomology, cultural limitations of support (language barriers), and confusing systems (schools, medical, and service coordinators) which all contributed to high levels of stress. Although the researchers intended to gain information that would give voice to people not typically represented in research, a limitation of the study was that it included primarily Spanish-speaking mothers, with no other minorities represented. To fill a gap in the literature, other minorities could be researched in the future.

The marital relationship can be in jeopardy as the parents—especially mothers who are typically the primary caregivers and highly involved with their children with autism—are burdened by time constraints and financial burdens, and often sacrifice social relationships in deference to protecting their child (Bastanfar et al., 2018; Dong et al., 2022; Harper et al., 2013). As children with autism become adolescents and young adults, their unique abilities regarding executive functioning (EF), social skills, education, and adaptive behaviors will help to determine the possibility of employment and independence (Wisner-Carlson et al., 2020). However, even as parents struggle while raising their child with ASD, other studies have been conducted that indicate that some parents have experienced positivity, personal growth, and

satisfaction with their quality of life (QoL) (Ferenc et al., 2023; Hartley et al., 2017; McStay et al., 2014a).

A covenantal marriage is one of intimacy, as described in Genesis 2:23–25. It includes more than a sexual relationship: the union results in the creation of a new family unit apart from the two families of origin (Köstenberger, 2004, as cited in Vorster, 2016). A covenantal marriage recognizes that marriage is not merely an agreement declared between two humans (Vorster, 2016); it is a sacred vow that was made before God by a religious couple, which sanctifies the marriage and recognizes divorce as opposing religious values (Paprzycka et al., 2019). A study that was conducted in Poland indicated that traditional and liberal marriages consider the love between the couple and their children's welfare as most critical to the union and asserted that devotion to their spouse and children was instrumental to remaining married even when under duress (Paprzycka et al., 2019).

Autism Spectrum Disorder

Autism does not discriminate, as this lifelong developmental disorder can impact all racial and socioeconomic groups (Cohrs & Leslie, 2017). The incidence of children diagnosed with ASD has increased significantly in recent years which also increases the number of parents who are caring for a child with ASD (Turnage & Conner, 2022). An abundance of research is available addressing the prevalence of ASD and the inherent challenges upon diagnosis of autism that contribute to the stress experienced by the parents (Da Paz et al., 2018; Dardas & Ahmad, 2015; Enea & Rusu, 2020;). Many of these studies discuss the difficulties that parents of children with autism endure, including the atypical behaviors of the autistic child, financial duress, social isolation, and complex family dynamics. The diagnosis of autism can be made reliably when the child is 2 years old. However, sometimes children are not diagnosed until they are older,

negating the opportunity for early intervention (CDC, 2023). It must be understood that the diagnosis of autism is just the beginning of a perilous journey, and just as each child differs in the symptomology of autism, so too are the challenges that face each marriage and family. Regardless of when a child is diagnosed, raising a child with ASD creates unexpected anxiety in parents (Di Renzo et al., 2021) as they negotiate to create a family other than what they had imagined. The dream of having a healthy child diminishes with the diagnosis and can lead to anger, guilt, and depression (Yassıbaş & Çolak, 2019). The Di Renzo et al. (2021) study of 61 participants found that maternal stress is higher than paternal stress, likely due to mothers serving as the primary caregivers in the home. The authors note that emotional regulation strategies coupled with balanced family functioning can mediate maternal stress and that fathers' stress is reduced in a positive romantic relationship (Di Renzo et al., 2021). This study opens the door for further research to be conducted that uses qualitative research with interviews and observation of parent–child interaction to gain a better understanding of each parent's perception of parental stress and whether couples who more readily accept the diagnosis of autism experience fewer negative emotions and parental stress, resulting in a more balanced family functioning. The phenomenological qualitative study conducted by Yassıbaş and Çolak (2019) sought to understand the experience of 10 parents with an average age of 43 who were raising an autistic child (average age 10 years old). The study queried (among other themes) the experience of pre-diagnosis and the diagnostic process, with the participants expressing negative emotions ranging from shock to depression, the effect on their marriages from arguments to discussion of divorce, and the impact on social support and stigma associated with ASD (Yassıbaş & Çolak, 2019). The same study recognized the positive effect of religious coping and spiritual support and the benefit to parents who can accept and adapt to having an autistic child (Yassıbaş &

Çolak, 2019); as such, further studies could be conducted on the role of spirituality as it relates to meaning-making of a life different than imagined. Furthermore, there has been limited, if any focus on the dynamics of managing a young autistic adult in the family, the impact on marital quality, and the effects of religiosity/spirituality on the couple and the family.

A diagnosis of autism does not predetermine the trajectory of the developmental growth of the child (Hyman et al., 2020). Hughes (2020) explains that the abilities and struggles of autistic individuals vary so greatly that a clichéd saying exists that purports that meeting one autistic person indicates that a person has simply met one autistic person. Parents recognize that the spectrum of outcomes for people with ASD ranges from remaining non-verbal to living as an independent adult, and this contributes to the stress experienced by the couple as they fervently seek all possible interventions (Lord et al., 2018). Hill-Chapman et al. (2013) discuss the atypical behaviors of children with autism, which can vary from repetitive physical behaviors (head banging) to presenting with unusual responses in affect in any given situation. In addition to the challenging behaviors of children with ASD, these children often have IQs that are below 70, have difficulty grasping other people's interpretation of events and garnering the beliefs of others, as well as understanding the context in which circumstances take place (Anchesi et al., 2023). Individuals with an IQ above 70 are said to be high functioning (Alvares et al., 2019), yet Duncan and Bishop (2013) stated that the success of people with an IQ above 70 is still largely variable.

The deficits experienced by children with autism contribute to a lack of social skills, interfere with adapting to their environment, and affect their ability to interact in a socially acceptable manner (Kodak & Bergmann, 2020). These deficits can contribute to a lack of peer relationships and tense family interactions (Kodak & Bergmann, 2020). Further, autistic

individuals have difficulties with activities of daily living (ADL), that include the basic hygiene tasks of bathing and dressing, and basic needs of feeding, working, and keeping a house (Marsack-Topolewski, 2022). These ADL tasks, termed daily living skills (DLS), incorporate adaptive behaviors that contribute to the functional independence of the autistic individual as they can achieve personal hygiene, prepare meals, master time management and finances, and become employed (Bal et al., 2015). Children with deficits in ADL can receive support to help them master the necessary tasks. However, if they cannot sufficiently perform ADL, they will have difficulty transitioning to adulthood (Wisner-Carlson et al., 2020). Difficulties with DLS could essentially impair a child with autism's ability to become an independent adult (Duncan & Bishop, 2013). The skills that are required for an individual to act independently in their ADL, socialization, and communication are referred to as adaptive functioning (McQuaid et al., 2021). Autistic individuals with a higher IQ are usually perceived to have better adaptive functioning; however, they lag in adaptive behavior which is surprising given cognitive ability (Tillmann et al., 2019; Kraper et al., 2017; Kanne et al., 2010). Adaptive behaviors use many cognitive, social, and affective skills and can indicate social acceptance and increased quality of life for autistic individuals (Bertollo & Yerys, 2019). Adaptive behavior relates to how an individual functions on any given day regardless of ability (Bal et al., 2015).

Executive function (EF) refers to skills that relate to a higher degree of cognitive ability when controlling thoughts and actions and are a critical component of adaptive behavior (Gardiner & Iarocci, 2017). Kraper et al. (2017) stated that regardless of having average cognitive skills, autistic adults can be challenged by ADL as compared to neurotypical adults with similar intellectual functioning. Extant literature described the role of EF in predicting the potential trajectory for people with autism and explains that EF is a critically deficient area

(Tschida & Yerys, 2021). This study included 337 children who met the DSM-V criteria for autism, Asperger's syndrome, or pervasive developmental disorder (not otherwise specified) and were between 6 and 18 years of age (Tschida & Yerys, 2021). Notably, this large-scale study was conducted in a school setting rather than a home setting, which was considered more indicative of real-world EF. The findings of the Tschida and Yerys (2021) study concluded that EF skills become more impaired relative to normative peer groups as children with autism age, and the authors question whether the EF challenges are due to a lack of appropriate accommodations. This is an important area of consideration given that EF impairments were found to increase with age and the necessity of EF skills for autistic young adults to become independent and gainfully employed. Further research should be conducted to determine the effects of EF impairments on seeking and maintaining employment for young adults with autism.

In the early 1900s, psychologist Alfred Binet understood that children who were slow to learn were not wanted in schools where they were perceived as abnormal, nor in hospitals where they were not considered to be ill. Therefore, his goal was to encourage psychologists to detect students who, despite intellectual shortcomings, could be included in school (Nicolas et al., 2013). Mental deficiency in the early 20th century was described by physicians on a scale from severe (idiocy) to less severe (imbeciles) to mildly impaired, which was described as feeble-mindedness (Nicolas et al., 2013). Given the lack of clear boundaries between each category, Binet and Simon created a mental test that measured intelligence (Nicolas et al., 2013). While intelligence was a focus of clinical psychologists in the early 1900s (Nicolas et al., 2013), Edgar J. Doll was revolutionary in recognizing social competence as contributing to the functional independence of an individual (Saulnier & Klaiman, 2022). Doll (1936) discussed what might be considered crude descriptions of those with intellectual deficiencies and the social competency

challenges of the idiot, the imbecile, and the feeble-minded. His stance was that even the highest functioning of the groupings, the feeble-minded, would be unable to have complete social independence nor have the ability to use good judgment in adapting to social situations (Doll, 1936). Doll's belief that social competence should be measured led to the introduction of the Vineland social maturity scale (1936), which is an instrument—now called Vineland adaptive behavior scales (VABS)—used to evaluate delays in adaptive behavior across several domains of socialization, communication, and DLS (Carter et al., 1998; Pugliese et al., 2014; Saulnier & Klaiman, 2022). Pugliese et al. completed a study of 447 children with high-functioning ASD between the ages of 4 and 23 years of age, utilizing the VABS as one test to measure adaptive skills via standardized, structured parent/caregiver interviews. Pugliese et al. found that EF problems correlated with adaptive behavior capability more than cognitive ability. They noted the increasing gap between these entities as subjects aged, highlighting the need for early intervention. Saulnier and Klaiman (2022) referred to Doll's focus on adaptive behavior as predictive of one's ability to gain functional independence. Doll held four principles of adaptive behavior, with the fourth being most relevant to those with ASD: rather than focusing on a person's capabilities, focus on how the person functions regularly without any prompts or support from others (Saulnier & Klaiman, 2022).

Adaptive behavior encompasses society's norms required for daily living (Tillmann et al., 2019). In addition to ADL, money management and driving are vital for autistic young adults to transition successfully to adulthood (Wisner-Carlson et al., 2020). Pugliese et al. (2014) purport that advanced adaptive behavior skills are critical to functioning as an independent adult. A study by Pathak et al. (2017) found that children with a higher IQ were more likely to have incongruencies between their adaptive behavior and cognitive function, and Saulnier and

Klaiman (2022) confirm that the gap is significant for autistic individuals between their cognitive abilities and adaptive functioning. Consequently, the lack of mastery of DLS, which is significantly impacted by difficulties with EF skills, impairs the ability of many young adults with autism to become independent (Tillmann et al., 2019; Saulnier & Klaiman, 2022; Farley et al., 2009).

Transition to Emerging Adulthood

Several transitions occur for parents during the child-rearing years of their autistic child, including the initial diagnosis, starting school (Brisini & Solomon, 2018), and the transition to adulthood (Wisner-Carlson et al., 2020). Emerging adulthood typically includes proficiency in taking responsibility for one's actions, competence in making independent decisions, and ability to financially support oneself (Arnett, 2006; Wisner-Carlson et al., 2020). Parents recognize the value of their young adult with autism finding employment as it is a means to social interaction and increased self-worth and not merely the opportunity to gain financial stability (Sosnowy et al., 2018). Young adults with ASD resemble their neurotypical peers as their goals also include having a social life, finding employment, and becoming independent (Clarke et al., 2021). Parents and young adults with ASD have similar goals to neurotypical young adults in meeting societal expectations of emerging adulthood; however, they recognize that the goals will have to be moderated by strategies that will help them be successful (Sosnowy et al., 2018).

The transition from high school is particularly difficult for autistic youth (Sosnowy et al., 2018). The Sosnowy et al. study included 21 parents of young adults with ASD who were between the ages of 18–29 and 20 young adults with ASD of the same age who were all asked questions regarding topics of transition such as employment, education after high school, need for support, independent living, and social relationships. The results of the study from the

parents' perspective included a desire for their young adult to reach sustainable independence while recognizing that the transition process could be lengthy and would vary with their young adult's abilities. The young adults with ASD in the Sosnowy et al. study revealed that the goal of achieving independence would be accomplished by making their own decisions, gaining employment, and living on their own while negating needing any support from their parents. However, the reality was that many received substantial support from their families, and the young adults expressed wanting help in managing finances and job training. Ultimately, the study confirms that the services that are offered for aiding in transition are insufficient based on the type of help that is needed to support young adults with autism who seek an independent life (Sosnowy et al., 2018). A review of a collection of 17 qualitative research studies that explored the transition of 121 autistic individuals to adulthood, as well as 186 parents/caregivers and 192 professionals, was conducted utilizing thematic analysis (Anderson et al., 2018). The authors sought to outline barriers to postsecondary outcomes as well as facilitators of support to postsecondary outcomes, and the first barrier confirms the findings of the Sosnowy study that often the unique needs of young adults with ASD were not met in postsecondary environments (Anderson et al., 2018). An additional barrier is that many parents have been integral in their autistic child's life and struggle to find the new balance of providing support while encouraging their young adult with ASD to demonstrate the ability to adopt independent life skills and responsibilities; professionals in the study believed that parents can be too involved while parents stress the importance of vocational services given the tremendous reduction in available resources post-high school (Anderson et al., 2018).

Differing cognitive abilities can contribute to the difficulties of young adults with ASD in attaining employment. A study by Anderson et al. (2020) used two terms for autistic individuals:

with intellectual disability (ASD-ID) and ASD with typical cognitive ability (ASD-CA).

Anderson et al. (2020) explain that these groupings are more palatable than defining individuals with ASD as low-functioning and high-functioning, as both groupings have separate strengths and challenges. Specific to ASD-CA, individuals in this grouping may have graduated from high school with their peers at 18 years of age, yet they are met with challenges post-secondary given that their cognitive abilities do not match some of their social behaviors, including lack of appropriate communication skills and ADLs. Autism can be considered an invisible disability because the autistic individual does not appear to be disabled; parents have experienced this stigmatization when judged for their parenting when their autistic child demonstrated negative behaviors (Corcoran et al., 2015). The same could be said of young adults with mild to moderate ASD who are seeking employment and exhibit unusual social behaviors that could be interpreted as rude or aggressive (Anderson et al., 2020). Further studies could be conducted that would explore the need for companies and organizations to gain an understanding of the behaviors of autistic young adults and the training necessary for them to experience success in the workplace.

Autistic young adults can use camouflaging as a behavior that allows the person to be perceived as void of problems and able to function well (Hull et al., 2017). However, camouflaging contributes to stress and poor self-esteem as autistic youth exert effort to appear capable and competent (Hull et al., 2017). When ASD is disclosed in employed youth with autism, they might encounter outright discrimination or encounter people who unintentionally treat them differently, both of which contribute to a lower quality of life (Solomon, 2020). Young adults with ASD have severe hardships and are faced with several obstacles that hinder their transition to adulthood, specifically employment, including social skills deficits and challenging behaviors (Sosnowy et al., 2018; Chen et al., 2014; Chiang et al., 2012). Chen et al.

expressed that even for high-functioning ASD youth, difficulties with ADL impede employment opportunities. In addition to the characteristics of autistic young adults interfering with employment, societal prejudices and unwillingness to hire those who might initially need assistance also contribute to the challenges of attaining employment (Anderson et al., 2020). As such, over half of autistic young adults do not work full-time, and their hourly wages are substantially below that of young adults with differing disabilities (Roux et al., 2013). Young adults with ASD who were unsuccessful during the pre-employment process or during employment identify feeling traumatized by the experience (Anderson et al., 2020). Unemployment has a significant adverse effect on the autistic young adult, within their family and economically, while also excluding the autistic young adult from being a contributing member of society (Solomon, 2020). Additionally, as young adults continue to age, unemployment might cause a decrease in learned skills and slow further growth of skills (Solomon, 2020).

Parental involvement in assisting their autistic young adults in a job search does not necessarily lead to success as the parents explain that limited opportunities exist that reflect their autistic young adult's skills and interests, nor were they able to find workplaces where current employees were willing to be accommodating (Sosnowy et al., 2018). A capstone review of 31 studies funded by a 5-year federal autism transition research project (ATRP) by Roux et al. (2023) attempted to identify methodologies for enhancing service access and delivery for autistic young adults. The review cited a significant lack of data infrastructure to make meaningful conclusions about the efficacy of methods to enhance outcomes in this population. Parents often had to supervise DLS preparation for those who could find work or volunteer positions and provide transportation to the workplace; additionally, some parents use their own relationships to

help their autistic young adult find a volunteer position (Sosnowy et al., 2018). Future worry for their autistic young adult causes parents to intervene in job searches given their habit of advocating for the child with autism; yet even the right intention of supporting their young adult can backfire should something go awry with the job, which threatens independence and could also contribute to the young adult's depression (Anderson et al., 2020). Research indicates that the family of the young adult with ASD will be involved in their lives long into the future, which leads to concerns and stress about the support that will be needed beyond what they are currently providing (Herrema et al., 2017a).

The lack of EF skills in young adults with ASD contributes to deficits in the expression of social skills and engagement with others, as well as difficulties in managing the increasingly complex requirements of emerging adulthood (Wisner-Carlson et al., 2020). Money management is a critical factor for an autistic young adult to function independently. It includes earning a living, budgeting their money for basic needs, and saving money in the event of an emergency. Moreover, this skill may need to be monitored throughout the lifespan of the autistic young adult (Wisner-Carlson et al., 2020). Without an inability to manage their money, autistic young adults may not be able to meet their basic needs (Wisner-Carlson et al., 2020).

While autistic youth remain heterogeneous, and their futures remain difficult to generalize given their different ASD symptom manifestations (McStay et al., 2014a), a study by Howlin and Magiati (2017) reported that people with ASD will have lifelong difficulties. Young adults with autism are found to have the least amount of independence, even among other young adults with intellectual disabilities, given their difficulties with problem-solving skills and low levels of self-determination (Cheak-Zamora et al., 2019; Chou et al., 2016). Research conducted by Sosnowy et al. (2018) advises of parents' concerns regarding the ability of their autistic young

adult to be willing to accept responsibility and the potential for their inability to make decisions and complete DLS. Anderson et al. (2013) stated that merely 20% of young adults with autism have moved out of the home where they lived during high school, indicating that they are struggling to achieve the independence of emerging young adults. Van Naarden Braun et al. (2015) found that individuals with ASD and a co-occurring intellectual disability (ID) are 40% of the ASD population through the year 2010. Autistic youth with an intellectual disability might remain in high school until the age of 21 and, rather than receiving a diploma, will earn a certificate of completion (Anderson et al., 2020). This population of autistic youth may be more likely to meet the expectations of systems that provide adult services and gain further vocational support than autistic youth who have typical cognitive abilities (Anderson et al., 2020). Still, Howlin and Magiati (2017) advised that children whose IQs are below 70 or who never gain language skills are not likely to attain employment or live independently. Parents' hopes for their autistic child originate in wishes for an outcome that is founded on past experiences and can be tainted by the uncertainty associated with the future, the potential of unrealistic expectations, and a lack of being adequately informed (Chen et al., 2018). McStay et al. (2013) confirmed the findings of other studies that explained that relative to parenting neurotypical children, parents of children with ASD are susceptible to much higher levels of parenting stress.

Parental Stress

The current perception of family life for parents raising children with autism is related to their perception of their imagined family, such as what the parents thought the characteristics of the family would include, how the relationship would evolve romantically once the couple had children, and how their partner would behave in their role as a parent (Hirsch & Paquin, 2019). One study found that the reality of the experience for families with an autistic family member

often includes challenging behaviors by the autistic child, conflicted marital relations, financial burdens, and limited sources of support (Romney et al., 2020). Consequently, the functioning of a family as perceived by parents of children with autism is reported to be lower than those families with children who are typically developing (Pisula & Porębowicz-Dörsmann, 2017). This study conducted in Poland only included high-functioning children with autism. However, the authors cited stressors in the marriage that would seem to indicate how much more proportionately challenging ASD stressors are to the couple and the family dynamics relative to raising neurotypical children (Pisula & Porębowicz-Dörsmann, 2017). Potential issues with this study included a low 53.7% response rate, adversely affecting the statistical significance of the results, and the dependence on self-reporting and independence of mother and father responses (Pisula & Porębowicz-Dörsmann, 2017). Caregiving, teaching basic living skills, and admonishing negative behaviors, all while encouraging positive behaviors, lead to increased stress and burnout for parents of children with autism (Kütük et al., 2021).

Most of the research that has been conducted regarding raising a child with autism has concentrated on stress (Bonis, 2016). Stress is caused by both internal and external events that cause a physical or emotional reaction (Allen et al., 2013). Raising a child with ASD can be stressful for parents as their child is more reliant on them for support, given their unique behaviors and needs (Allen et al., 2013). Corcoran et al. (2015) purported that increased negative emotions are the result of the emotionally draining experiences of raising a child with autism. Parents reported that from the moment of the autism diagnosis of their child, they were met with the loss of the imagined life for their child, which resulted in disbelief, grief, and disappointment (Corcoran et al., 2015).

The characteristics of the autism disorder that require parents to make daily decisions to

support their child, the difficulties in communication and expectations, the level of social support, and the relationship of the couple each contribute to high stress levels (Anchesi et al., 2023). Parents struggle with their child's behavioral and social skills challenges and the future concern for their child's eventual independence (Bitsika et al., 2013). Goepfert et al. (2015) theorized that the continued inability of the autistic child to reach developmental milestones can result in renewed grief as the loss continues.

Although it is hoped the parental response to the disability can be malleable in a positive, nurturing manner, there is often a time delay in that response, as the specific functional aspect in question is often fluid and unpredictable. The Goepfert et al. study referred to the narratives that parents create around their hoped-for child and the challenges that the parents face when the developmental path of their autistic child might lead them into crisis. The authors in this study trended toward supporting family and narrative therapy interventions to help the couple and the family accept the difficulties of their autistic family member while also making meaning of their lives to be a balanced family (Goepfert et al., 2015). Parental stress is ongoing, given their concern for their child's future care and whether the child would be supported as necessary for them to have a productive life (Corcoran et al., 2015). Peculiar to aging parents of adult children with ASD is that they are impacted by watching their peers become empty nesters and the dissimilarity of experiences, which can cause them to feel socially isolated given the stigma and misunderstandings of autism, as well as the daily burdens of caring for their loved one (Marsack & Perry, 2017).

A growing number of parents are navigating life with an autistic young adult, shifting the focus from their future as a couple to the future of their young adult child (Marsack-Topolewski & Graves, 2019). This study of 51 parents (aged 50 and older) and their children with autism

(aged 18 and older) identified four themes that highlighted the anxiety associated with long-term planning for the care of the child, with a common thread of a lack of societal support for assisting families and parents in dealing with their young children with autism, both currently and long-term (Marsack-Topolewski & Graves, 2019). This mixed methodology study originally began with 320 parents; however, only 186 of the 320 parents participated in semi-structured interviews, and 51 parents were contacted for follow-up (Marsack-Topolewski et al., 2019). Of the 51 participants, 45 were mothers aged between 50 and 74 (Marsack-Topolewski et al., 2019). The disparate age range could adversely affect the themes, and there was no discussion of selecting the final 51 participants with the potential of an apparent female bias.

Children with autism display challenges with social skills and interacting in relationships, which contribute to parental stress (Anchesi et al., 2023). Shawler and Sullivan (2015) discussed a child's disruptive behavior and the stress resulting from confusion about how to use discipline. The authors described a circular pattern of poor parenting, which leads to the child acting out, which increases the parents' stress, which contributes to poor parenting (Shawler & Sullivan, 2015). Extreme aggression by the child, including self-injury, contributed to the fear parents had for the safety of their child and other people (Swaab et al., 2017).

While neither the type of disability nor the gender of the child contributed to the heightened levels of parenting stress (Woodman, 2014), the negative behavior of the autistic child, including self-regulation and disobedience, tended to increase the pressure endured by mothers, which lead to heightened stress (Zaidman-Zait et al., 2016). One study found that mothers, more than fathers, had more unmet support needs, which may result from many of the demands of childcare being their responsibility (Hartley & Schultz, 2014). A follow-up study by Hartley et al. (2018) indicated that mothers are susceptible to experiencing negative parenting

interactions because of negative marital tension and behaviors. This study affirms that mothers experience bidirectional spillover that negatively affects their marriage and mothering (Hartley et al., 2018).

Raising an autistic child contributes to overall parental anxiety and depression (Bitsika et al., 2013). This study highlighted the increased stress and anxiety of parents of ASD children relative to their normative population. The authors noted that those parents who developed and exhibited psychological resilience were better equipped to deal with the stresses involved in managing an ASD child (Bitsika et al., 2013). Criticisms of this study were the disparate participation rate between mothers (73) and fathers (35) and the broad age range of participating parents (29 to 63 years of age) and their ASD children aged between 3 and 36 years. The behaviors of a child with autism are stress-inducing for parents, which can cause the couple to criticize, blame, and argue (Romney et al., 2020), thereby draining the coping resources of the couple, resulting in psychological distress and emotional pain (Chan & Leung, 2020). The depression that parents feel results from disharmony in the marriage, dissatisfaction with parenting, triangulated relationships, and feeling overwhelmed with the demands of caregiving (Chan & Leung, 2020).

A study in China found that the time invested in raising children with autism detracts from the time that the couple can devote to one another, which negatively affects the relationship (He et al., 2022). Couples are likely to vent their frustrations on one another by yelling and being critical rather than taking out their stress on their ASD child (Romney et al., 2020). This marital strain can put the marriage relationship in jeopardy (Chan & Leung, 2020) as parents of children with autism experience negative emotions that put them at risk for divorce, isolation, and lives that are less meaningful than parents of typical children (Schieve et al., 2007, as cited in Swaab

et al., 2017). Couples who are in distress are vulnerable to a cycle of negativity. Gottman and Gottman (2017) advised of the tendency for couples who are in distress to interpret any comment from their partner, whether neutral or potentially even positive, as negative. Gottman and Gottman referred to Robert Weiss, who observed that couples who have overall optimistic feelings about one another are likely to process the relationship positively, and this feeling overrides negative behaviors of the partner; when couples are in negative sentiment override, they tend to view each other as adversaries rather than comrades.

Existing studies discuss the stress and tension experienced by couples who have a child with autism, include the pressures from the lack of time, resources, finances, and services (Romney et al., 2020). Corcoran et al. (2015) reported that the time and financial stressors of finding services continue even when the child is older. The financial stress on the parents of a child with ASD includes costs associated with the child, loss of productivity and income, and increased out-of-pocket expenses (Rogge & Janssen, 2019). A study by Marsack and Perry (2017) found that the financial burden can be the result of needing to leave a job to allow for caregiving, turn down promotion opportunities, or even relocation as they endeavor to find services for their autistic child.

Maternal Stress

The marital couple and the parent-child relationships are disrupted by anxiety and stress, which can culminate in depression in mothers and fathers (Hickey, Hartley, & Papp, 2019). Mothers often bear the responsibility of caring for children with autism as they are typically the primary caregivers and often quit their jobs so that they can be at home with their autistic child. This can leave them feeling resentful, alone, and unfulfilled (Sim, Fristedt et al., 2019). Mothers are pushed further than their limits as compared to fathers, which contributes to mothers'

increased reports of anxiety and depression (Bitsika et al., 2013). Mothers are particularly vulnerable in raising a child with ASD as they might feel incompetent, experience conflicting emotions, and succumb to depression (Di Renzo et al., 2021). Mothers desire family cohesion, and when they feel that they are unable to have satisfying interactions with their autistic child, they may be unable to mitigate their negative emotions (Di Renzo et al., 2021).

Maternal stress has been found to be higher than paternal stress, with deficits in sociability, health, and behavior of their autistic child contributing to the stress perceptions of mothers (Allen et al., 2013). Higher deficits in social skills can contribute to increased stress experienced by mothers, which can jeopardize the relationship between the mother and the child (Allen et al., 2013). Notably, as the child with ASD ages and becomes a young adult, the deficits in language and social skills are no longer able to be dismissed by age and, therefore, contribute to increased stress (Allen et al., 2013). The Dong et al. (2022) study conducted in China confirms a study by McCloskey and Pei (2019) which indicated that mothers with higher stress are more likely to be depressed.

Paternal Stress

Mothers and fathers often have feelings of grief and loss through the experience of raising a child with ASD (Frye, 2016), and fathers, especially, express anger and frustration as they feel helpless to effect change in the life of their autistic child (Burrell et al., 2017). Fathers who can empathize by putting themselves in the place of the mother are explained to have higher cognitive empathy, which helps to ameliorate the mother's parenting pressure; conversely, fathers who have high emotional empathy identify with the negative emotions of the mother and become negative themselves, which heightens the mother's negative emotions (Dong et al., 2022).

Fathers often note that the mothers of their children with autism play a more significant role in engaging in the demands of the family and that the fathers play a supporting role to their spouse (O'Halloran et al., 2013). However, fathers stated that their desire to help their autistic child master skills (i.e., academics) can frequently be met with resistance from their overprotective partner (O'Halloran et al., 2013). Fathers experience stress when their autistic child has deficits in sensory processing (the ability to regulate sensory information and respond appropriately) (Ricon et al., 2017), as well as deficits in cognitive awareness (Allen et al., 2013). Fathers in these studies often voiced concerns about their child with ASD when considering the importance of academics as it relates to gaining eventual independence. They expressed worries about their autistic child's lack of athletic skills as it impairs the father-child relationship and future engagement with friends (O'Halloran et al., 2013). However, fathers sought to take on the responsibility of playing a role in helping their child with ASD in their quest for independence and acceptance in society, even as they remain unsure of whether these were achievable goals (Burrell et al., 2017). O'Halloran et al. (2013) emphasized that fathers accept that future support will be necessary; they merely want their autistic child to reach some level of independent living, including friends and perhaps a mate.

A study by Burrell et al. (2017) identified parents as filling in for one another when the other parent needed a break, with fathers identifying that they would assume caregiving responsibilities during the evening and on weekends/holidays. The balance of care can be complicated as Seymour et al. (2020) explained that while fathers may feel guilty for taking time for themselves, the mental health of fathers is supported by having a respite from their autistic child, which permits time for fathers to spend with their partners and their other children, as well as tending to other responsibilities and enjoying time for self-care—described as necessary to

escape the worries about their autistic child and other familial demands.

Resilience

A study by Da Paz et al. (2018) replicated other studies that found that coping skills are critical in raising a child with ASD, given that autism is a lifelong condition. The challenges can result in parental psychological distress for many years. The study by Da Paz et al. identified three dimensions of parental adjustments: acceptance, self-blame, and despair. Of these three indices, reduction in self-blame and despair were better predictors of parental adjustment than acceptance. The study used a sample of 183 females extracted from the stress, aging, and emotions study (SAGE) with two groups of mothers. Group One included 92 mothers who were raising a child with ASD, and Group Two included 91 mothers raising neurotypical children. Da Paz et al. speculated that when mothers accepted the diagnosis of autism, they were often found to have fewer depressive symptoms. A potential flaw in this study was the self-reporting of the ASD diagnosis by the mother rather than a formal diagnosis. Another issue was the inclusion of mothers who met the criteria for major depressive disorder. Ineffective coping mechanisms are found to contribute to negative emotions (Lazarus & Folkman, 1984, as cited in Enea & Rusu, 2020).

Resilient parents can overcome the daily stress associated with the demands placed on them by their autistic children (Bitsika et al., 2013). In the research conducted by Da Paz et al. (2018), the study found that when children had higher deficits and more severe ASD symptoms, acceptance of the condition was more readily attained, perhaps due to the inability to deny or hope that the condition would cease to exist; conversely, parents whose children have less severe deficits or more subtle symptoms might continue to pursue mainstreaming their children with autism as they endeavor to find a different diagnosis or even a cure, thereby resisting acceptance

(Da Paz et al., 2018). Acceptance of the child's ASD is important as it aids in avoiding depression and moving past self-blame and despair, contributing to psychological resilience and higher life satisfaction (Da Paz et al., 2018). Further, positive parental self-efficacy results from working through and overcoming stressful situations (Han et al., 2018). Romney et al. (2020) stated that the external stress induced by raising a child with autism can be moderated with supportive coping mechanisms in place, such as stress-reducing conversation, as outlined by Gottman and Gottman (2015). Stress-reducing conversation includes empathic listening, allowing the partners to accept one another and understand the stress they are experiencing (Gottman & Gottman, 2015). Resilience in a family arises from its ability to manage risk and adversity (Al-Jadiri et al., 2020). It has also been found to protect parents from anxiety and depression (Bitsika et al., 2013). Family-centered interventions and prioritizing the relationship with sharing parenting responsibilities should promote relationship satisfaction (Sim, Fristedt et al., 2019).

Family Systems

Families, like autistic individuals, are heterogeneous (Sim, Fristedt et al., 2019). Children with ASD have challenging behaviors that can affect the entire family, and the stress that began when the child was first diagnosed increases with each new behavior as mothers' psychological well-being is compromised given negative interactions with their child (Di Renzo et al., 2021). Fathers may be more vulnerable to depression depending on how impacted the child is by the ASD symptoms, how depressed the mothers are, and the psychopharmacological regime of the child (Kütük et al., 2021). Siblings are often disenchanted by the amount of time that their parents spend with their autistic brother or sister (Corcoran et al., 2015). The satisfaction and fulfillment of family members is an important contribution to siblings displaying appropriate

behaviors (Laghi et al., 2017). Unlike the diagnosis of ASD, which cannot be changed, a family's reaction to the diagnosis and accompanying difficulties can be altered (Goepfert et al., 2015). Families who are balanced along the dimensions of cohesion and flexibility can gain resilience as they overcome adversity; families that cannot find the balance may be hindered by a lack of information, ability, or desire to change the functioning of the family (Carr & Kellas, 2017).

Bowen (1978) discussed differentiation of self as the ability of a person to counterbalance togetherness and individuality on both emotional and intellectual levels (Gladding, 2011). Gladding described Bowen's differentiation as occurring along a continuum from poor to moderate to moderate-good to good differentiation. Kerr and Bowen (1988) explained that a foundational level of differentiation is determined by the emotional separation that one achieves with one's family of origin. In a marriage, differentiation from the family of origin is expected, as expressed in Genesis 2:24, "That is why a man leaves his father and mother and is united to his wife, and they become one flesh" (*Holy Bible, New International Version*, 2015). Balswick and Balswick (2014) also used the concept of differentiation. They explained that differentiated people are those who are sufficiently separated socially and psychologically from their parents while maintaining a close relationship with their families, while undifferentiated people present as either extremely close and dependent on their families of origin or are shut off and disengaged from their families of origin. Differentiation is a critical part of parenting in that it permits obtaining a clear sense of self, which contributes to an individual's ability to interact with others independently, and the resultant self-sufficiency enables deeper levels of connection and mature marital intimacy (Balswick & Balswick, 2014). Differentiation of a child with ASD can be

compromised when parents do not recognize the strength of their child's abilities (Goepfert et al., 2015).

Most of the support for a child with special needs comes from the family, and the influence on the family is circular in that the special needs child affects the family, and the response from the family affects the special needs child (Han et al., 2018). Families are the foundation for the long-term support and protection of the autistic family member (Sosnowy et al., 2018). Life-long ongoing financial, housing, and employment monitoring are continued concerns (Herrema et al., 2017a). Parents might feel relieved to have siblings or relatives available for future care, although they are hesitant to put too much pressure on them; parents are less confident of future care if families do not have that support system in place (Sosnowy et al., 2018).

The circumplex model recognizes that families are not stagnant but change throughout years, including responses to high stress or trauma (Olson et al., 2019). Families with an ASD member face numerous stressful challenges given the demands of the disorder (Goepfert et al., 2015). Adaptation in the family system can lead to satisfaction, and flexibility of the family members results in small celebrations of success. In some cases, parents reported a stronger union for enduring the strain on the relationships (Corcoran et al., 2015). Family satisfaction is displayed through functional cohesion, flexibility, and communication. It contributes to positive attachment, while engagement in negative emotions among family members creates negative family communication (Olsen et al., 1989, as cited in Laghi et al., 2017). Families whose communication supports balance along the dimensions of cohesion and flexibility are far more resilient than families that are unbalanced, regardless of the adversity that the family faces (Carr & Kellas, 2017).

High levels of parental stress create unbalanced family functioning (Di Renzo et al., 2021). The negative emotional climate can affect the development of the child and the family (Hickey, Nix, & Hartley, 2019). Negative emotions and turmoil in one family subsystem can spill over into other subsystems, creating layers of frustration (Chan & Leung, 2020). However, a family that functions well in areas of cohesion and flexibility can grow and make meaningful connections (Laghi et al., 2017), and a union that is founded on religiosity and spirituality can rise above the challenges and find a richer connection between the couple (Mullins, 2016).

Marital Relationship

Marital Conflict

Heightened parental stress hinders the maintenance of marriages (Handley et al., 2020). Higher rates of marital conflict exist between fathers and mothers of children with ASD that occurred while the children were present (Papp & Hartley, 2019). Children in ASD families who are discussed during marital strife may cause those children to feel responsible and blamed for parental conflicts (Papp & Hartley, 2019). The negative emotional climate can affect the child's and the family's development (Hickey, Nix, et al., 2019). Conflict that occurs between the parents of children with autism contributes to increased conflicts in the marriage, which effectively lowers the loving bond between the married partners (Chan & Leung, 2020). A previous study discussed the negative influence that a child with autism has on social and family relationships and provided the example of siblings exhibiting dysfunctional behaviors that lead to self-harm or depression (González-Herrera et al., 2021). The family system suffers from the turmoil between the parents, and the escalated emotions of mothers contribute to them being more critical of their relationships with their children and their partners (Hickey, Hartley, et al., 2019). When raising a child with autism, couple and parenting boundaries are challenged due to

the child's negative behaviors (Langley et al., 2017).

The years of raising a child with autism challenge the marital relationship due to a lack of financial resources and a lack of time for each other. Therefore, the relationship suffers due to the inability to nurture one another (Romney et al., 2020). As the child grows to young adulthood, the stress experienced by parents can be exacerbated by the autistic young adult's inability to live an independent life (Anderson et al., 2020; Forbes et al., 2022), and the enduring marriage can be jeopardized given the ongoing challenges of the now young adult. The financial duress of continuing to pay for their young adult's expenses, the lack of resources that could help supplement financial burdens and caregiving (Chan et al., 2018), social exclusion and a shift in perspective about the retirement years (Marsack & Perry, 2017) can cause increased stress, worry, and depression, which contribute to disruptions in the family and marital discord (Chamak & Bonniau, 2015; Hartley et al., 2017; Herrema et al., 2017a; Marsack & Perry, 2017).

A married couple experiences several transition periods in their autistic child's life that create relational turbulence, including diagnosis and starting school. During times of upheaval, the couple must process the transition and use good communication skills (Brisini & Solomon, 2018). Relational turbulence theory, as described by Solomon et al. (2016), prescribes that times of transition leave the couple at risk of relationship turbulence, which can result in either an undermining of the relationship or a growth opportunity. If the turbulence is not adequately dealt with, the perception of turmoil jeopardizes the health of the individuals and the relationship; however, proper communication during times of volatility can help the couple experience cohesion and the resultant growth in their bond (Solomon et al., 2016). Learning to rely on one another and managing stress by sharing the workload and working as a team leads to a sense of togetherness (Romney et al., 2020).

Marital Satisfaction

Much research has been conducted that confirms the amount of duress that marital couples experience while raising a child with autism. The level of stress and marital satisfaction for parents raising an autistic child is in accordance with their perception of their children, their marital partner, and demands on the family (Easler et al., 2022). As such, raising a child with autism does not necessarily have only negative results for the marriage. Some couples with an autistic child have reported that their marriages are stronger for having endured the stress associated with the challenges and that they have learned the benefit of making their marriage a priority in ways that they might not have otherwise (Romney et al., 2020). Rearing children with autism has been found to permit a couple to garner a sense of shared responsibility, and the utilization of effective teamwork and togetherness fortifies the marriage (Karimi et al., 2019).

Parents of children with ASD have similar hopes for their children as do parents of neurotypical children, including quality of life and social relationships (Finke et al., 2019). The perspective of hope for the future changed along the development of the child's lifespan as educational struggles became more apparent and parents of older children focused more on vocation (Finke et al., 2019). The limitations of young adults with ASD in being able to manage their futures contributed to difficulties experienced by their parents, with mothers expressing higher levels of stress given the desire to control the situation (Van Hees et al., 2018). The recognition by the marital partners that they are functioning as a team through the challenges of raising their autistic child lends itself to resilience in the marriage, permitting them to rise above the disruptions (Sim, Fristedt, et al., 2019). Further, a shared belief that working together for the good of the relationship and sharing the experience of raising their child with ASD provided a mutual understanding of the other partner's efforts, which helped to strengthen the marriage

(Sim, Cordier, et al., 2019). Spending time together as a couple contributes to the satisfaction of the marriage (Sim, Fristedt, et al., 2019). Love, connection, and empathic understanding are a universal desire of human nature; learning to work together to master expressing intimacy and admiration in a relationship, rather than moving away from one's partner, can increase satisfaction in a marriage (Rajaei et al., 2019). Effective communication, which includes the ability to relay thoughts and worries openly with one another while making decisions together, contributes to maintaining a healthy marriage (Handley et al., 2020).

Social Support

Parents who are raising a child with ASD tend not to focus on themselves because they are consumed with the problems in their child's life; they also tend to isolate themselves from others, which results in stress that remains hidden (Bastanfar et al., 2018). Parents may feel shame or guilt over the behavior of their child with autism, which causes them to avoid social situations (Goepfert et al., 2015). The negative behaviors of children with ASD cause parents to retreat from social relationships as they attempt to accommodate their child, and the lack of socializing with friends can contribute to parents behaving negatively towards one another (Romney et al., 2020).

Parents can become their own sources of support for one another as they recognize that they are experts in the unique challenges of their children (Burrell et al., 2017). Some fathers are reluctant to rely on friends to discuss their challenges at home, while other fathers seek out friends who also have children with disorders so they can openly share their worries without feeling judged (Burrell et al., 2017). Burrell et al.'s study affirmed the results of other research that found that parenting a young adult with autism continues past childhood, and the struggles continue through the development of the lifespan. In the opinion of Goepfert et al. (2015), social

isolation is further exacerbated because of the lack of societal understanding of the behaviors of children with autism. Studies have been conducted that address the burden of the isolation experienced by parents of children (Iadarola et al., 2017), which may lead to higher stress and more disagreements between the parents (Romney et al., 2020).

A study by Marsack & Perry (2017) referred to the continued social isolation as parents age and are parenting their young adult with autism. This qualitative study addressed the lack of research on parents of adult children with autism and recognized (1) the general public does not understand the behaviors of an adult with ASD, which results in stigma as it relates to parenting ability, (2) the potential for continuity of caregiving for the parents of adult children with ASD, and (3) the impact that caregiving has on their personal time impedes the parents' social life (Marsack & Perry, 2017). The study was not without limitations, including that their sample was drawn only from people who were involved in autism support groups and national organizations, no marker for the severity of the adult child with ASD was established, and many of the caregivers were female.

For many people, an important factor aiding in the benefit of social support is that extended family members are not only present, but also understand the challenges experienced by the family of the autistic child (Bitsika et al., 2013). This study found that when parents perceive that familial support includes a grasp of the difficulties of raising a child with ASD, they are less likely to be anxious or depressed and have a more positive outlook on their ability to meet the demands of the autistic child (Bitsika et al., 2013). A cohesive community that provides a trusting relationship can act as a protective factor against parental stress. This, in turn, can lead to decreased symptoms of depression in mothers (McCloskey & Pei, 2019). Couples who belong to ASD support groups and those who attend church find social support which helps

them to feel less alone in their stress (Romney et al., 2020). Social support contributes to a couple's ability to create and maintain intimacy in their marriage as the couple parenting an autistic child can find appropriate childcare to allow them the opportunity to spend time together (Johnson & Piercy, 2017). Families who have people in their lives who can request emotional support are more likely to experience resilience (Al-Jadiri et al., 2020), which previous studies advise as a necessary component to reduce stress.

Quality of Life

The lifelong challenges associated with a child with autism can have a negative impact on the family's quality of life as they endure stress that challenges their well-being (Herrema et al., 2017b). The Herrema et al. (2017b) study was designed to include family members of autistic adults with co-morbid mental health issues. It included 109 participants (95 female and 14 male) who completed an online survey in the United Kingdom. The study's findings asserted that a lack of preparedness for the future of the autistic adult contributed to diminished well-being for the family member, as did a low level of intolerance for uncertainty, which contributed to worry and stress (Herrema et al., 2017b). The study primarily included mothers who were recruited from autism organizations, which may have made them more knowledgeable about the potential challenges to well-being. Additionally, the study did not disclose the nature or the severity of the mental health issues of the autistic family member. Further research could be conducted on the challenges to the well-being of mothers and fathers who are parenting young adults with mild to moderate autism without co-morbid mental health issues.

The quality of life of the autistic child and the child's problem behaviors are often believed by parents of the autistic child to be their responsibility and within their control (McStay et al., 2014b). Many parents will set aside their own needs to do anything to help propel

their children forward (Hoogsteen & Woodgate, 2013; Iadarola et al., 2017). Most parents' lives revolve around autism as they devote their time and support given the challenges with which they are faced (Hoogsteen & Woodgate, 2013). Social support, parenting self-efficacy self-compassion and decreased parental stress contribute to a greater quality of life for parents of an autistic child (Bohadana et al., 2019).

Upon learning of the child's diagnosis with autism, studies inferred that couples made a cognitive shift that enabled them to change their perceptions and expectations of their relationship and the child they are raising (Johnson & Piercy, 2017). This cognitive shift led couples to adapt to life with their autistic child, which contributed to finding meaning in their relationship and the ability to overcome negative consequences (Romney et al., 2020).

Conversely, couples who were unable to shift their cognitions about life with an autistic child were challenged to work together to shift their relationship and experience partner intimacy (Johnson & Piercy, 2017). These cognitive shifts contributed to the couple's ability to adapt to their life with an autistic child, and a perspective of positivity was a critical component to achieving adaptability (Romney et al., 2020).

Relational shifts noted to contribute to increased intimacy between parents who are raising a child with ASD included working together to take care of each other and the child, participating in advanced communication skills, overcoming the lack of time that the couple has for one another, and displaying increased emotional connectivity toward one another (Johnson & Piercy, 2017). Achieving intimacy is a constant process of necessary shifts, and some couples noted that the process became easier with time, explaining that they could experience a deeply committed, intimate relationship (Johnson & Piercy, 2017).

Religiosity, Spirituality, and Meaning-Making

The high expectations of newlyweds can be derailed when they recognize that they are mere mortals, as is their spouse (Agu & Nwankwo, 2019). The reality of marriage is that it is comprised of two fallen human beings who exist in a broken and licentious world (Thomas, 2015). The World Population Review (2022) indicated that the divorce rate for married couples is about 50% for first marriages, 60% for second marriages, and 73% for third marriages. Couples who regard the presence of God in their marriage recognize His divine plan to bring them together and are apt to be devoted to one another by tending to their partner's needs (Jung, 2020). Three assumptions exist for couples who claim to have a Christian orientation, including that they believe in the existence of God and want to be in communion with Him as well as embracing that God acts for the benefit of the union (Anderson & Worthen, 1997, as cited in Maxwell et al., 2018). Mahoney et al. (1999) conducted groundbreaking research on marital couples' engagement in joint religious activities, including praying together and for each other, attending church services, and discussing spiritual matters and God's presence in their union. This research discovered that spouses believed that their marriage enveloped the presence of God (Mahoney et al., 1999). Religious rituals that the couple experience together—such as praying—provide a foundation for the marital union and an improved quality of life while reinforcing the marriage and creating meaning and purpose in the couple's lives as they pursue their individual and couple relationship with God (Marks & Dollahite, 2012, as cited in Lakatos & Matos, 2019).

In traditional and liberal marriages, the declaration of love seems adequate for the commitment made during the exchange of vows, yet the understanding between the parties is that the relationship can terminate if it becomes unsatisfying (Paprzycka et al., 2019). This secular contract differs from the sacred vows expressed between couples insofar as the sacred vow includes the presence of the Divinity, and hence, couples maintain their commitment to one

another as promised before God (Mahoney et al., 2003; Mullins, 2016; Nelson et al., 2011). Maxwell et al. (2018) posited that it is considered a covenant when two people enter marriage with God and with each other. *Spirituality* is uncovering what is sacred to an individual, which can refer to the divinity of God or a transcendent universe, as well as other areas of life that embody a divine presence, including familial relationships (Mahoney, 2012). *Sanctification* is the religious worldview through which individuals perceive their lives and contributes to meaning in life, marital satisfaction, and devotion to the marriage (Abu-Raiya et al., 2015). Boniwell et al. (2013) separated sanctification between theistic (recognizing the presence of God in one's life) and non-theistic (identification of divine qualities of life, including value and purpose). Christian marriages viewed as sanctified include cognitive processes such as the exchange of vows and wedding rings strengthened by religious or spiritual beliefs (Boniwell et al., 2013).

Gall and Guirguis-Younger (2012) expressed that a person's spiritual disposition incorporates a person's religious identification and subsequent use of spirituality in areas of coping and meaning-making. Challenges can lead to growth by gaining coping skills or can result in people opting to remain in chronic struggles (Exline, 2012). Sørensen et al. (2015) explained that the existential needs of people include value and purpose, and the authors expressed that when humans are faced with challenges in their expectations for their lives, they will use meaning to restore balance. Agu and Nwankwo (2019) articulated the importance of framing thoughts and behaviors to support the health of the marriage. Religious couples extend loving-kindness and patience in their marriage, as opposed to lashing out in anger at one another, which contributes to spending more time with one another (King et al., 2022). Specific to aging couples, shared time together is important to both the individuals and the marriage as they

become the primary source of support for one another as social networks become smaller (King et al., 2022).

Areas of struggle in a person's life create negative emotions arising from the perspective that the conflict may not be easily overcome, which can lead to physical distress (Exline, 2012). During conflict, the actions toward the other spouse can be determined by their religious beliefs (Rauer & Volling, 2015). Religion includes a system of beliefs and values that acts as a compass for individuals throughout their lives. In times of disruption, religion can guide individuals to available resources to help them cope with struggles (Abu-Raiya et al., 2015). While spiritual and religious struggles overlap, spiritual struggles are defined as challenges with God or the universal spiritual realm, and religious struggles are centered on the teachings of the church or organized religion (Exline, 2012). The result of these struggles can be anger with God and placing blame on Him when events go seriously awry, sensing an ending of their relationship with God; this leads to further conflict as people are uncomfortable expressing negative feelings about God (Exline, 2012). Davis et al. (2014) explained that those who struggle with spirituality and doubt their faith might fear judgment from other people and, therefore, retreat socially; further, spiritual struggles can result in poor psychological adjustment through the utilization of negative religious coping. Conversely, Davis et al. defined functional beliefs as resulting in positive religious coping, given that a person believes that God or the universe will maintain the integrity of the world and will, therefore, use their belief to help alleviate stress.

An association with organized religion can help facilitate meaning-making in one's life, which can serve as a foundation during challenging times (Sørensen et al., 2015). Higher levels of spirituality in the marital couple contribute to increased satisfaction within the marriage given that fewer insults are given, and devotion is expressed to one another (Perry, 2014). Mothers who

identify as having high levels of spirituality can perceive their child with ASD as a positive contributor to their lives because the child provides a source of pride and personal growth, which provides a sense of meaning to their lives (Ekas et al., 2019). Spiritual beliefs strengthen problem-solving skills, and Rauer and Volling (2015) indicated that when viewing marriage as sacred, wives' religious beliefs encouraged them to approach problems more proactively and that husbands' religious beliefs helped them to be less volatile during challenging times. Spiritual intimacy has been studied to determine whether couples would be kinder to one another during times of conflict, especially relating to the stress and challenges associated with the transition to parenthood (Kusner et al., 2014). Research has concluded that the tendency towards spiritual intimacy in the marriage contributed to the couple resisting the use of negative emotions towards one another to keep the union protected (Kusner et al., 2014), which is in keeping with the principle of negative sentiment override of Gottman and Gottman (2015).

Traditionally, couples who viewed marriage as sacred with vows made before God believed there could be no dissolution of the union (Paprzycka et al., 2019). A study in Poland among Catholic couples found that religiosity contributes to the permanence of marriage. However, even with the mentality that marriages should not be dissolved, justifiable reasons for divorce exist (Paprzycka et al., 2019). Further, of the couples in the study, merely half felt that religiosity required people to stay in an unsatisfying relationship (Paprzycka et al., 2019). The study concluded that religiosity was not critical to whether the relationship would remain intact; other essential components, such as the welfare of children and the love expressed between the couple, also factored into devotion to the marriage (Paprzycka et al., 2019). Krok (2015) purported that religiousness is important in forming relationships between parents and children because boundaries are set that establish unacceptable actions and positive activities that will

contribute to healthy interactions. The study found that religiousness was positively associated with intimacy, safety, and emotional well-being, representing characteristics of a caring and constructive family system (Krok, 2015).

An enduring marriage that uses constructive engagement, reveres communication, shared caregiving responsibilities, and respect for the marital union can find success and growth from the experience of raising a young adult with autism (Romney et al., 2020; Feeney & Karantzas, 2017, as cited in Karimi et al., 2019). The Romney et al. study exposed the critical contribution that communication, spirituality, and adaptability make toward couples finding meaning in their lives. Parents of children with ASD who hold religion in high regard reported that they found meaning in their lives as they overcame stressful situations and that their religious views contributed to a strong foundation for their marriage (Romney et al., 2020).

Pioneering research regarding joint religious activities in marriage, conducted by Mahoney et al. (1999), indicated that relationships created during religious activities can be a source of social support that can help a marital couple cope during times of marital distress. A study by Ekas et al. (2019) noted that increased levels of spirituality heightened the contributions that children with autism made to their mothers' lives; additionally, mothers benefit from social support found in religious settings because it allows them to experience spiritual growth as they can focus on positive aspects of raising a child with a disability (Alon, 2019). A marriage that is founded on shared religion has been found to have increased love and satisfaction between partners, especially in the areas of intimacy (connection and closeness) and commitment (the desire to have an enduring relationship that satisfies the need to feel love and express love) (Cassepp-Borges, 2021).

Research Gaps in the Literature

No one appeared to address the issue of the impact on the long-term marriage and the couple who has sustained their relationship through the challenging and turbulent years of raising their autistic child and are now met with further challenges as they seek to help their young adult with ASD reach a certain level of independence. The transition to this next phase of life for the autistic young adult is met with the challenges of finding services that will afford them optimal opportunities due to their deficits in EF and lack of social cognition (Wisner-Carlson et al., 2020). Mastering adaptive behaviors such as ADL, functional communication, and social relationships with others contributes to the independence of a young adult with autism (Wise, 2020, as cited in Wisner-Carlson et al., 2020). The literature reviewed touched on the minimal services available to autistic young adults but did not delineate substantial advances in promoting a healthy transition to independence for this population, instead maintaining the role that the parents will continue to play.

Religiosity and spirituality have been studied and found to positively affect marriages, as churches can be sources of social support (Romney et al., 2020). However, Ekas et al. (2019) differed in that their study exposed some mothers experiencing negative attitudes from congregation members who were judgmental and critical, perhaps due to a lack of education about ASD symptoms. This gap in the literature reveals that religion and spirituality might offer some people the opportunity to gain social relationships that could make positive contributions in their lives while also purporting that social support can be negated even in houses of worship due to people's ignorance regarding the ASD population. The specific group of long-term married couples who are parenting a young adult with autism warrants further exploration of the benefits or challenges of religiosity and spirituality and its application in their lives.

Romney et al. (2020) investigated how couples can make meaning through their

experiences of raising a child with ASD and posit that the important contributors are communication, spirituality, roles, and adaptability. The Romney et al. study recognized that future research could investigate how couples manage stress and thereby make meaning of the experience of raising a child with ASD. This research seeks to understand the impact on couples raising a young adult with autism as the parents go beyond the childhood challenges and enter the new realm of seeking independence for their young adult even as they are preparing for their own futures as imagined empty nesters.

Chapter Two Summary

Autism spectrum disorder is not detected in utero; hence, upon diagnosis, parents are surprised and mourn the loss of the dream for the child that they thought they were raising. Once the shock of the diagnosis is comprehended, parents are presented with a myriad of challenges, including problem behavior of their autistic child, stress, anxiety, depression, and financial duress, all of which contribute to marital strife. Raising an autistic child varies with the intensity of the disorder; however, all parents are subjected to understanding a different way of childrearing. The nervousness of uncertainty, the anxiety of the unknown, the crushing stress of financial expenditures, and ultimately, the fear of the future for the child who will become an adult all contribute to the stress in the family. To date, very little literature is available that explores couples in an enduring marriage who are parenting a young adult with autism, including the challenges and coping mechanisms that are unique to their lived experiences.

The circumplex model of marital and family systems describes balanced families as those that can be flexible and can change when necessary. Families with an autistic member will need to be flexible as roles and circumstances change throughout the years. A young adult with autism could disrupt the family system, given that they are not able to become fully independent adults.

A family that is too rigid would become unbalanced as they adhere too firmly to roles and expectations and are likely to be enmeshed as their emotional connections are overly strong, which leads to volatility within the system. A connected family is concerned for its members' well-being of, values sharing roles and responsibilities with good communication, and will be balanced and able to withstand changing dynamics.

The specific portions of this study have been selected specifically to garner a more robust understanding of the lived experiences of couples in a long-term marriage who were parenting a young adult with ASD. This transcendental phenomenological study seeks to discern the couples' perceptions in an enduring marriage as they withstand further anxiety, stress, and worry as their young adult needs continued support into the very years that they hoped would bring them freedom. The depth and richness of this study will provide stakeholders and parents knowledge that will assist in helping to improve the marriages and families of those with an autistic family member.

CHAPTER THREE: METHODS

Overview

The purpose of this transcendental phenomenological study was to gain an understanding of the lived experiences of long-term married couples who are parenting a young adult with mild to moderate autism. By focusing on the lived experiences of these parents, this study will explain the impact that the continuation of parenting their young adult with autism has had on their marriage and the coping strategies that they used to maintain the health of their marriage. This information will benefit the parents, mental health workers, and other family members or caregivers of young adults with autism. This chapter contains the descriptions of the research design, research questions, the setting, the participants, and my role as the researcher. In addition, data collection, data analysis, and ethical considerations are also discussed.

Research Design

The intent of this study was to understand the lived experiences of couples who are in an enduring marriage and parenting a young adult with autism. Therefore, the appropriate design for this type of research was a qualitative, phenomenological, transcendental approach. Qualitative researchers produce interpretations of their observations of the research study participants' perspectives (Gilgun, 2012), and this interpretative research allows a deeper understanding of the participants' lived experiences (Fife, 2015).

Phenomenology

Moustakas (1994) explained that a phenomenon exists in consciousness and advised that any phenomenon can initiate a study. As a qualitative approach that seeks discovery, phenomenology seeks to understand the everyday experience to gain an understanding of a phenomenon (Heppner et al., 2016). Phenomenology has its foundation in philosophy and the

works of Edmund Husserl, having been used in science, sociology, and education (Creswell & Poth, 2018). Husserl was interested in uncovering the differences in knowledge (sourced in perception) between the real and the non-real, which were also described as facts and essences (Moustakas, 1994). Essence is described by Van Manen (2016) as a linguistic description of the phenomenon, which is clearly explained so that the nature and significance of the phenomenon can be understood. Notably, perception is not always an accurate description of what exists in consciousness given that perceptions (also referred to as intentions) are intuitive or signitive (Moustakas, 1994). Intuitive perceptions are full, while signitive perceptions signify an absence which seek to be filled. Signitive perceptions contribute to the understanding of other individuals' experiences as they are in direct relation to one's own experiences (Moustakas, 1994). Fife (2015) posited that an individual's lived experiences determine one's reality.

The question in a phenomenological study ought to be lived by the researcher (Van Manen, 2016). A phenomenological study requires the researcher to identify a relevant concern that is of interest to them and then reflect on emerging themes of the lived experiences of the research study participants (Creswell & Poth, 2018). The research study participants are a homogenous group and are studied regarding their subjective experience of the phenomenon as well as their objective experiences of what they have in common (Creswell & Poth, 2018). The phenomenological researcher is expected to comprehend the essence of the phenomenon that is being studied and to compose exhaustive descriptions of the lived experiences of the research participants (Heppner et al., 2016). This study qualified as a phenomenological transcendental qualitative study given that it sought to contextualize the lived experiences of couples in an enduring marriage who are parenting a young adult with autism and explore what those experiences meant to these individuals (Heppner et al., 2016).

Transcendental Approach

Husserl recognized epoché as a process by which the researcher can rise above their preconceived notions and prejudgments (Moustakas, 1994). Van Manen (2016) suggested that a concern when conducting phenomenological research is not that the researcher does not know enough about the phenomenon but rather that the phenomenon might be too familiar. The transcendental phenomenological researcher needs to bracket and question their own biases (Heppner et al., 2016) as they seek to look at the phenomena in a fresh and open way (Moustakas, 1994). If the researcher perceives that they already know the answers, the potential exists that they will block out any information that does not align with what they previously learned. The researcher must listen closely, hoping to glean information they do not yet know or understand. In remaining open while listening to the research participants, the researcher will be able to hear the participants' experience with the phenomenon (Moustakas, 1994). I am the mother of a young adult with autism and have been married for 36 years; hence, I have bracketed out my preconceived notions, thoughts, and feelings by maintaining a journal during my research to recognize any bias or judgment on my part while gaining an understanding of the lived experiences of the study participants (Creswell & Poth, 2018; Moustakas, 1994).

This transcendental phenomenological study was conducted to explore the ongoing challenges to the enduring marriage in the years beyond childhood as their child enters young adulthood and they are faced with new situations even as they were expecting relief from some of their responsibilities. The purpose of this study was to uncover the challenges to the marriage and to learn the coping mechanisms of the couples that helped them sustain their long-term marriage. This study will inform couples, families, and mental health professionals who seek to support these parents and families.

Phenomenological research requires understanding the lived experiences of several study participants who have a phenomenon in common and determining a deep understanding of the components of the phenomenon (Creswell & Poth, 2018). Semi-structured interviews were conducted with long-term married couples who are parenting a young adult with autism to permit observation and discovery of the participants' lived experiences using open-ended questions to encourage the couples to discuss aspects of their experience (Henriksen et al., 2021). Multiple interviews with the participants were anticipated, and the meetings were recorded with the participants' permission and explanation of confidentiality (Creswell & Poth, 2018). The disclosures by the interviewees permitted me to gain insight into the challenges to their enduring marriage and how they were able to maneuver around the difficulties.

Research Questions

Research questions should describe the essence of the phenomenon and not seek to assign meaning or interpretation (Heppner et al., 2016). As such, research questions should be designed as an avenue toward understanding the participants' lived experiences (Heppner et al., 2016). The questions were open-ended (Creswell & Poth, 2018) and were intended to reveal the complex emotions that parents of young adults with autism experience as their child remains under their care during the years that might have been enjoyed as empty nesters, as well as exposing coping mechanisms that have helped them maintain their enduring marriage. I used one central research question and three more specific sub-questions (SQ).

Central Research Question: How do long-term married couples describe their experiences of moving past the challenges of raising a child with ASD only to enter the new realm of challenges of parenting a young adult with ASD with mild to moderate symptoms that require some support?

SQ1: How do long-term married couples describe areas of their marriage that are stressed when parenting a young adult with autism?

SQ2: How do long-term married couples describe the role of religiosity in sustaining their marriage through the difficulties of raising a young adult with autism?

SQ3: How do long-term married couples describe the effects of hope and discouragement in marital discord or marital satisfaction, especially as they relate to concerns about the future of your young adult with autism?

Setting

This study focused on the lived experiences of parents in an enduring marriage who were parenting a young adult with mild to moderate autism. Participants for this phenomenological research study were parents of young adults attending a program in South Florida. The interviews were conducted long-distance, given the proximity of the researcher and the participants, and were held using the Zoom platform.

Participants

A homogeneous group of participants was chosen for this criterion-based phenomenological study. Purposive sampling requires that specific criteria are met during the selection of participants (Padilla-Díaz, 2015), and criterion-based sampling requires that the participants have experienced and are able to describe their lived experiences of the phenomenon (Creswell & Poth, 1998, as cited in Heppner et al., 2016). Heppner et al. expressed that an absolute number of participants in a phenomenological study does not exist; yet it has been suggested that three to 15 participants are sufficient to gain an understanding of the lived experiences shared by a group of similar participants (Creswell & Poth, 1998, as cited in Padilla-Díaz, 2015). The most common method to determine the adequacy of qualitative sample size has

largely been saturation (Guest et al., 2020; Hennink & Kaiser, 2022; Sandelowski, 1995). Data saturation, as described by Fusch and Ness (2015), requires that the data be rich—in other words, intricate and detailed—as well as thick, which suggests accumulating a substantial amount of data. Data saturation is reached when the researcher no longer finds much new information contributing to the research question (Guest et al., 2020). Hennink and Kaiser explained that a small number of interviews is sufficient in a study of a homogenous population that uses a narrow focus (between nine and 17). This study included eight couples who are in an enduring marriage (married more than 18 years), who are parenting a young adult with mild to moderate autism, and who participated in open-ended interviews. The participants were recruited from interested parents who have their young adults enrolled in a program for young adults with autism.

Procedures

Upon completion of my proposal defense, I submitted an application to Liberty University's Institutional Review Board (IRB) and received approval to begin my research (see Appendix A). Once I received approval, I worked with the clinical director of a program for young adults with autism via phone calls and email to explain the study's purpose and recruit the study participants. I sent the clinical director a flyer (see Appendix B) that could be sent to potential study participants. Once the potential participants responded, the couples were sent a participant recruitment letter via email and asked to complete a questionnaire to be certain that they met the criteria, including length of marriage, the age of their young adult with autism, and their ethnicity (see Appendix C). The participant recruitment letter also included a consent form for the participants to review and sign (see Appendix D). The participants who met the criteria were sent a confirmation letter via email, which extended an invitation for the couple to join the

study (see Appendix E). Upon receiving positive responses from the potential participants, I chose eight couples who best met the criterion for the study. I explained that my role would not be as a counselor but rather my role would be to seek information via recorded interviews.

Interview questions (see Appendix F) were created to gain a deep understanding of the challenges, coping skills, and meaning-making of the couples in long-term marriages who were parenting a young adult with autism. The questions were designed to render enough information that I would be able to determine the lived experiences of the study participants, which is the focus of a phenomenological interview (Rubin & Rubin, 2012, as cited in Padilla-Díaz, 2015). Interviewees may answer questions narratively, for example, by making analogies, so the researcher needs to be prepared to seek further information to gain clarity (Bevan, 2014); therefore, the researcher must be adept at managing the interview process (Padilla-Díaz, 2015).

The suspending of the researcher's understanding, or bracketing, is essential for transparency in interpreting the participants' lived experiences (Creswell & Poth, 2018). A journal is a valuable tool to help the researcher later reflect on the recorded thoughts and feelings expressed therein (Vicary et al., 2016). My young adult daughter is autistic, and the years after diagnosis up until this point have greatly affected my life, my husband's life, and our marriage. The challenges we endured during her childhood continue, albeit differently, in these years when we were hoping to become empty nesters. While I know our lived experience and perspective, I was curious to know whether other people in our situation were having similar experiences. To remain conscious of the need to remain neutral as I sought the lived experiences of the study participants, I kept a journal of my feelings and emotions, thereby bracketing any biases or preconceived notions (see Appendix G).

The Researcher's Role

The interest in this phenomenon arose out of my experience of raising a child with autism, which has its own problems regarding the development through the lifespan. However, new complex issues became apparent as my daughter became a young adult. My husband and I are in a long-term marriage, and the experience of hoping for an independent life for our daughter has been met with struggles that have challenged our marriage and relationship with our daughter. I wanted to explore the negative effects of parenting a young adult with autism on a long-term marriage. I hoped to identify how some couples manage the stress, avoid divorce, and potentially grow their relationship through faith and meaning-making of the experience.

Phenomenological research studies a heterogeneous group experiencing an identified phenomenon that interests the researcher, and it requires the researcher to set aside judgments, assumptions, and feelings in pursuit of a fresh perspective (Heppner et al., 2016). A qualitative researcher seeks to identify a phenomenon and systematically disclose the meaning of the lived experience (Van Manen, 2016). Van Manen explained that phenomenology is both systematic and explicit in exposing the phenomenon—systematic in the use of questions, reflections, and intuiting, and explicit because its goal as a human science is to articulate the participants' lived experiences. I contacted the clinical director of a program for young adults with autism and subsequently contacted all the participants via emails, an online survey, phone calls, and Zoom interview meetings. I assumed the role of qualitative researcher using semi-structured interviews, which allowed for an interpretive process of the phenomenon given the descriptive experiences of the participants (Creswell & Poth, 2018). I did not display any reactions of bias or preconceived notions during the interviews and bracketed out my own experiences as I learned of the common experiences shared by the study participants (Creswell & Poth, 2018).

Data Collection

The qualitative researcher is the instrument for data collection (Hayashi et al., 2019; Teherani et al., 2015;). *Constructivist research* is a modality used in qualitative research wherein the researcher educes from the participants their perception of reality (Teherani et al., 2015). The focus of a phenomenological study is to understand the *what* and *how* of the lived experience (Neubauer et al., 2019). Neubauer et al. explained that the first stage of a phenomenological study is to bracket out the researcher's previous knowledge, understanding, and assumption of the phenomenon, and the second stage is to reduce each participant's experience through thoughtful consideration and a construction of their experience is created. The data collected for the second stage was accomplished through interview questions and semi-structured interviews.

Interviews

An interview protocol was established to promote consistency with all participants in each interview (see Appendix G). Before conducting the interviews, I discussed the purpose and procedures of the study, explaining the role of confidentiality and the importance of the participants sharing their experiences honestly and openly. The participants provided written consent to participate in the study and to have the interviews audio- and video-recorded. A transcription company transcribed the interview recordings verbatim, and I noted emerging themes.

Interview Questions

The questions that were asked of the participants are as follows:

Introduction:

1. Where would you like to go on vacation and why? (Icebreaker question.)
2. Please tell me a little about yourself and your family that you would share with someone you are meeting for the first time.

Young Adult with Autism:

3. Tell me about your experience when your young adult graduated high school.
4. Where is your young adult with autism now and what are they doing?
5. Explain your relationship with your young adult with autism.
6. Identify periods of hope and periods of despair that occur when raising your young adult with autism.
7. What are your current top three concerns about the future of your young adult with autism?

Effects on Marriage:

8. Describe how the challenges of raising a young adult with autism affect your marriage.
9. Describe how you anticipated your life would be at this point in your marriage.
10. Describe to me times of turbulence in your marriage that stemmed from raising a child with autism on the way to becoming a young adult with autism.
11. How do you navigate the challenges that are brought into your marriage because of your young adult with autism?

Coping and Success:

12. To what do you attribute the success of your long-term marriage through the challenges of raising a young adult with autism?
13. Please describe how your faith has helped you cope with the challenges of raising a young adult with autism.
14. What advice do you have for parents who have not yet arrived at the stage of young adult for their child with autism?

Conclusion:

15. What would you like to add about parenting your young adult with autism that I might not have covered?

Questions 1 and 2 were intended to help the research participants relax and settle into the interview process as they began to open up about themselves. Questions 3–7 were designed to capture the parents' experiences beyond the years of raising a child with autism. The young adult years bring forth new and different challenges as the young adult and the parents enter a phase wherein levels of independence are anticipated. Questions 8–11 elicited descriptions of the challenges and struggles that the parents might be experiencing given any ongoing involvement they are required to have in their young adult's life. Questions 12–14 allowed the couple to explain the success of their enduring marriage and intended to find a commonality amongst the participants as to how they overcome ongoing stress. The concluding Question 15 permitted me to begin to wrap up the interview while also gaining an understanding of each couple's unique experience by exposing thoughts that the interview questions did not allow them to express.

Data Analysis

The objective of data analysis is to interpret the collected data and search for patterns, themes, and clusters of similar circumstances (Moustakas, 1994). The perceptions that result from going through the data are called *horizons* by Husserl, as he maintained that discovering meaning from one perspective opens another horizon for other perspectives (Moustakas, 1994). Through the process of horizontalization, the researcher recognizes that every perception is important and seeks to find statements of significance experienced by the participants (Creswell & Poth, 2018; Moustakas, 1994). Accordingly, this phenomenological study sought to discover the true meaning of the participants' lived experiences. Interviews were conducted with the

participants using semi-structured questions that helped unveil the couples' experiences.

In phenomenological research, the researcher attempts to set aside personal experiences with the phenomenon and set the focus on the participants in the study (Creswell & Poth, 2018). The process of phenomenological reduction, as described by Moustakas (1994), includes bracketing and horizontalizing, which results in the creation of clusters of meaning. Additionally, statements that are not relevant or that are duplicates and redundant are set aside (Moustakas, 1994). I used a journal to bracket my personal experience and understanding of being in an enduring marriage and parenting a young adult with autism. As such, my perspective was not part of the research, which ensured that the data was not altered, as is a requirement of the concept of epoché (Moustakas, 1994). The transcripts were reviewed multiple times, affording me the opportunity to gain a sense of the whole interview, and I wrote notes in the margins while summarizing the transcripts to help me determine the *what*, *when*, *how*, and *who* during the examination of the material (Creswell & Poth, 2018). Key ideas and short phrases were recorded to serve as a memo trail to aid in the retrieval of the data (Creswell & Poth, 2018). Yin (2016) explained that five analytic phases exist in qualitative research: compiling the data into meaningful order that will serve as a database (i.e., recorded and transcribed interviews), disassembling (coding the data using MAXQDA), reassembling and interpreting the data, and making conclusions based on the entire study. This system-based method of organization allowed me to capture ideas and document the concepts as multiple files, permitting me to identify how these concepts interacted as the project moved along (Creswell & Poth, 2018).

The next stage of data analysis was to code the data into meaningful and identifiable segments (Creswell & Poth, 2018). Qualitative data software (MAXQDA) was used to assist with transcription analysis, coding, and text interpretation. Yin (2016) explained that the use of

computer-assisted qualitative data analysis (CAQDAS) tools allow formal organization of the collected data as the researcher needs to create files for each data record (i.e., file name, date, identifiers). Significant statements were identified and clustered into meaningful themes or patterns devoid of repetition (Creswell & Poth, 2018). Yin specified the identification of patterns as part of the reassembling process and explained that the researcher must consistently question and analyze the data in search of patterns. Textural descriptions of what the participants experienced can include verbatim examples, and structural descriptions of how they experienced the phenomenon were written to gain a contextual understanding (Creswell & Poth, 2018). Additionally, as Moustakas (1994) advised, I journaled about my experience of parenting a young adult with autism and how this situation has influenced our long-term marriage. The textural and structural descriptions were compiled into a composite description to capture the essence of the experience of long-term married partners who are parenting a young adult with autism; this step serves as the pinnacle of a phenomenological study (Creswell & Poth, 2018).

Trustworthiness

Qualitative rigor, or trustworthiness, can be challenging for qualitative researchers given that the data that is collected is not based on exact precision (Cypress, 2017). Qualitative research requires consistency in transparent research practices, data analysis, and conclusions wherein the researcher does not manipulate the phenomenon of interest (Cypress, 2017). Lincoln and Guba (1985) purported that trustworthiness is accomplished by utilizing the concepts of credibility, transferability, dependability, and conformability (as cited in Adler, 2022). Adler (2022) further asserted the importance of transparency explaining the research methods used, which includes reflexivity and triangulation. Creswell and Poth (2018) explained that engaging in reflexivity allows the researcher to disclose their experience, biases, and prejudices;

triangulation is the process of cross-checking the research to ensure accuracy (Adler, 2022). In this study, I was able to achieve triangulation by coding and corroborating the data into different themes (Creswell & Poth, 2018). The trustworthiness of this research was accomplished by being mindful of the rigor of qualitative research which requires reliability and validity of clear, consistent, and accurate data. The interviews were all consistently conducted by me via Zoom.

Credibility

To achieve credibility in a qualitative study, the researcher ought to expose their experience and verify the data with the study participants. This requires the researcher to remain engaged in the research, use strong observation rituals, and maintain an audit trail (Cope, 2013). Member checking verifies the credibility of the findings of the gathered data by having the participants play the crucial role of judging the accuracy of the interpretations of the rough drafts of the researcher's work (Creswell & Poth, 2018).

Transferability

The data collected in a qualitative research study should be relevant to individuals not directly involved in the study (Cope, 2013), and other researchers should find consistent results when conducting their own research (Hayashi et al., 2019). Transferability relates to the trustworthiness or rigor in assessing qualitative research (Adler, 2022) when considering its applicability to other settings (Cope, 2013). The clear and detailed description of the context of this study (Hayashi et al., 2019) should help inform other studies of the experience of couples who are in an enduring marriage who are parenting a young adult with autism.

Dependability and Confirmability

An audit trail allows the researcher to review the process by which they came to their final findings (Creswell & Poth, 2018). The log of information contained in an audit trail will

explain the small steps that led to the analysis of the whole study (Creswell & Poth, 2018). This tracking document enables the researcher to outline key descriptions of the details that emerge (Creswell & Poth, 2018) and helps to make decisions about the dependability of the study findings across later studies that might be conducted (Cope, 2013).

The conformability of the study is achieved by the researcher recognizing the biases, values, and experiences accompanying them in their research (Creswell & Poth, 2018). Reflexivity involves the researcher discussing their experience with the phenomenon and how those experiences contribute to their interpretation of the phenomenon (Creswell & Poth, 2018). The exercise of reviewing the researcher's biases, values, and experiences aids in bringing an awareness of how the researcher's experiences may contribute to the study's findings, conclusions, and interpretations (Creswell & Poth, 2018). I kept a journal and recorded my observations during the interviews, including descriptive quotes from the participants that contributed to the themes emerging in the study (Cope, 2013).

Ethical Considerations

This study was guided by the standards of the IRB at Liberty University, and a review was completed before assessing the participants to ensure that the three principles of ethics were met (Creswell & Poth, 2018). I was mindful of extending respect for the participants in the study and ensuring their confidentiality and privacy while also communicating that participation was voluntary and informing them of their right to withdraw from the study (Creswell & Poth, 2018). To ensure the display of concern for the welfare of the study participants, I did not place the participants in any potential risk that would put them in harm's way (Creswell & Poth, 2018). All participants were treated justly, fairly, and equitably during recruitment and throughout the study. The data collected was protected per the guidelines of the IRB, and materials were stored

using appropriate security measures. The names of the participants were masked, and pseudonyms were assigned to adhere to privacy and confidentiality regulations. All recorded data was stored on my laptop, which is password-protected, and any files containing recorded data were kept in a password-protected file on my laptop. In addition, the data was saved to a flash drive and kept secure in a locked drawer where audio recordings and any other study documents were also stored and protected. Careful consideration was given to the proper storage of the data collected, and the suggestion by the APA 2010 that the data and materials must be stored securely for five years will be followed (Creswell & Poth, 2018).

Chapter Three Summary

This transcendental phenomenological study investigated the lived experiences of couples in an enduring marriage who are parenting a young adult with autism. Eight couples who participated in semi-structured interviews were recruited for this study. As a phenomenological researcher, I kept a journal to fulfill my role as a research participant. The data that was collected from the participants in the study sought to expose themes among long-term married couples who are parenting a young adult with autism. Once the interviews and transcriptions were completed and the transcriptions were reviewed several times, they were coded utilizing MAXQDA, enabling themes and patterns to emerge. The transcripts were emailed to the study participants for their perusal to ensure the validity and accuracy of the data. Priority was given to the trustworthiness of this study, including credibility, transferability, dependability, and conformity, as well as protecting the privacy of the study participants and mindful storage of the data collected.

The current study allowed the participants to share their experiences of the effect on their enduring marriage of parenting a young adult with autism. The guidelines regarding the

involvement and protection of human subjects that were established by the Liberty University IRB were followed, and the researcher safeguarded the respect and privacy of the study participants. The research provided the opportunity for the readers to understand and identify the phenomenon as it pertained to the participants, which may inform stakeholders and aid in further research of this population.

CHAPTER FOUR: FINDINGS

Overview

The purpose of this transcendental phenomenological study was to gain an understanding of the lived experiences of couples in an enduring marriage who are parenting a young adult with autism. Qualitative research aims to understand meaning and analyze data that is collected via words and observations (Adler, 2022). Qualitative research tools include interviews and questions, which are created and analyzed in a manner free from preconceived notions and bias and seek to bracket out common responses (Martirano, 2016).

This qualitative study used a phenomenological approach to describe the experiences of eight long-term married couples and to give voice to the experiences of both mothers and fathers of young adults with ASD. The data was collected from participants through semi-structured interviews and was then coded and clustered, resulting in meaningful themes.

The chapter begins by introducing the eight couples and then discusses the results of the data analysis. The focus is on analyzing the research data and identifying significant findings. The chapter concludes by explaining how themes were developed, discusses how the research questions were addressed, and provides a chapter summary.

Participants

Sixteen individuals, or eight couples, participated in this study. The couples were each assigned alphanumeric characters that identified them as C1, C2, C3, C4, C5, C6, C7, and C8. To identify the individuals, they were assigned a pseudonym to protect their confidentiality. For example, C1 indicates Couple One; C1-H refers to Couple One Husband; and C1-W refers to Couple One Wife. The succeeding couples were all assigned pseudonyms that followed the same

pattern. The participants are long-term married couples who are parenting a young adult with ASD.

This section will present a group description that will identify the participants' similarities and is then followed by individual portraits of the participants. Transcendental phenomenological study requires the researcher to suspend their own judgment or subjectivity, yet interacting with participants directly can challenge their ability to remain objective. As such, a research journal was maintained (see Appendix H) to disclose any potential effects of my experience and perspective as the research process unfolded and themes became apparent.

After receiving IRB approval on February 2, 2024, the search for participants commenced immediately and concluded on May 17, 2024. The clinical director of a program in Florida was contacted to obtain the names of participants for the study. It became apparent that the process was ponderous and inefficient, and a request to change the methodology for recruitment was sent to the IRB on March 28, 2024, with approval for the modification granted on April 10, 2024. The modification permitted the recruitment of participants utilizing broader referrals of couples who met the study criteria. The first interview occurred on March 28, 2024, and the final couple was interviewed on May 19, 2024. Table 1 describes the couples' ages, the years each couple has been married, and the age and gender of their young adult with autism.

Once the potential participants came forward, they were sent a prescreening questionnaire (see Appendix C). They were determined to meet the criteria for the study, which included being in a long-term marriage of at least 18 years and parenting their young adult with ASD (aged between 18 and 35). Upon receipt of signed consent forms, the participants were contacted via email to arrange a virtual interview wherein both individuals in the couple would be present, and they were sent a link to attend a Teams meeting once a date had been agreed upon. At the start of

the interview, the participants were informed that the researcher would be an information gatherer and would not be serving in the capacity of a therapist or a counselor. Further, the participants were informed that the interviews would be recorded and transcribed for the purpose of the study but would be held in strictest confidence.

Table 1

Demographic Characteristics of the Participants

Participants	Ages	Years Married	Age of Young Adult	Gender of Young Adult
Couple 1	60 (W), 61 (H)	35	24	M
Couple 2	58 (W), 60 (H)	39	30	M
Couple 3	58 (W), 59 (H)	32	29	M
Couple 4	57 (W), 60 (H)	32	24	M
Couple 5	46 (W), 47 (H)	29	22	F
Couple 6	67 (W), 71 (H)	28	23	M
Couple 7	65 (W), 67 (H)	38	31	M
Couple 8	50 (W), 48 (H)	25	23	F

Note. (W) denotes the wife and (H) denotes the husband

The Group

Table 1 identifies the participants' commonalities and individualities. The 16 individuals included 15 who identified as White and one who identified as Asian American/Pacific Islander. The youngest couple was aged 46 and 47, and the oldest couple was 67 and 71 years. The least number of years married was Couple 8, who was married for 25 years, and the longest marriage was Couple 2, who was married for 39 years. The ages of the young adults with autism ranged between 22 and 31 years of age. Six of the young adults with ASD were male, and two were

female. Six of the couples were obtained from a program in Florida for young adults with autism, and the remaining two couples were obtained through personal acquaintances of the researcher who knew of couples with young adults with autism. The participants appeared to have varying socioeconomic statuses.

The data gathered revealed that all these couples are highly involved in their autistic young adults' lives. Six of the young adults with autism are living on their own, with support from a program in Florida, though two of the couples expect their young adult with autism to return home at some point. The two couples who participated that are outside of that program have their young adult with autism living with them. One couple has purchased a condominium for their young adult with autism, who will remain living in Florida, and another couple anticipates moving their young adult with autism back to their home state but securing an apartment outside of the couple's home.

Couple Portraits

The following portraits of the couples describe the participants based on information garnered from their interviews.

Couple 1

The couple is 60 and 61 years old and has been married for 35 years. Both C1-W and C1-H were engaged in answering the questions and comfortable sharing their story. Both C1-H and C1-W are physicians, with C1-H still working full-time and C1-W working part-time until the pandemic. The couple has two sons, with their oldest son recently getting married. Their second son is a young adult with autism.

Couple 1-W describes their autistic young adult son as “a super complicated kid from day one,” which C1-H defines as “problems with emotional lability.” Their son attended a wilderness

camp therapeutic boarding school for his last years of high school, and it was there, at the age of 17, that he was diagnosed with autism. Couple 1-H discussed the late diagnosis of their son by explaining:

Fairly quickly at wilderness the counselor there said, I don't want to scare you, but have you ever thought that [your son] could be on the autism spectrum? And actually, we had, C1-W had. [Our son] has had professionals since he was three or four and C1-W had actually asked several times and people were like, oh no, he makes good eye contact and stuff like that. But I think now if he would be 5 years old, I think people might think different.

Their young adult with ASD is currently living in an apartment and attending an adult transitional program in Florida, away from his family. Couple 1-W and C1-H sent him to this program in the hopes that he would gain vocational education, though they have “come to realize that he is not likely to be fully, gainfully employed full-time for the rest of his life.” Still, they want him to find part-time employment to secure some income and for the “satisfaction and feeling like you're contributing,” which would help his self-esteem. Thus far, he has “not made a lot of progress towards that point.”

The couple attributed the success of their marriage to choosing well. While C1-W indicated that she had to carry a lot of the burden, she maintains that she and her husband were aligned, and they both acknowledge that their lives have been enriched by having their young adult autistic son. At this stage in their lives, C1-W believes that at 60, most people “have had stuff happen to them in life that was not what they thought would be.” Their relationship with their young adult son with ASD is “pretty good,” but they recognize that given financial constraints, they will not be able to keep him in the program for the long term, and that he will be

coming back to live near family, which will “be a layer of stress again.” They feel “lucky” to have been able to afford to send their young adult with ASD to a program, but also know that their hopes of retiring at 65 years of age “is not going to happen” due to the expense.

Both C1-W and C1-H were brought up in homes where their parents were in long-term marriages and stated that they are pragmatic in their marriage. They do not expect marriage to be “glamorous,” and they “realize that you’re just going through things as a team.” While each of them might irritate the other, the important thing to do is to minimize the irritants while recognizing that “you never get rid of them.”

Couple 2

The couple is 58 and 60 years of age and has been married for 39 years. Couple 2-H indicated that he had told C2-W that she could do most of the talking, but he was actively involved in the conversation once the interview was underway. C2-H became emotional on two separate occasions. The couple share two sons aged 30 and 28; their young adult with ASD is the oldest, and their younger son is a minister. Couple 2-H has semi-retired but still works as a researcher for a large university, while C2-W was a nurse but opted to become a stay-at-home mother when she had children.

Couple 2-W homeschooled her children after her young adult with ASD finished kindergarten, and at the end of his senior year, he began taking college classes. Couple 2-W recognized that her autistic young adult son’s unhappiness was “disrupting our entire family dynamic,” and he was sent to an inpatient life skills program for people with substance abuse. Although he did not have substance issues, he needed mental health support at the facility. The couple’s young adult son with ASD has a comorbid diagnosis of childhood onset bipolar which heightened his anxiety. Although he was quite anxious when he first left home, he lives in an

apartment and attends a supported living program in Florida, away from his family. He has been there for five years, and the couple indicate he has made “astounding progress.” He completed a four-year degree online and works full-time at an insurance company doing data entry.

Couple 2-W stated that “from the beginning of our marriage, I just insisted that we talk about things,” and credits their communication as helping them endure the challenges related to their young adult son with ASD. The past 5 years have gone from “heartbreaking,” to their young adult son now thanking them for everything they have done for him with genuine appreciation. The autistic young adult son now expresses, “I really think y’all raised me really well,” and no longer sees them as “overbearing” people. The couple feels “fortunate to be married to the right person,” and C2-W says, in speaking for C2-H as well, that “neither one of us would ever see divorce as an option.”

The couple’s parents were in marriages that spanned more than 60 years. The couple feels fortunate to be united in their thinking and is “on the same page” even as frustrations arise, as any other couple might experience. They acknowledge that “the problems that are out there are not about each of us as an individual,” and just view problems as things to work through. Couple 2-W explained, “We very seldom have a difference of opinion that we can’t resolve or come to some kind of compromise.”

Couple 3

The couple is 58 and 59 years of age and has been married for 32 years. C3-W and C3-H were open about the challenges they experienced as individuals and as a couple. The couple shares two sons, ages 29 and 27; their young adult with ASD is their older son, and their younger son is a lawyer. Couple 3-H is still a full-time practicing attorney, and C3-W has retired from her part-time career in healthcare consulting.

Couple 3-H described his young adult son with ASD as being keenly aware of what his peers are doing, which propelled him to go to college. However, his experience in college was challenging, given his inability to complete his schoolwork and his lack of interest in “making any connections at school.” Couple 3-W indicated that even with tutors from the special education disability department at the college, when her autistic young adult son received an assignment, “he just is frozen” and “doesn’t know where to start to break it up into small pieces.” Ultimately, they placed their son in a program in Florida where he has met success and has nearly finished his undergraduate degree with the help of tutors. C3-H explained that his son with ASD would like to continue his education and “get his MBA because that is where he has seen success is in school,” but his parents want him to find a job that is suitable for him at this point. Couple 3-H indicated that he bought a condominium for his son to live in away from home, and they gave him a car.

The couple recognized that family therapy has shifted the dynamic and explained, “Our energy is changing, which is helping his energy to change.” They fear this next transition will be difficult as their young adult son with ASD graduates from college and are grateful that they are able to provide for their son. They “wonder what families do who don’t have the resources.” Couple 3-H stated, “executive function issues are real,” and “it’s not something that you can grit your teeth and work through.”

Both sets of parents of the couple are in long-term marriages and have seen very few divorces. Couple 3-W explained, “In Indian culture, you get married to a stranger that you don’t know in an arranged marriage, and the philosophy is that you’re starting from zero, so you have nowhere to go but up.” Couple 3-H noted they “have this genuine love and affection for each other,” and “you have to go through stresses, and you have to deal with them.”

Couple 4

The couple is 57 and 60 years old and has been married for 32 years. Couple 4-W and Couple 4-H were enthusiastic about their 24-year-old autistic son, especially about his social life. They also have another son who is 22 years old. Couple 4-H is employed full-time in the banking industry, and C4-W has been a stay-at-home mother.

Their young adult son with ASD graduated from high school and attended a transitional post-secondary program in Ohio, which C4-W explained has a “curriculum around self-advocacy, building independence, managing your life, your schedule, your needs and also audit actual college classes.” He lived away from home in an apartment for 2 years, though he visited his parents regularly. Thus, they “made him move home.” Their autistic young adult works full-time for a company that provides valets for car dealerships, which C4-W explained is great for him because he is very social. The job provides him with “a lot of interaction with people.” However, C4-W recognized this is “not a job he can make a career out of.” C4-H noted, “That’s the problem with autistic kids, they’re usually underemployed.”

Couple 4-H discussed the ongoing challenges with parenting a young adult with autism and “certain things that you think that he will have learned by now . . . you have to keep reminding him or stay after him.” Further, C4-H explained, “I’m against the clock on how do we get him to some degree of independence.” The couple’s autistic young adult son wants to move out of state, but the couple stated that economically, they are not able to support him.

The couple has parents in long-term marriages, with C4-H’s mother having passed away when he was 18; his father remarried and remained so until he passed away. Couple 4-W stated that she and her husband have a “good ying and yang” with their emotions, and C4-H indicated that they have “stayed together all these years” because “they have talked through these different

things.” Couple 4-H credited C4-W as the “one who has been so supportive” of their young adult son with ASD and “finding out all these different things and just being the glue that kind of keeps all of this together.”

Couple 5

The couple is 46 and 47 years old and has been married for 29 years. They met in middle school and have been together ever since. The couple share five children, ages 16 to 28, and their middle daughter, aged 22, is their young adult with ASD. Couple 5-H works full-time as a certified financial planner, and C5-W has been a stay-at-home mother. Couple 5-W was sometimes hesitant to speak, often deferring to her husband.

The young adult daughter with ASD did not earn her high school diploma, but the school district “needed to continue to provide her with an education” as she was under the school’s umbrella until she was 22 years old. The couple found a program in Florida that supports young adults with autism, and the school district paid the tuition until their young adult daughter with ASD turned 22 in April 2024. The couple has been paying the rent for their autistic young adult daughter and is currently paying tuition, but they intend to bring her home and secure an apartment 35–40 minutes away from their home in the next few months. Their young adult daughter with ASD has not been successful in maintaining a job and is currently unemployed. Couple 5-H noted, “jobs are hard for her . . . it has to be the right fit with the management team that really understands her needs.”

Couple 5-H identified that at this point in the life of their young adult daughter with ASD, they have recognized over the last year or two that they “just can’t correct her anymore. There’s not going to be a time when we say something where now [I] get it, and [I] don’t have autism, or [I] don’t have those issues.” Further, he noted that they “have to allow those mistakes

to happen . . . and then deal with the consequences.” Still, their marriage has rarely been under duress, and in those moments when “it’s a lot of stress and pressure for something that’s happened . . . we just go back and forth on what the decision is. . . . and we tend to come to some type of agreement.”

The couple is the product of parents in enduring marriages, and C5-H indicates that he is as close to C5-W’s parents as he is to his own, given that they have always treated him as their son. Couple 5-W explained that her husband is “the brain that organizes and takes care of and plans for” and that she is “the heart, the hippie . . . just everybody love each other and find everybody’s sparkle.” Couple 5-H noted that during times of heightened emotions, C5-W will suggest they take a break and revisit the conversation later. Couple 5-W acknowledged the need to remember everything she loves about C5-H and to forgive “each other’s weak moments” and that while their marriage “is not perfect, it’s pretty near perfect.”

Couple 6

The couple is 67 and 71 years old and has been married for 28 years. They were married later in life, and they have one son, who was conceived via IVF. This son is a young adult with ASD, and he is 23 years old. Couple 6-H is still working, while C6-W has recently retired. Couple 6-W is stressed about their son, and C6-H recognizes that C6-W shoulders much of the burden. Couple 6-W became emotional several times during the interview as she expressed the amount of worry she experiences about her son.

The couple’s young adult son with autism struggled in high school, dropping out in ninth grade. He was diagnosed with autism at 15 years of age, as well as being oppositional. The school district where the couple resided supported them in finding a therapeutic boarding school where the structured environment allowed him to graduate from high school. He tried a

specialized transitional program in Massachusetts, but purposely got himself kicked out. C6-W explained, “He had learned over the years certain behaviors to do to get what he wanted.” The couple then tried a program in New York, but they “kind of found the kids were a little less functioning” than their young adult son with ASD, and he was “kicked out of there a couple of months later.” The couple found the transitional program in Florida, where he currently attends, but he “didn’t last long” on his first attempt. He was home for a few months but has settled into the program and has been there for about a year. He still maintains his manipulative behavior, which currently disrupts his ability to keep a job as he will stay in bed and claim “my alarm clock didn’t go off.”

The young adult son with ASD receives monthly Social Security disability payments from which he pays his rent, but the couple pays for the program. Couple 6-H noted that while they live a comfortable lifestyle, “the reason I’m not retired is because of the expense of this place.” Couple 6-H explained that their young adult son with ASD is “very dependent” on C6-W to the point where C6-W indicated she “is losing her hair with all the stress,” and C6-H noted their autistic young adult son’s behavior “is turning her stomach inside out” and that “every time he spends a day in bed it’s gut wrenching for her.”

Couple 6-W expressed that she has had some resentment due to her husband working full-time and the amount of time she has spent searching for “places for [her son] to go.” Couple 6-H affirmed that C6-W did “everything that we just talked about finding resources, coordinating, dealing with the doctors, finding these programs, dealing with health forms.” Moreover, while C6-W is no longer working, she continues to do the same thing for her young adult autistic son and worries that he “may need to be in a supportive environment the rest of his life.” Still, C6-W claimed, “I couldn’t do this myself. I love him dearly. I waited a long time; I

was 40 when I married him.” Couple 6-W continued, “We’ve had fights, but in the end, I love him.”

Couple 7

The couple is 65 and 67 years old and has been married for 38 years. Couple 7 has two children: a daughter who is 28, and a 31-year-old son with ASD. Couple 7-H is an entrepreneur still working and enjoying his career; C7-W was a physician assistant until their daughter was born, at which point her son began having some issues. Couple 7-W decided to stay home with their children after their son’s diagnosis; she has been committed to researching all avenues to aid in the support of their son.

The couple’s young adult son was diagnosed with autism when he was a teenager “because he just didn’t fit any of the diagnostic boxes.” Upon graduation from high school, their autistic son “expected to go to college because that’s what people do.” He attended a life program in South Carolina where he attended college classes with some accommodations, lived in a dorm, and experienced normal college life. However, during his second year, he had a conflict with the new director and was asked to leave the program. After much research and work with a consultant, they found a transitional living program in Florida where he has done well. He works three mornings a week on an assembly line and volunteers at a food bank three afternoons a week. Couple 7-H gave most of the credit to C7-W for their autistic young adult son’s success and acknowledged that he played a small part and that they have “dealt with it as a couple.” Further, C7-H indicated the “need to recognize that it’s really a family team effort” and that he is “willing to acquiesce to [C7-W’s] better judgment given her success rate.”

The transitional living program in Florida has had a profound impact on the couple’s autistic young adult son’s social life in that “he has, for the first time in his life, a real circle of

friends.” Couple 7-W indicated that being a student at the program “cannot go on forever” and that their young adult autistic son will have to leave Florida and come back home and “assimilate into a life here.” Couple 7-W believes that leaving his friends will make it a difficult transition as they regularly get together on an ongoing basis.

Couple 7-W’s parents were married for 40 years until her father died suddenly; her mother never remarried. Couple 7-H’s parents divorced when he was five, but both parents remarried and had successful long-term second marriages. Couple 7-H recognized that parenting a young adult son with autism is a “sensitive topic . . . and you go into it knowing you are on uneven terrain to begin with.” Additionally, “it’s a little bit of a marriage minefield and you need to go into every conversation knowing that this is a difficult situation.” Couple 7-W noted, “When there’s a problem, we just try to talk about it. We don’t yell and we’re not arguers . . . we get mad at each other and then we just try to talk it out.”

Couple 8

The couple is 48 and 50 years old and has been married for 25 years. Couple 8 has three children; their oldest is a 25-year-old son who is married with two small children; their youngest son is 21 years old and lives independently for the time but anticipates moving back home. Their daughter is their young adult with autism, and she is 23 years of age. Couple 8-H retired from the Marine Corps. C8-H has found a second career as a certified instructor in a shooting club, and C8-W works in banking.

The couple’s young adult daughter was diagnosed with ASD when she was 6 years old. She attended school through 10th grade but did not graduate from high school per her parents’ decision. Couple 8-W explained that when they moved to South Carolina, their daughter, who also has epilepsy, had a difficult time. They were unable to “match her with the right teacher,”

which led to her being “so stressed out going to school” that she was “a nightmare” when she came home. The couple recognized that she was not “diploma bound” and the situation was exhausting for C8-W who had had enough and said, “I can’t do this anymore, I’m not fighting this. Let’s pull her out of school.” Currently, their young adult daughter with ASD is living at home and is unemployed. However, she has been showing an interest in getting a job. The couple has completed paperwork with the Department of Disability for South Carolina, and once she is accepted, they will see if there is a program where “perhaps she could get a diploma.”

Couple 8-W recently changed her career to work banker’s hours, allowing her to spend more time with her young adult daughter with autism. Couple 8-H recognized the importance of getting their young adult daughter with ASD life skills that will “set her up for independence.” The couple’s young adult daughter with autism has shown a recent interest in cooking, and C8-W instructs her to make a list of ingredients and holds her accountable if something is not on the list. Couple 8-W indicated that their autistic young adult daughter is showing interest in things that would offer “a little bit more independence for her.”

Couple 8-H stated that his parents are in an enduring marriage; C8-W’s mother was divorced three times, and she “told my mother that I was not going to make the same mistakes that she made.” However, C8-W indicated, “I was raised in an environment where you have to just understand that we’re all different and it’s okay to be different, and it’s okay to not like each other every day as long as you love each other.” Couple 8-W mentioned that tolerance and acceptance are important attributes, and C8-H noted, “it’s a team effort overall.”

Descriptive Interview Data

As explained in Chapter 3, bracketing is essential for transparency in interpreting the participants’ lived experiences (Creswell & Poth, 2018). The researcher’s voice is thus silenced,

which allows the participant's voices to be highlighted (Moustakas, 1994). This qualitative study collected data using open-ended questions during face-to-face (virtual) semi-structured interviews, during which the researcher served as the research instrument and sole interviewer. As shown in Table 2, the interviews with eight couples (16 participants) produced 500 minutes of audio and visual recordings, with the mean length of interviews being 62.5 minutes. The transcribed interviews generated 192 pages. The average number of transcribed pages per interview was 24.

Table 2

Descriptive Interview Data

Interview	Duration (minutes)	Transcript Pages (single-spaced)
Couple 1	48	18
Couple 2	53	22
Couple 3	66	27
Couple 4	82	25
Couple 5	54	18
Couple 6	70	34
Couple 7	82	28
Couple 8	45	20
Total Data Collection	500 minutes	192 pages

Note. This table represents the length of each couple's interview, resulting in 192 pages of data from 500 minutes of video-audio recordings.

Results

The results of this qualitative research study are presented in this section. The purpose of this transcendental phenomenological study was to learn about how long-term married couples are challenged by parenting a young adult with autism while still being able to maintain and grow their own relationships. The findings from the participant interviews resulted in four themes among the long-term married couples.

Theme Development

This qualitative study required the researcher to become immersed in the interview transcripts to discover recurring shared experiences. Descriptive codes were created that correspond to thoughts and ideas expressed by the participants during the interviews. A code is the interpretation of the data by the researcher, including interview transcripts, that assigns meaning to all data, ultimately resulting in pattern detection and themes (Saldaña, 2021). Codes created and revised by the researcher provide the ability to move between data collection and extensive data analysis (Saldaña, 2021). Themes were established as short phrases capturing the participants' thoughts expressed during the interviews.

The interviews were conducted using Teams virtual conferencing. The interview recordings were then imported to MAXQDA, and transcripts were generated. The transcripts were reviewed by the researcher and then forwarded to the participants for member checking. Repetitive review of the transcripts permitted the researcher to gain a deep appreciation of the data collected. Descriptors were formulated and assigned to the various characteristic verbiage of the transcriptions. They included stress, finances, hope, despair, marriage positives, marriage negatives, faith, siblings, the young adult with ASD, mother, future of young adult with ASD, and the parents' parents' marriages. Qualitative research requires the researcher to set aside their

own biases; this allows the researcher to keep an open mind and wade through the uncertainty that accompanies not knowing what concepts will emerge (Holton & Walsh, 2017). As a first pass effort, structural coding enabled the coding of the data in accordance with the research questions, after which segments that were similarly coded were grouped for further coding and analysis (Saldaña, 2021). Coding is a repetitive process insofar as the successive coding cycles will help to synthesize the qualitative data, resulting in pattern recognition (Saldaña, 2021). Axial coding is meant to identify which codes best represent the themes and helps eliminate codes that are not as relevant (Saldaña, 2021).

Memoing permitted the comparison of comments made by the couples to recognize emerging patterns. As discussed in Chapter Three, significant statements were identified and clustered together into nonrepetitive themes (Creswell & Poth, 2018). A thematic data analysis was performed using the assistive software MAXQDA and hand-coding. The coded content was grouped into color-coded categories according to excerpts from the interview transcripts. After thorough reviews of the transcripts and satisfaction that the color-coded categories described the lived experiences of the participants, the researcher determined that saturation had been met. The four themes of the effect on long-term marriages of parenting a young adult with autism were developed. The themes were then aligned with the sub-research questions as follows: Themes 1 and 2 were assigned to Sub-Question One, Theme 3 was assigned to Sub-Question Two, and Theme 4 was assigned to Sub-Question Three. The four themes are illustrated in Table 3.

Table 3

Thematic Descriptors

Theme No.	Theme	Descriptors	Participants
1	The participants experienced stress given status, future worry and financial	1, 2, 8, 9, 11	All participants

Theme No.	Theme	Descriptors	Participants
	burden of parenting a young adult with ASD.		
2	The participants recognized that parenting a young adult with ASD can be turbulent even as they acknowledge growth of their autistic young adult.	3, 4	All participants
3	The participants' upbringing and spirituality contribute to their experience in a long-term marriage.	7, 12	All participants
4	The long-term marriage is unified despite the challenges associated with parenting a young adult with ASD.	5, 6, 10	All participants

Note. An illustration of the four themes that were developed based on data analysis and coding and identification of participant involvement in each of the themes.

Central Research Question

The Central Research Question of this study asked, "How do long-term married couples describe their experiences of moving past the challenges of raising a child with ASD only to enter the new realm of challenges of parenting a young adult with ASD with mild to moderate symptoms that require some support?"

Couples in enduring marriages recognize challenges as they attempt to move from raising a child with ASD to parenting a young adult with ASD. The participants expressed concern about their autistic young adult's lack of viable employment and an inability to be self-sufficient, while disclosing the economic impact that this has on the participants' household. However, they have grown in their capacity to appreciate small advances in the trajectory of their young adult with ASD and remain committed to their enduring marriages by revering good communication, expressing love and respect, adhering to spiritual guidance, and remaining aware of their own

upbringing as it relates to the marriage.

Sub-Question One

How do long-term married couples describe areas of their marriage that are stressed when parenting a young adult with autism?

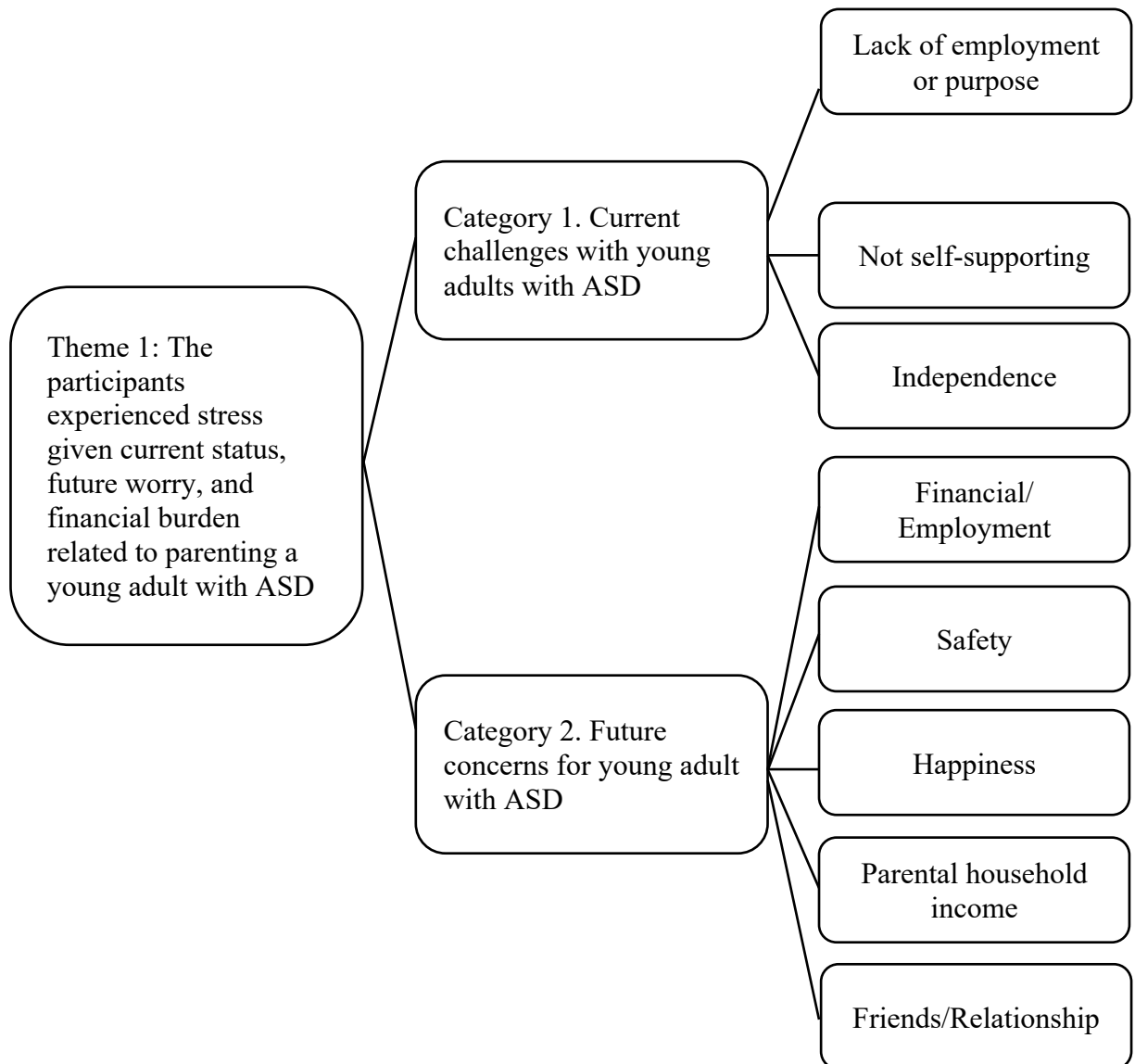
Long-term married couples explain that the stress they feel is multi-layered, and many state that it is ever-changing. In Theme 1, the participants experienced stress given the status of their young adults with autism, especially given that none of these young adults are self-supporting and the current employment of the two young adults with ASD who work full-time does not yield wages that would enable independence. Additionally, the participants noted the presence of worry about the future of their young adults with autism because of the lack of ability to support themselves and who would care for them when the parents were no longer able. The participants discussed the financial burden related to parenting a young adult with ASD, whether past, present, or future expenses. In Theme 2, the participants described the turbulence that they experienced while parenting a young adult with autism and further discussed ways that they could see the challenges. Even as the stress is still palpable, the participants can describe ways that they can alleviate stress and appreciate the little advancements of their young adults with ASD.

Theme 1. The participants experienced stress given the status of their young adults with autism, future worry, and the financial burden of parenting a young adult with ASD. Two categories were created that helped to develop Theme 1. Category 1 describes the parents' concerns regarding what their young adult with ASD is doing now and the financial burden that they endure due to the ongoing support and the monetary impact they experience while parenting their autistic young adult. Category 2 identifies concerns for young adults with ASD as they

anticipate what the future might hold regarding levels of independence, long-term relationships, and, ultimately, happiness. The codes and categories that contributed to the development of Theme 1 are shown in Figure 1.

Figure 1

Codes and Categories in Development of Theme 1



Note. This figure illustrates the development of Theme 1 using axial categories and codes. Two categories and seven codes contributed to the development of the theme.

Category 1. Current challenges with young adults with ASD. This category includes three codes: Lack of employment or purpose, not self-supporting, and parental household income. In Category 1, the challenges presented to these long-term married couples who are parenting a young adult with ASD are described. Of all the autistic young adults of the participants, only two are employed full-time: C2 stated that their young adult with ASD has a full-time job in data entry (since December 2023); another young adult with ASD is employed full-time as a valet for a car dealership, although C4 explained that their young adult with ASD does not make a wage that would support his independence. Two of the other six young adults with ASD have menial part-time jobs for a few hours a week and volunteer for a few hours at local charities. The other four young adults with ASD are not employed, although C3 indicated that their young adult with ASD is in college and finishing his four-year degree this fall (however, the next steps have not been determined). Couple 2-W, whose son has earned his undergraduate degree and is employed full-time, still expressed:

His challenges pose a financial burden that we wouldn't otherwise have. We have to plan more carefully and limit the things we would like to do. A lot of thinking about the future and how can we be sure things are in place for when we're no longer here.

Couple 3 differed on their opinions of next steps for their autistic young adult. Couple 3-H has had a fulfilling and consuming career and has been able to provide a condominium and a car for his son; yet his concern is that his autistic son will not be able to find purpose if he cannot find gainful employment upon graduation from college. Couple 3-W would like their son to work in a grocery store in a routine-oriented position, but C3-H does not agree that their son would want to do that sort of work. Consequently, they are contemplating whether their son

should continue in school, where he has known success, and perhaps earn a Master of Arts degree in business administration. Couple 1-H concurred about the other benefits of working:

I think we've come to realize that he's not likely to be fully gainfully employed full-time for the rest of his life. But we are hoping that he could at least be part-time employed because of the value . . . there's just so much other than money, you know, the satisfaction and feeling like you are contributing and social interactions.

All of the young adults with autism in this study are reliant on their parents for financial support. Six of the young adults with ASD attend a program in Florida for which the parents pay the tuition and living expenses for their young adult with ASD, and two of the young adults with ASD live at home. Table 4 illustrates the status of the participants' autistic young adults, none of whom have a solid next-step plan.

Table 4

Participants' Current Status of Young Adult with ASD

Couple	Age of Young Adult with ASD	Current Status
Couple 1	24	Attends program in FL, not employed, expected to return to home state at some point
Couple 2	30	Attends program in FL, earned undergraduate degree, works full-time in data entry, parents supplement program expenses and living expenses
Couple 3	29	Attends program in FL, parents purchased condominium, will earn undergraduate in Fall 2024, not employed
Couple 4	24	Lives at home, works full-time as valet for car dealership
Couple 5	22	Attends program in FL, not employed, will return to home state and parents will pay for apartment

Couple	Age of Young Adult with ASD	Current Status
Couple 6	23	Attends program in FL, employed few hours a week
Couple 7	31	Attends program in FL, employed few hours a week, expected to return home at some point.
Couple 8	23	Lives at home, unemployed

Note. An illustration of the status of where the participant's young adults with ASD are living. The program in Florida provides therapy, tutoring, mentoring, support with understanding how to pay bills, vocational assistance, and social activities. The cost of tuition is à la carte based on how much support each young adult with ASD requires.

Couple 1-H stated:

I always wanted to retire at 65, and that's not going to happen. The programs are extremely expensive. We haven't had to borrow money to do it, but lately we haven't been able to save very much either. And then there's the concern about what happens after we're gone.

Couple 6-H explained that the program in Florida helped his son get a part-time job which will help him become accustomed to showing up at work, but stated, "It's a place that gives him employment that we pay for him to get this job." In addition to paying for him to have this job, Couple 6-H explained frustration because, "His attendance is not good there. He will have episodes where he'll just stay in bed all day." The couple's young adult with ASD "does not respond well to discipline" and C6-W said, "You can hear my frustration. I don't know what to do with him." This is especially challenging for Couple 6 given that C6-H explained, "We are

not wealthy.” C6-H continues to work at the age of 71 because of the expenses associated with parenting his young adult son with ASD, and they are unable to travel as they would like to do, given the financial commitment to the program.

Couple 4 stated that their young adult son with ASD would like to move from Ohio to live in Florida, yet C4-W reflected on the time he lived away from home in Ohio saying that he “came home every other weekend.” In addition to a genuine concern of the loneliness their autistic young adult would experience, the couple has told him, “You need to have something that’s going to support you when you move down to Florida, and you need to prove it up here.” Couple 6 advised him that his current job as a valet does not provide the income for self-sufficiency. They explained that their young adult son with ASD would like to have a job with the airlines, but they asserted that he “needs to take a test” that requires “90% accuracy” and that’s not likely to happen. Furthermore, C4-H does not believe that a job as a gate agent would be suitable because they “deal with a lot of situations and you have to think fast on your feet and pivot when you get a fairly irate passenger.” Couple 4 acknowledged the difficulties of their son relocating to Florida but their young adult son with ASD perceived that they were telling him, “I can’t live my dream.”

Couple 5 has had their daughter at the program in Florida since September 2023. She has timed-out on the support that she got from her school district, which had been paying the tuition until April 2024. Couple 5 is paying for a few extra months of tuition plus living expenses until, Couple 5-H explained, their young adult daughter with ASD will move into an “apartment up probably 35–40 minutes north of where we are” with the intention that she will “get some services through Department of Developmental Services, which we’ve been working with for probably 2 to 3 years. And then she’ll kind of live on her own, hopefully, and get a little job. We

will supplement the apartment.” Couple 5-W noted that during her time in the program in Florida, “She’s never been real successful in finding a job.”

Couple 7-W indicated that their young adult son with ASD has done well at the program in Florida, but she explained, “I do feel that it would benefit him to [be] pushed vocationally a little bit more than he gets pushed.” Couple 7 intends to bring their son back home where he would initially live in the family home. The couple anticipates that their young adult son with autism will eventually “have his own condo or something, located within walking distance, or being able to access services that are required so that he can be somewhat independent.” Couple 7 discussed their autistic young adult having difficulty when something goes wrong in his mind, and he calls C7-W stating, “I am miserable, I am depressed.” While it doesn’t happen often, and C7-W can “talk him down from his emotional” outburst, she said that when it happens, she is “despairing” and cannot sleep that night. Couple 6-W, who lives near to the program that her autistic son attends in Florida, noted that she drive to will pick her son up to take him to a medical appointment rather than pay for an Uber given the expense; yet, she said that seeing him once a week is “too much” and “it’s not great for him because he becomes dependent on me.” Couple 8 discussed that their autistic young adult daughter is “just basically staying at home” while they are awaiting completion of paperwork that has been submitted to the Department of Disability and hoping that she can enter a program that will get her a diploma where she will be able to “gain life skills” and training that will “set her up for independence.”

Category 2. Future concerns for young adults with ASD. In Category 1, the challenges expressed were in relation to the participants’ current concerns and financial burdens around their young adult with autism. Category 2 discusses the concerns that the participants have about the future for their autistic young adult, with financial concerns overlapping in both categories.

There is concern about the social lives of their young adults with autism, notably friends and long-term relationships, as well as becoming involved in relationships that are not healthy due to the vulnerability of young adults with ASD.

The participants' concerns were palpable as they discussed the outlook for their young adults with autism, especially because of the current uncertainty, given that none of the participants' autistic young adults are independent, nor looking to be independent soon. Couple 2-H indicated, "We want our son to be able to maintain or grow in any way that he can and just be happy. We're not looking for him to become what he's not able to." A concern of C2-W is not only that her young adult son would have relationships in the future, but she also expressed concern regarding his vulnerability given difficulties with social cues, "A third concern that I would say is just I worry about his long-term relationships, like getting into the wrong romantic interest." Couple 3-H noted his concerns were "That he's able to become independent, in terms of getting a job, that if something were to happen to us, how would it be for him? And his health."

Couple 4-H expressed a significant worry about his son when he said, "My greatest fear is when we're not around and he is older and truly on his own and he is not able to make a sustainable income and he's homeless." Couple 4-W indicated that she has assured C4-H that their autistic young adult will not be homeless, but stated the concerns that stress her were "a financial future, financial independence, a job, friends, and family." Couple 7-H recognized that C7-W and he will transition their young adult son with ASD out of the program that he has been attending, and stated his area of stressful concerns were, "That he is able to live independently, number one. Happily, and safely. We're very hopeful that he can at least have some semblance of independence without living in the kind of cocoon of a program." To give appropriate weight

to all the participants' comments regarding their ability to overcome stress by looking for the positives, see Table 5 for excerpts from the remainder of the participants' interviews.

Table 5

Participant Concerns About Future of Young Adult with ASD

Couple	Participant	Excerpt from Interview
Couple 1	C1-W	"I think it is just his ability to stay in a safe living environment and have a community that is not isolated and have health care. We aren't going to live forever, and then what happens to [her son]? That makes me sad."
Couple 5	C5-H	"Development of friendships and long-lasting real relationships."
	C5-W	"I'm nervous about her interpersonal skills. I am nervous about that because she's not going to be under the umbrella of school. She's going to be in the real world, and I don't know what that looks like."
Couple 6	C6-W	"When we say to him we're old, we're not going to be here forever. He doesn't get that."
	C6-H	"There's two aspects of that. One is taking care of himself. And then there's the financial aspect of that."
Couple 8	C8-W	"I want her to have interaction on a daily basis. Maybe if she has a friend. That she has life skills . . . setting her up for independence."

Note. These excerpts from participant interview transcripts show that most couples cited similar concerns of the future of their young adults with ASD.

The participants agree about their concerns for the future of their autistic young adults regarding future independence, the ability to have financial wherewithal to support themselves, friendships and/or relationships, and their ultimate happiness. Most of the couples interviewed currently have their young adults with autism in a program that is away from home. Three of those families anticipate transitioning their autistic young adults back home, which also poses a

concern for them. Couple 1-W stated, “We have been able to afford to do this thing and it’s been worth it. But you know, in another year or two, whenever we make the decision that he’s coming back, then it’ll be a layer of stress again.” Couple 7-W identified the tremendous friendships that her young adult son with ASD has made in the program and explained this causes some concern as they anticipate his next steps:

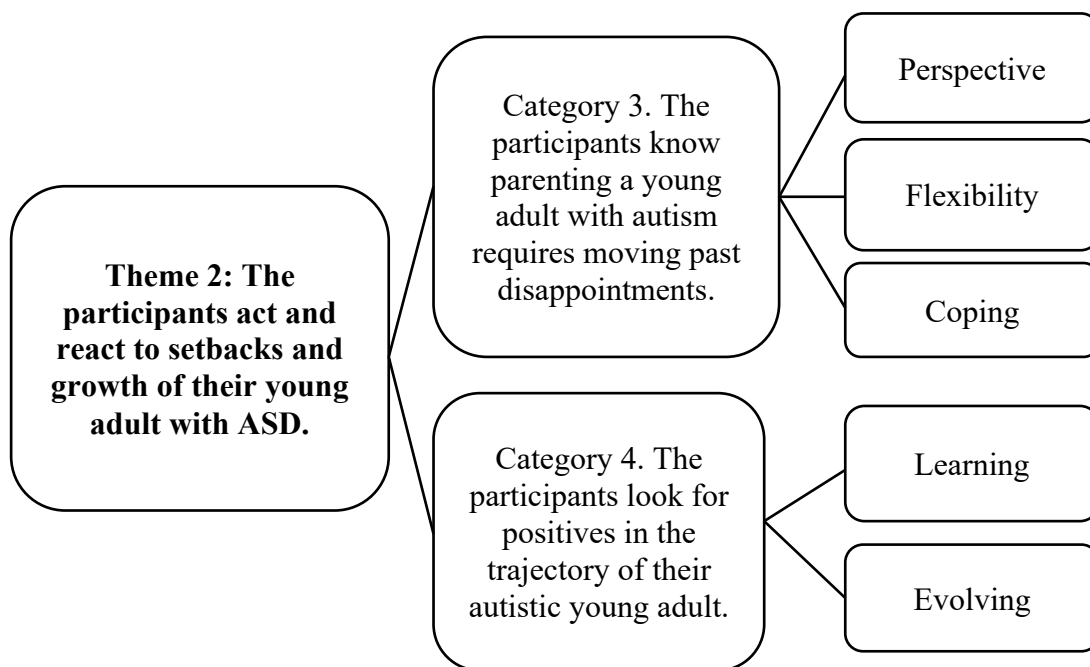
He has a group of friends that engage on an ongoing basis with activities, and they call each other, and they get together and go over to each other’s apartments. I think that’s probably going to be the most difficult part of his transition is leaving that environment where he has, for the first time in his life, a real circle of friends.

Several couples expressed concerns about the impact of the autistic member on their other children and the worry of those children being responsible for the autistic family member once the parents are no longer able to care for their young adult with ASD. Couple 5-W explained, “I’m still surprised at the baggage that our other children carry because of the years of what it was like when [her daughter] was home. That hasn’t gone away for many of them.” Couple 7-W indicated, “I am concerned about our daughter having to deal with that part of [her son’s] life.” Couple 4 discussed their son caring for their young adult with autism, with C4-H indicating it would be a “burden,” and C4-W noting, “It’s a burden, but he will in a pinch. But we have enough family and friends that know our fears and that’s why we are in the process of making sure that whatever is all set up.”

Summary of Theme 1. In Theme 1, the participants explained the stress that accompanies parenting a young adult with ASD. Two categories contributed to the development of Theme 1. In Category 1, the participants’ current challenges with their young adult with autism were described. The participants explained the difficulties that they experience due to the

financial burden associated with parenting a young adult with autism, whether their own current financial struggles or concern about the future finances of their young adult with ASD. Some of the participants discussed their inability to retire because of the expense of caring for their young adult with autism. The participants described their concern about the lack of self-sufficiency for their young adult with ASD and wonder how the lack of a sense of purpose will affect their young adult with ASD. Category 2 described the participants' concerns for the future of their young adults with ASD. The participants nearly mutually agreed across each of the identified codes (independence, financial/employment, safety, happiness, friends/relationships) as they all anticipate the uncertain future of their young adults with ASD.

Theme Two. The participants act and react to setbacks and growth of their young adult with ASD. The participants recognized that parenting a young adult with ASD can be turbulent even as they acknowledge growth of their autistic young adult. The codes and categories that were used to develop Theme 2 are shown in Figure 2.

Figure 2*Codes and Categories in Development of Theme 2*

Note. This figure illustrates the development of Theme 2 using axial categories and codes. Two categories and five codes contributed to the development of the theme.

Category 3: The participants know that parenting a young adult with autism requires moving past disappointments. The codes that are relevant to this category include perspective, flexibility, and coping. Long-term married couples understand that parenting a young adult with autism is stressful due to the adjustments that are made to help their autistic young adult be successful in their endeavors. Additionally, the participants acknowledged that they do not have all the answers. This category supports the notion that parenting a young adult with autism swings between times of pessimism and optimism, requiring fluidity to move between the two ends of the spectrum.

Couple 1-W described the stress when their young adult son with ASD was at home, “It felt like we were walking on eggshells all the time because he was going to explode.” On the

upside, C1-W further indicated that having their autistic young adult in a program away from home, “shields us from that sort of day to day up and downness.” While Couple 1 autistic young adult son has not “made headway in supporting himself . . . he has made headway in life skills . . . he can cook, he can shop, he can do his clothes.” While C1-W said, “It’s very easy for me to find moments of hope, but they get dashed,” she still has the perspective, “There’s something about being 60, like most people by the time they hit this age, have had stuff happen to them in life that was not what they thought would be.”

Couple 1-W and Couple 5-H mentioned that parenting a young adult with autism is like being on a roller coaster, and Couple 2-W also used the same symbolism, “It’s like a roller coaster . . . I will say, somehow, we’re usually not both at the bottom at the same time. If one of us is feeling pretty low, the other one is maybe okay at that moment. So far.” Couple 2-W continued by explaining:

I think probably the lowest time maybe would have been right before [her son] left home. And I just felt like I can’t do this anymore. I just can’t. I can’t have this unhappy, miserable kid in my house anymore. And that made me feel so guilty to even have that feeling. It’s my child and I love him . . . It was disrupting our entire family dynamic. I didn’t know how to help him.

Their son has been enrolled in a program in Florida for the last 5 years, has earned a four-year degree, and is employed full-time. C2-H indicated that their young adult son with ASD recently told him and his wife:

‘Thank you and mom for everything you have done for me.’ So, there’s an appreciation there that’s genuine. That really helps a lot. Looking back, it helps you to realize whatever we invested financially, even for right now, it’s been well worth it.

Couple 8 have their young adult autistic daughter living in their home, and she has never attended a program away from home. Couple 8-W noted that some days she just cannot deal with her young adult daughter with ASD, and that she is “tired of the battles.” Couple 8-H discussed, “Every day it’s something a little bit different” and that they have adopted an attitude of “improvise, adapt and overcome, and you choose and pick your battles.” C8-W said, “I usually just walk away.” Still, Couple 8-W shared the perspective:

Never give up because it actually does get better. It’s easier now, as challenging as it is with her as an adult, it’s still easier than when she was in elementary school and middle school and high school. It’s rewarding; it’s like everything that I’ve learned having her. I was never a patient person and having her has taught me a lot of patience.

Another aspect of moving past disappointments incumbent upon parenting a young adult with ASD is to be flexible in expectations in the trajectory of achievement. Couple 3 enrolled their young adult son with autism in college right after high school. C3-W explained, “Since everybody else in high school was going to college, he wanted to go.” However, C3-W noted:

He missed his small group of friends from high school, he had no interest whatsoever in making any connections at school. And on top of that, he found the schoolwork to be very difficult. So, we’re paying for credits, but he’s getting zero credits.

Couple 3 enrolled their son in a program in Florida for young adults with autism, and C-3W advised, “Now he is living with a roommate. He’s learning different things. He’s driving. He’s almost done with his undergraduate degree.” The program tried to determine why their young adult son with ASD was having difficulties with school, and originally enrolled him in one class. Couple 3-W explained, “Once they figured it out, he did really well. He’s got straight As, but he does lean on the tutors” at the program. Their young adult with ASD will earn his undergraduate

degree this fall.

The young adult with ASD of Couple 4 also wanted to go to college after high school because everyone else was going to college. Couple 4 enrolled their young adult son with ASD in a local college program that was oriented toward transitioning high school students with intellectual or developmental disabilities, allowing them to engage in college academics and social activities. However, Couple 4 realized that the cost was greater than what their autistic young adult son was getting out of the program. C4-W noted, “We were paying full tuition but not getting a degree, it was only a certificate.” Couple 4-W continued, “C4-H is very numbers-oriented, and he had a real hard time paying that. I was very emotional; I knew it was definitely more for the social.” Couple 8 compromised and decided to have their autistic young adult son move back home and attend the program for one more year. C4-H said, “He was able to maximize what he could get out of it. There was a point of diminishing returns.”

Couple 8-H discussed the “constant regurgitation” in support of C8-W who stated, “Sometimes I feel like I’m raising the child all over again. Brush your teeth, take a bath, wash your hair, put deodorant on, clean your clothes, clean up your room,” and noted that C8-W has learned that she cannot “do soft-parenting with her.” When her daughter is being manipulative, C8-W is “almost like a drill instructor. Nope. Not happening.” Couple 5-H also mentioned still raising versus parenting their young adult daughter with ASD, “Did you brush your teeth this week? Did you take a shower this month?” Couple 8-H said:

I think we’ve recognized this, which has been hard for us over the last year or two, where you just can’t correct her anymore. And so, we have to kind of now allow those mistakes to happen and for things to happen and then deal with the consequences of those things. Couple 8-H further advised, “You have to be flexible. There’s ups and downs daily. It’s never

the same. And it's never fixed. It's never just like, oh, okay, we're done. You're always going to be addressing issues." Couple 3-H mentioned, "I was always of the view, push him and he'll work hard and that'll give him some resilience. And of course, I was wrong . . . He thinks a little bit differently. That's what makes him interesting in my mind." Couple 7-W discussed the "cyclical" nature of life as she said, "there'll be bad times, but they'll get better. You just have to wait it out . . . bad things never last unless they're absolutely, horrendously bad."

Category 4: The participants look for positives in the trajectory of their autistic young adult. While the journey of their young adult with autism may be fraught with challenges, the participants noted the progress that their young adults with autism have made. The codes that accompany this category are learning and evolving. Each couple noted the positives of the current success that their young adult with ASD is experiencing.

The participants explained that the progress of any trajectory for their young adults with ASD is not quick, nor does it follow a well-defined plan. However, the participants were all able to find positives even as stressed as they have been parenting their young adults with autism. Couple 2-H discussed their young adult son, "He wanted to get better. He wanted to feel differently. He wanted to be successful . . . It wasn't like this happened over a few days. But looking back . . . it's just hard to believe how things worked out." Couple 4-H noted:

You can tell he's on the spectrum, but he's able to function, he's able to communicate, every year he gets a little bit better about certain things. So, my hope is that if he can land the right type of job opportunity, I think he can be productive . . . It's been a slow march. Not always linear, but it's been progress throughout his life.

Couple 7-H reflected that his son "has always exceeded expectations. You know, defying the experts who predicted he would be performing at a much lower level The highlight for me

is that I'm just proud of him" while C7-W affirmed those sentiments as she said, "I'm so proud of him and every accomplishment that he makes that's positive and growth-inducing, growth-indicating. He continues to grow and learn and develop and become more and more able to discern and analyze." To give appropriate weight to all the participants' comments regarding their ability to overcome stress by looking for the positives, Table 6 contains excerpts from the remainder of the participants' interviews.

Table 6

Participants Overcome Stress by Focusing on Trajectory of Young Adult with ASD

Couple	Participant	Excerpt from Interview
Couple 1	C1-H	"He can cook. He can shop. He can do his clothes. And he is better emotionally than he was."
	C1-W	"When he comes home, the family's like, oh my God, [her son] is great. So, I think right now, the way our life is right now, this is exactly as we would have predicted."
Couple 3	C3-W	"We're learning as much as he is, and we're changing our energy . . . which is helping his energy to change. And I am hopeful that he will become independent and be happy."
	C3-H	"I'm impressed by the way [my son] is always looking forward as to what he's going to do next. And he thinks it's all going to work out."
Couple 5	C5-H	"The independence that she got [at the program] was really a game changer for her We are hundreds of miles away. Try to figure it out, talk to us. We'll walk you through it. But you are going to have to manage. And she really has."
	C5-W	"Everybody was scared to death when she was coming home for the first time. It went so well that the next time, little nervous, and then the last time we didn't even think about it . . . it was beautiful."

Couple	Participant	Excerpt from Interview
Couple 6	C6-H	“We described all this; we didn’t describe him. He’s not that bad. All the things we just said makes it sound like he’s a horrible person. He’s not. He’s actually a pleasant kid.”
Couple 8	C8-W	“And now she’s talking about wanting to do things that are showing a little bit more independence for her. She started to take an interest in cooking and looking up recipes and trying to figure out what she can make next. She’s talking about wanting to have a job where in the past she didn’t want to have a job.”

Note. These excerpts from participant interview transcripts show the couples are united in expressing optimism for the trajectory of their autistic young adult.

Summary of Theme 2. In Theme 2, the couples explain that disappointments are inevitable when parenting a young adult with autism. However, they express that they have learned to progress through the challenges and can state optimism as they recognize growth. Two categories contributed to the development of Theme 2. In Category 3, the participants’ application of perspective, flexibility, and coping were described. The participants spoke about the complications that they have endured as they have transitioned to parenting a young adult with ASD, and how they were able to gain an attitude of fluidity regarding expectations. The parents have also demonstrated their ability to adjust their thinking and behaviors in managing their young adults with ASD. In Category 4, the participants expressed positive statements about the progress of their young adults with ASD. The positive statements ranged from finding something to celebrate about their autistic young adult’s behavior, to their ability to be somewhat self-sufficient, to exceeding expectations, and to showing indications of continued growth. Collectively, the parents have identified that by adjusting their expectations of their young adults with autism, they have been able to recognize at least a modicum of success that their young adults with ASD are experiencing. This permits the participants to alleviate some of the stress in

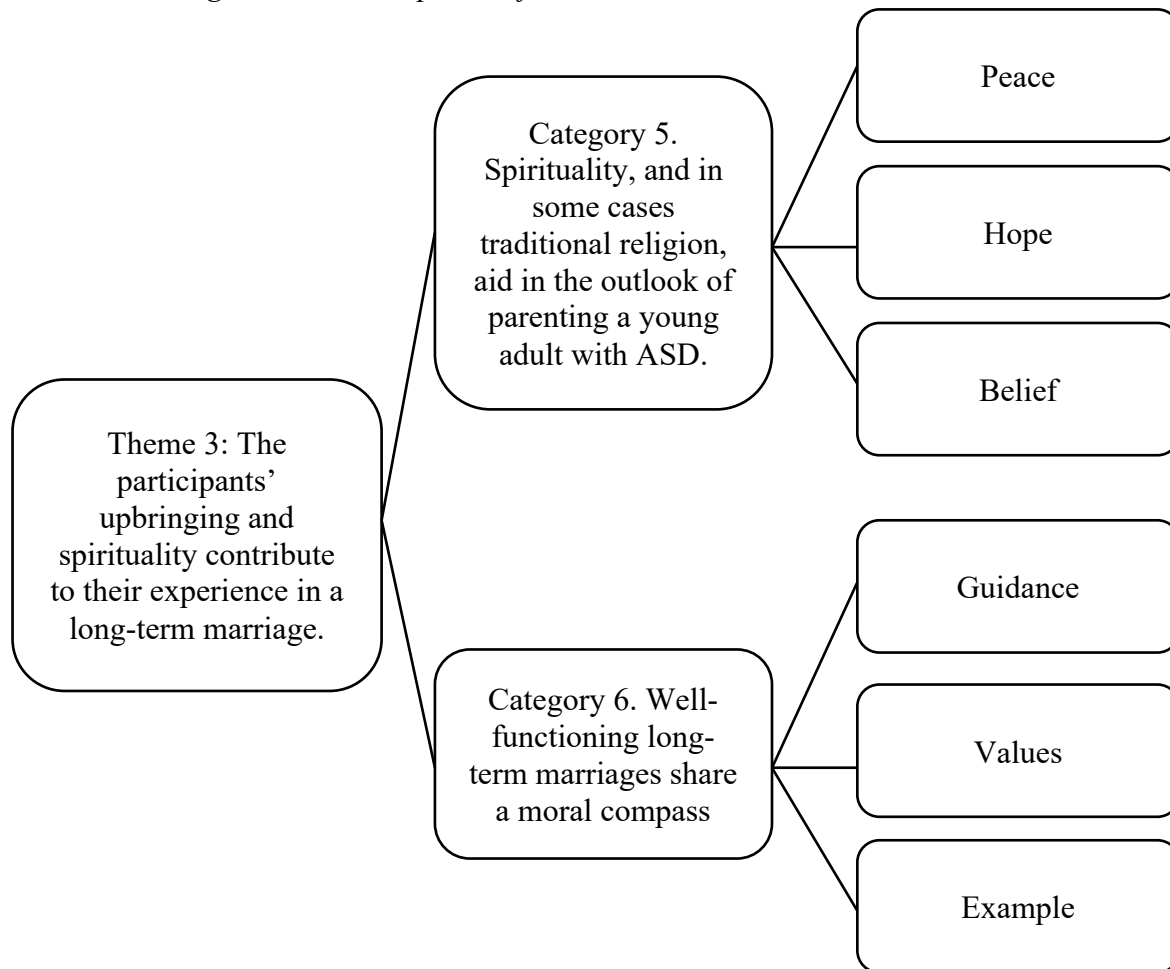
the moment that is associated with parenting a young adult with autism.

Sub-Question Two

How do long-term married couples describe the role of religiosity in sustaining their marriage through the difficulties of parenting a young adult with autism?

Long-term married couples explained that spirituality is a part of their lives, whether traditional religious affiliations or spiritual guidance, and recognized that faith was sustaining during challenging times. The participants noted that aside from religion, the role models of their parents' marriages provided a foundation that allowed them to sustain their marriage.

Theme 3: The participants' upbringing and spirituality contribute to their experience in a long-term marriage. Two categories were created that helped to develop Theme 3. Category 5 describes that well-functioning long-term marriages of couples who are parenting a young adult with autism revere spirituality in their lives. Category 6 describes that upbringing contributed to long-term marriages. The codes and categories used to develop Theme 3 are shown in Figure 3.

Figure 3*Codes and Categories in Development of Theme 3*

Note. This figure illustrates the development of Theme 3 using axial categories and codes. Two categories and six codes contributed to the development of the theme.

Category 5. Spirituality—and in some cases traditional religion—aims in the outlook of parenting a young adult with autism. This category has three codes: peace, hope, and belief. The participants identified areas where faith helped them cope with parenting a young adult with autism. In this category, the participants explain the role of spirituality and religion as it pertains to their marriage and parenting a young adult with autism.

Most of the couples noted that although they have a religious affiliation or are led

spiritually, they are not regular attendees of religious services. The statement that was affirmed by the couples was the belief or faith that they had in their marriage and in one another, as well as the example that their parents set for them. Table 7 outlines the historical religious affiliations of the participants in terms of how they were raised.

Table 7

Participant Religious Affiliations

Couple	Participant	Religious Affiliation
Couple 1	C1-H; C1-W	Catholic; Disciples of Christ
Couple 2	C2-H and C2-W	New Testament Ministries
Couple 3	C3-H and C3-W	Catholic
Couple 4	C4-H and C4-W	Catholic
Couple 5	C5-H; C5-W	Catholic; Protestant
Couple 6	C6-H and C6-W	Jewish
Couple 7	C7-H; C7-W	Lutheran; No affiliation
Couple 8	C8-H and C8-W	Catholic

The couples all spoke about their religious affiliations regarding the home in which they were raised. Whether or not the couples are attending religious services at this point in their lives, they all regard God or spiritual guidance as relevant. Couple 1-H indicated, “A lot of my faith is sort of internal and praying . . . I pray a lot” and noted, “There have been bumps in the road, but not between us.” Couple 2 has a son who is a minister and are active believers. Couple 2-W said:

I think our faith is really the most important thing in our lives, individually and collectively. I give God a lot of credit in this. Every time that I didn’t know what to do,

there's somehow been an answer, and I don't take that for granted.

Couple 2-H furthered the conversation:

That statement right there carries a lot of weight, and it is not a whole lot more that can be said. We've been through some pretty dark times . . . but there has been a light that came. Sometimes we couldn't see it at the end of the tunnel, but somehow things would open up.

Couple 3-H explained that C3-W and he were both raised in the Catholic religion which C3-H reported helped to "shape their morals and values," and he further stated, "Life is more than about you, the whole idea of selflessness, service to others . . . and to have this hopefulness." Couple 3-W reported that the Catholic faith "has a structure to it which I definitely needed," and advised that "it has an impact on staying together." Couple 4-W has recently begun to attend Catholic church again. C4-W noted, "Going to church makes me feel better after I go." Couple 4-H recognized faith as "an inner thing" that "gives me some peace around some things" and that "prayer has been an important thing."

Couple 5, despite their Protestant and Catholic upbringing, have both pulled away from any religious affiliation, yet recognize the importance of forgiveness and treating each other kindly and with respect. Couple 5-W explains, "We follow these bands that are all about just peace, love, togetherness, unity, and kind of that has taken the religion for me." Regarding parenting her young adult daughter with ASD, C5-W stated, "I feel like the way that I've found peace in all of this is realizing that there is no God." She reflected that "it's not me not praying enough, or not doing enough on my end for her healing." Couple 5-W found "relief to know that this is just life," and to be "free of all of that and just realize it's about our hard work." Couple 5-H released his Catholic faith years ago as he recognized "It doesn't make sense to me anymore

and I have kind of grown out of it.” He further reported:

I had to let that religion go in order to be a better father and in order to understand the trials and tribulations that [his daughter] was going through. I had to let it go and I’m glad that I did. I still have a lot of peace around letting that go.

Couple 5-W continued:

The way it’s presented to me in biblical form just doesn’t make sense to me. I just feel like the judgmental side, that’s not who I am as a person . . . I can’t believe God would be that way . . . I’m just human and I gave birth to you guys . . . I would never want to see harm come to you. So how could an all-loving God that created us want something like that?

Couple 6-H advised that C6-W and he were raised in “conservative Jewish families with strong religious background,” and that they have not been attending synagogue but are looking to become involved in synagogue again, as they have recently moved to a new state. Couple 6-W acknowledged that she prays, but that she does not believe that faith “has really made a difference.” Couple 7-H was “brought up as a confirmed Lutheran” but does not attribute religion as playing a huge part in parenting a young adult with autism.” Couple 7-W advised that she is “not a religious person, but I consider myself a spiritual person. I meditate and when I feel the need for spiritual guidance.” Couple 7-H concurred as he stated. “Spiritual awareness has been helpful.” He noted the importance of religion and faith, but that “If going to church made you a Christian, then being in a garage made you a car.”

Couple 8 were both raised Catholic, and C8-W said (and C8-H affirmed), “I’m Christian and I believe in everything that I’ve been brought up to believe in. And that’s the foundation of everything . . . And we know at the core of everything in our life, that it’s God.” As a military

family, Couple 8 also explained that they follow the Marine Corps motto, “God, family, country.”

Category 6. Well-functioning long-term marriages share a moral compass. This category has codes of guidance, values, and example. The participants recognized their upbringing as an important contributing factor because they had role models in their parents’ long-term marriages, which contributed to their staying together through the challenges of parenting a young adult with autism.

Of note is that of the 16 participants, 14 people are the product of long-term marriages for their parents. Couple 1 discussed friends who have divorced, but C1-H suggested that perhaps their ability to overcome difficulties “comes from our parents . . . I feel like our marriage is like my parents’ and her parents’ marriage.” Couple 1-W explained that they do not keep their wedding vows “top of mind,” yet C1-H stated, “It’s sort of like breathing.” Couple 1-W continued, “There’s like literally no concept of anything else,” to which C1-H affirmed, “Anything other than death do us part.” Couple 1-H discussed that keeping divorce “in your back pocket as an option . . . maybe that makes it easier not to stay.” Couple 2 shared that C2-H’s parents are married for 64 years and that C2-W’s parents were married for about that long when C2-W’s father passed away. C2-H acknowledged that both sets of parents were role models and that he “appreciated their influence.” Couple 3-W reported that both sets of parents were in long-term marriages and that as a couple, “they have seen very few divorces,” even as she disclosed “we’ve had some ongoing stressors that a lot of people would have gotten divorced over.”

Couple 4 has parents who maintained long-term marriages, with the mother of C4-H having passed away when he was 18 years of age and his father remarrying and remaining so until he passed away. Couple 4-W stated, “Our values, the things that we want . . . We are sort of

oriented together . . . and just trying to keep our compass straight.” Couple 5 discussed their parents’ marriages at the outset of the interview insofar as C5-H and C5-W began dating in middle school. Couple 5-H noted that C5-W’s parents are “really . . . like a mother and father to me.” Couple 5-W said, “My parents, they were just best friends and such an example of what love and marriage is supposed to look like” while C5-H stated, “I had a mom, dad, I had one sister, good family upbringing . . . and they are still in their house, still involved in our family.”

Couple 6 has parents who were in long-term marriages, and C6-W recognized that she replicated her mother in that they both married and became mothers after the age of 40. Though she noted that her mother stayed married, she believed that she was not happy, and said, “It was hard for her. I never really spoke to my mother about that because it wasn’t done back then.”

Couple 7-W indicated that her parents were married for 40 years when her father died, and her mother never remarried; C7-H explained that his parents divorced when he was about 5 years old, but they both remarried and “have very successful long-term marriages with wonderful people . . . I am equally as close with my stepparents as I was with my biological parents . . . that’s pretty significant.” Couple 8-H’s parents are in a long-term marriage. The mother of C8-W was divorced three times, and she “told my mother that I was not going to make the same mistakes that she made.”

Summary of Theme 3. In Theme 3, the couples explain that religion or spirituality are a part of their lives, but they are experienced differently for each couple, ranging from couples who express that God is at the helm of everything, to couples who seek spiritual guidance through prayer and meditation, to one couple opting to become atheists as they cannot imagine a God who would allow harm to their young adult autistic daughter (yet they still honor the act of forgiveness and seek unity and peace as elements to be embraced). The couples have witnessed

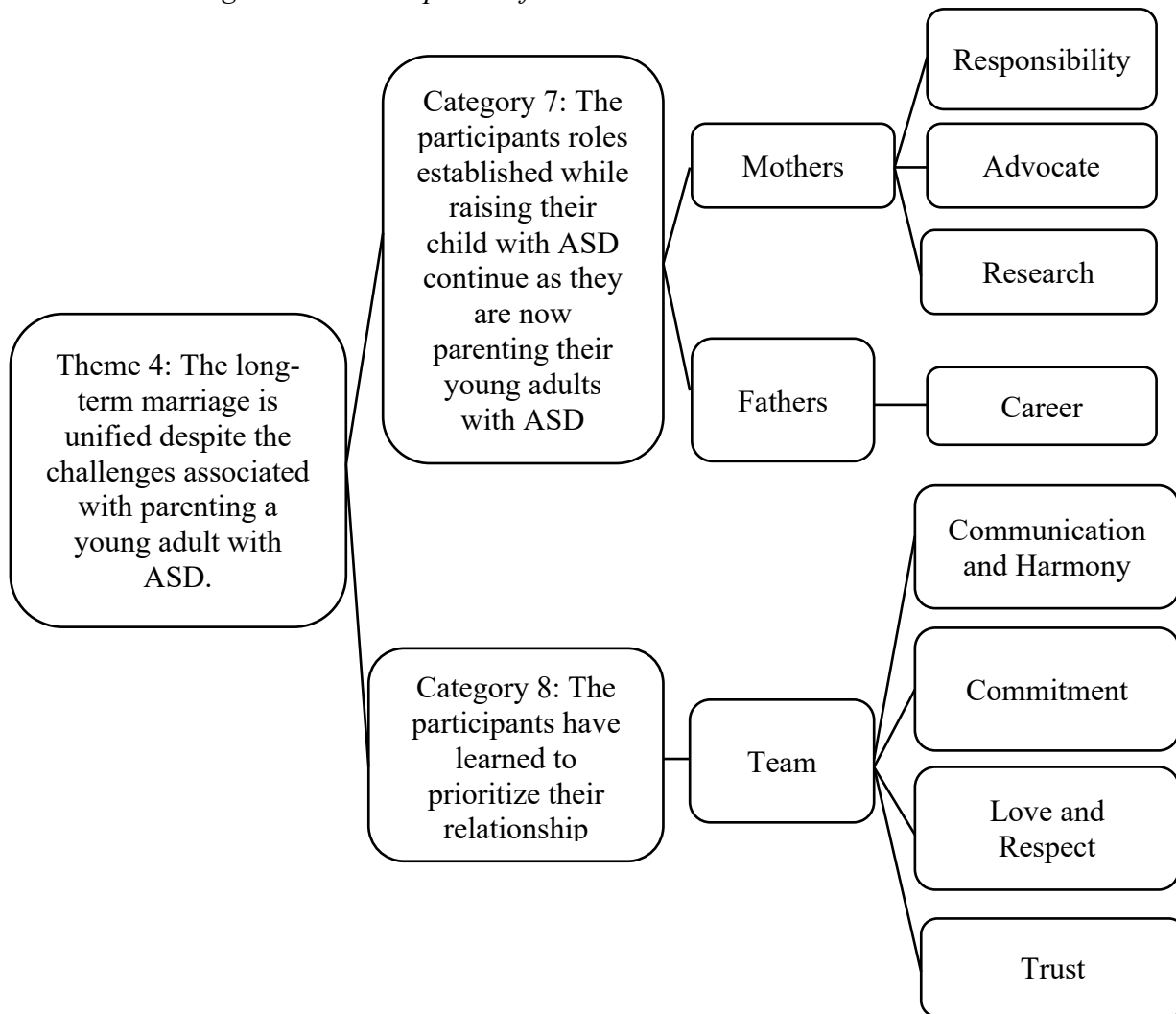
the success of their parents' long-term marriages, with two people experiencing successful remarriages of their parents (whether because of death or divorce) and one participant learning from the mistakes of her thrice-divorced mother.

Sub-Question Three

How do long-term married couples describe the effects of hope and discouragement in marital discord or marital satisfaction, especially as they relate to the concerns of the future of their young adult with autism?

Long-term married couples explained that they experience hope and discouragement in parenting their young adults with ASD, which includes future concerns. The participants noted that the effects of hope and discouragement do not have a large effect on marital discord or marital satisfaction. The prioritization of the relationship is an important factor in an enduring marriage.

Theme 4. Long-term marriage is unified despite the challenges associated with parenting a young adult with ASD. Two categories were created that helped develop Theme 4. Category 7 describes the roles that were established while raising children with ASD, which in some cases created discord but has ultimately resulted in reverence for the contributions that the mothers have made in the advancement of their young adult children with ASD. Category 8 identifies the prioritization of marriage as the couples have learned to function as a team. The codes and categories which contributed to the development of Theme 4 are shown in Figure 4.

Figure 4*Codes and Categories in Development of Theme 4*

Note. This figure illustrates the development of Theme 4 using axial categories and codes. Two categories, three codes, and eight sub-codes contributed to the development of this theme.

Category 7. The participants' roles established while raising their child with ASD continue as they are now parenting their young adult with ASD. This category includes two codes and four subcodes. In Category 7, the couples reflected on the roles that they settled into when they were raising their autistic child, which at the time caused some frustration but have now become areas of appreciation for the work that was done, affording opportunities for their

young adults with ASD.

Couple 1 were both physicians, with C1-W working part-time. Couple 1-W recognized that she felt “there was some sort of unequal distribution of caring for [her son].” She discussed a time that their young adult son went to a therapeutic camp and that her habit became continually checking how he was doing, “If things were good, I would feel good, and then if things were bad, I would feel bad. It was unhealthy, but I didn’t know what else to do . . . It was a really difficult home situation.” Couple 1-H explained that he “didn’t drop everything and rush home every day because, it’s pretty selfish of me . . . but I just didn’t want to be home because it was just so tense. And I don’t like tense.” Couple 1-W acknowledged that she “felt a level of resentment,” and that she was frustrated because she “really had to carry a lot of the burden, but that the resentment was simply gone” when their young adult son left their home. She noted that they know that “this little party is going to end soon,” because “sooner or later [her son] will be under our auspices again.” Couple 1-W also stated, “It’s been a nice respite for us to have professionals really help guide us.”

Couple 2-W understood, “I didn’t know how to help him. If I could have been working in a way that was effective, it would have been different.” Couple 2’s young adult autistic son has been at the program in Florida for about 5 years, and C2-W stated, “He still is high maintenance, and he still takes a lot of my time and efforts,” even as she indicated that through their “investment” in the program in Florida, “We’ve found professionals that really know how to reach these kids in a way that we just didn’t how to reach [her son].” Couple 2-W and C7-W both advocated the importance of research. Couple 7-W called herself, “an obsessive researcher,” and C7-H commented that C7-W “is largely responsible for [his son’s] success,” and that he is “willing to acquiesce to [C7-W’s] better judgment, given her success rate.” Couple

2-W and C7-W also mentioned the stress that they endured due to both experiencing the “sandwich generation.” Couple 2-W explained the momentary challenge that this caused in their marriage as they navigate caring for aging parents and their young adult son with ASD.

Couple 3-W explained the roles that were established early as their son was placed in the NICU as an infant, and because “everything was so out of control, I made it my business to get everything in control. So, I became a control freak, and for my husband, his outlet was working.” In recalling times when their autistic young adult son was flailing and just sitting in his room, she noted, “Watching that was hurtful, and I didn’t know how to fix it, especially since I am focused on controlling everything so that it doesn’t get out of whack. I felt helpless, powerless.” Couple 3-W researched and found the program in Florida, which C3-H proclaimed, “was a real turning point in our lives.” Even as their young adult son with ASD is living in Florida while attending the program, C3-W explained that C3-H is “still working, and it’s stressful, and it overwhelms everything in our life as it has for our whole marriage. So, I do feel resentful, yes I do.”

Couple 4 and Couple 5 both include stay-at-home mothers. Couple 4-W noted, “I’m good at gathering and everything. I’m always out there collecting information, meeting people, learning about things, because I just want to make sure that I’m covering every potential.” The established roles for Couple 4, as C4-W explained, “I’m the emotional one. He’s the money one. So, I’m more worried about his emotional health. He’s more worried about his financial health.” Couple 5 have been together since middle school, married right out of high school, and had two children before C5-H graduated from college. They quite easily fell into traditional roles in their marriage, and, as C5-H explained, they have maintained an attitude that “We’re each other’s strengths and we cover each other’s weaknesses.”

Couple 6 were both employed full-time, with C6-W recently retiring. Couple 6-H stated

that C6-W “does everything, finding resources, coordinating, dealing with doctors, finding these programs.” Couple 6-W said that she is “an advocate for my son; I’d do anything.” She revealed that even while she was working, she was managing her autistic young adult son as she continues to do, “because if I don’t do it, no one else will.” Couple 6-W noted that she remains very involved with orchestrating their young adult son, even with him enrolled in a program in Florida, and calls herself an “enabler.” Couple 6-H discussed conversations that C6-W had with their young adult with ASD which did not appear to be fruitful, saying that his young adult autistic son has never said, “Yes, mom, I see your point. I see what you are saying. I understand that and I’ll act differently.” Couple 6-H explained, “That doesn’t happen, and I get frustrated.”

Couple 8 have both been employed full-time, with C8-H having spent time in the Marine Corps. Couple 8-W expressed some irritation during the years when C8-H was deployed and when he would come home she would say, “Do you see what I’m putting up with? You have no idea. And then it would become frustrating where I’m like, I’m out, bye, later.” She would later recognize, “That’s not fair, he’s in the military. It’s not like he wanted to leave.” Yet, given the time that C8-H spent away from home, their autistic young adult daughter engaged with C8-W more than C8-H. Couple 8-W explained:

That’s what becomes very exhausting. It’s just I was the one who was always there, always having to tell her this or tell her that or reassure her with something. So, it’s like she just doesn’t believe him when he says it.

Category 8. The participants have learned to prioritize their relationship. This category includes one code and four subcodes. Category 8 describes marriage as a team that incorporates communication, commitment, love, respect and trust.

The hope and discouragement that the participants experienced as long-term married

couples parenting young adults with ASD did not derail their relationships. The hopes and discouragement regarding the future of the young adults with ASD centered around financial concerns, relationships, and attaining some semblance of independence, as the long-term married parents began to acknowledge they are racing against the clock. However, the overarching theme among the participants was that they have learned to communicate and work as a team, even as they recognized that they had separate responsibilities in parenting a young adult with ASD.

Couple 7-W mentioned a conference that she went to when her autistic young adult son was a child, and she remembered and revered something that the speaker told the audience when asked about the most important thing that a parent could do for their autistic child. Couple 7-W said the speaker answered, “‘Stay married.’ She said children with autism need more than one parent, and autistic parents need more than one parent because it’s too much of a job for one person. And I remember really struck me.” Couple 7-W spoke about their marriage:

I trust him more than anybody else I’ve ever known in my whole life. I know that he is going to do the right thing. We talk and we’ve sort of matured and learned how to curb our lesser basic instincts. I used to yell and scream, and I haven’t done that in a long time.

Couple 7-H continued:

We have never had a yelling, screaming marriage. We don’t give each other the silent treatment. We are smart enough to know that if it’s good it is going to get bad. And if it’s bad it’s going to get good. And the good times far outweigh the bad times. So, we try and focus on the future and the positives.

Couple 8-W, whose mother was divorced three times, has learned:

You have to just understand that we’re all different and it’s okay to be different and it’s okay to not like each other every day as long as you love each other. I don’t always have

to like him because sometimes I don't like the things that he does. Sometimes I don't like the things my children do. But I still love them. And you don't just say, 'I'm done' because I didn't like that . . . the success is accepting.

Couple 6 is amid significant challenges with their young adult son with ASD, but C6-W quite simply asserted:

I couldn't do this my myself. I love him dearly. I was 40 when I married him . . . and I did not plan on having a child with disabilities. We've had fights, we've had good fights. But in the end, I love him.

Couple 2-W discussed the importance of communication in their marriage, and stated:

I just feel fortunate to be married to the right person. I feel like there was something greater than myself involved in that. Neither one of us would ever see divorce as an option. So, we would be willing to work really hard. We went into it for keeps is what I am saying.

Couple 2-H noted:

Looking back, to some extent that experience helped us to understand that life is not always what you think it's going to be . . . Things are different, they're different for everybody. You see things a little different from the perspective of others.

Couple 4-W discussed, "We talk, and we reason through things, and that's just been how we've stayed together all these years, we've just talked through these . . . differences on different things." Couple 5-H expressed, "We do not have sarcasm in our relationship." He further said:

We would not have made it, and we wouldn't make it if we didn't have the tight relationship that we have and the love for each other, and just the understanding of the other person. Both strengths and weaknesses. Our kids would even say our relationship is

the bedrock of how this place is still standing after all that we've been through.

Couple 1-W uniquely disclosed, "I just think we have a good marriage. We just chose well. It's not like we are these great people, or we've even had to work very hard. We're very similar... and we innately have the same views about stuff." Couple 1-H stated:

You just realize that you're just going through things as a team and there are things that irritate you, and there's things I do that irritate her. You try to minimize those and realize you never get rid of them. It's a pragmatic way of approaching it.

Couple 3-H advised:

I think we're both very committed to each other. We have this genuine love and affection for each other. You have to go through stresses, and you have to deal with them. She's very direct. And I'm not used to being as direct, letting things work themselves out. But she pushed me on that stuff, and we'll have to address things . . . I think it's the commitment to the background that we both have.

Reflecting on her autistic young adult son with ASD, C 1-W stated, "I actually think, in a weird way, it enriched our lives in great ways that would never have happened if we'd only had this little clone of ours." Couple 2-W added, "It helps us to be empathetic towards all kind of problems that people have. Couple 1-H said, "People are judgmental. It makes you much more open minded, it's made me a less judgmental person than I used to be."

Summary of Theme 4. In Theme 4, the participants reviewed the roles that were established for them as mothers and fathers raising a child with ASD. These roles were deemed to cause some frustration in the earlier years, but they have become areas of appreciation as fathers are grateful for the research that the mothers have done, which has resulted in growth for their young adults with ASD. The participants value their marriage as a unified team and

prioritize the relationship while utilizing communication, love, and respect, which creates harmony and trust.

Research Question Responses

This study sought to answer a central research question and three research sub-questions regarding the lived experiences of couples in enduring marriages who are parenting a young adult with autism. The answers to these research questions were gathered from the collected and thoroughly analyzed data that was acquired through semi-structured interviews.

The themes and categories with codes and subcodes are presented in Figure 5. Theme 1 addressed current challenges and future concerns about the young adult with ASD and Sub-Question 1. Theme 2 addressed setbacks and growth of the young adult with ASD and Sub-Question 1. Theme 3 addressed religion and spirituality and Sub-Question 2. Theme 4 addressed the strength of marriage and Sub-Question 3. The central research question and sub-questions will be answered in the next section using components of each theme and the categories and subcodes contained therein.

Figure 5

Themes, Categories, Codes, and Sub-Codes

Theme 1: Current Challenges and Future Concerns

- Category 1: Current Challenges
 - Lack of Employment or Purpose
 - Not Self-supporting
 - Parental Household Income
- Category 2: Future Concerns
 - Independence
 - Financial/Employment
 - Safety
 - Happiness
 - Friends/Relationship

Theme 2: Setbacks and Growth

- Category 3: Move Past Disappointments
 - Perspective
 - Flexibility
 - Coping
- Category 4: Positives of Trajectory
 - Learning
 - Evolving

Theme 3: Upbringing and Spirituality

- Category 5: Spirituality and Religiosity
 - Peace
 - Hope
 - Belief
- Category 6: Moral Compass
 - Guidance
 - Values
 - Example

Theme 4: Unification in Long-Term Marriage

- Category 7: Roles
 - Mothers
 - Responsibility, Advocate, Sought help
 - Fathers
 - Career
- Category 8: Prioritize Relationship
 - Team
 - Communication and Harmony, Commitment, Love and Respect, Trust

Central Research Question: How do long-term married couples describe their experiences of moving past the challenges of raising a child with ASD only to enter the new realm of challenges of parenting a young adult with ASD with mild to moderate symptoms that require some support?

The experiences of couples in long-term marriages who are parenting a young adult with ASD share commonalities among the participants of this study. Long-term marriages have adopted a team mindset supported through honest communication, focusing on the relationship by keeping it at the helm of their family, expressing love and understanding towards one another, and trusting each other. The current challenges of parenting a young adult with ASD that are

experienced by couples in enduring marriages are a continuation of the challenges that they had while raising a child with ASD. The difference in the challenges is age-related regarding development through the life span of the young adult with ASD, as the parents worry about post-secondary school issues such as obtaining employment, as well as the financial constraints experienced by the parents as they continue to support their autistic young adult. The concern about the young adult with ASD stretches beyond the current situation to worries about the future regarding happiness, friendships/relationships, financial stability, and seeking some semblance of independence without being a burden on siblings and other family members. The parents recognize and applaud any growth of their young adult with ASD and are optimistic about the potential trajectory due to each small step that is a success; they have learned to accept setbacks as part of the journey that they have already been taking. Faith in something greater than oneself provides peace, and a moral compass contributes to the values and commitment to the marriage despite the challenges of parenting a young adult with ASD.

Research Sub-Question One: How do long-term married couples describe areas of their marriage that are stressed with parenting a young adult with autism?

Participant interviews highlighted some of the stresses that are experienced by couples in long-term marriages, noting that the stresses are multi-layered and ever-changing. None of the participants young adults with ASD are self-supporting, though two of the autistic young adults are employed full-time. The parents continue to financially support their young adults with ASD, which hinders their ability to retire (depending on the age of the participant) or enjoy the things that they thought they would be doing now, such as traveling. An additional stressor is the concern about the future as the worry about the independence of their young adult with ASD remains very uncertain, especially given the inability to find employment. The lack of friends or

a relationship adds to an ongoing worry of loneliness. Further, the question remains about who will care for their young adult with ASD when they are no longer able to do so.

Research Sub-Question Two: How do long-term married couples describe the role of religiosity in sustaining their marriage through the difficulties of parenting a young adult with autism?

The participants explained that spirituality is a part of their lives, whether traditional religious affiliations or spiritual guidance, and a recognition that faith and/or prayer sustained them during challenging times. Spirituality provided an understanding of something bigger than the participants as a guiding force in their lives, whether God, or spiritual guidance that supports peace, unity, service to others, and selflessness. Faith did not necessarily mean a faith in God, but a faith in, and commitment to, one another. The participants noted that aside from religion, the role models of their parents' marriages provided a foundation that contributed to sustaining their marriage.

Research Sub-Question Three: How do long-term married couples describe the effects of hope and discouragement in marital discord or marital satisfaction, especially as they relate to concerns about the future of their young adult with autism?

The hope that was expressed by the participants related to the personal growth and development of both the young adult with ASD and the parents. The parents who have their children enrolled in a program in Florida noted that the experience of having their autistic young adults out of the home has provided a sense of freedom because they are no longer in the home (for the moment, in some cases) and that professionals are helping their young adult with ASD learn and evolve. The parents whose autistic young adults are living in their homes find hope in the desire of their young adult with ASD to move towards finding a job or finding a better job.

Discouragement experienced by the participants is related to the feeling of “constant regurgitation” (a phrase used by C8-H) of all that is involved in supporting their young adults with ASD, whether continuing to need hygiene reminders, anticipation and direction towards the next steps for the autistic young adult, and the financial burden and worry about future financial expenses. Neither marital discord nor marital satisfaction is particularly impacted by hope and discouragement, as the participants have learned to prioritize their relationships and have matured in their communication skills with one another, gaining an understanding that stress is a part of life that should not disrupt their commitment to the marriage.

Chapter Four Summary

In this study, eight couples completed semi-structured interviews and answered questions about parenting a young adult with ASD and the effect that it has had on their long-term marriage. This qualitative phenomenological study addressed a central research question and three research sub-questions. The central research question aimed to understand the experiences of long-term married couples who have moved from raising a child with ASD to parenting a young adult with ASD. This central research question was supported by three sub-questions that permitted a clearer understanding of the participants’ lived experiences. The specific examples contained within each theme contributed to answering the central research question.

The transcriptions from the semi-structured interviews were thoroughly analyzed utilizing hand-coding and MAXQDA in search of repetitive phrases, words, and patterns. The data analysis produced four themes presented in this chapter, which addressed the research sub-questions. These themes provided structure and guidance for the researcher in pursuit of understanding the participants’ lived experiences in addressing the central research question.

Sub-Question One (SQ1) aimed to understand stressors of parenting a young adult with

ASD. Two themes were identified from participant interviews to address SQ1. In Theme 1, the participants described the stress endured, given the status of where their young adult with ASD is currently. The stress is attributed to the lack of employment of the young adult with ASD and the resultant inability to be self-supporting, which causes an ongoing financial burden for the parents. The participants are also stressed as they anticipate the future of their young adult with ASD, especially as it relates to potential employment, independence, relationships, safety, and the happiness of their autistic young adults. Theme 2 examined how the participants can recognize growth, even as continued setbacks or challenges remain. The participants have learned to move past the disappointments that accompany parenting a young adult with autism and have adjusted to celebrating small successes in the trajectory of their autistic young adult.

Sub-Question Two (SQ2) sought to understand the role of religiosity in sustaining the long-term marriage for couples parenting a young adult with ASD. One theme was identified from participant interviews to address SQ2. In Theme 3, the participants described how their upbringing and spirituality contribute to their experiences in a long-term marriage. Spirituality or a religious affiliation are attributed to providing optimism and peace as the participants recognize a power greater than themselves and an understanding of the importance of service and selflessness. The participants share a moral compass as their upbringing provided guidance and contributed to their values as they relate to enduring marriages.

Sub-Question Three (SQ3) sought to understand the role of hope and discouragement as it relates to marital discord or marital satisfaction. Theme 4 described the unification of enduring marriages despite the challenges that the participants have experienced while parenting their young adult with ASD. The roles that parents assumed while raising their child with ASD continue as they parent their young adult with ASD, with fathers revering the work that the

mothers have done—and continue to do—even as they acknowledge their absence during the growing up years. Ultimately, the couples have learned to prioritize their relationship and recognize the importance of communication and the expression of love and respect in maintaining harmony in their enduring marriage.

CHAPTER FIVE: CONCLUSION

Overview

The purpose of this transcendental phenomenological study was to understand the lived experiences of long-term married couples who are parenting a young adult with autism. This chapter will discuss the findings of the study as they relate to existing literature, provide a summary of the study findings, address the central research question and research sub-questions, and will discuss theoretical, practical, and empirical implications. A Christian worldview perspective will also be addressed. Further, the delimitations and limitations of the study are discussed, and topics for further research are provided. Lastly, the chapter describes the final summary of conclusions garnered from this study.

Summary of Findings

This section will summarize the research findings of the study and will provide answers to the central research question and three research sub-questions. The purpose of this transcendental phenomenological study was to describe the lived experiences of couples in enduring marriages who are parenting their young adult with ASD. This study sought to understand the challenges faced by these couples as they continue to parent an autistic young adult.

The theory guiding this study was the circumplex model of marital and family systems which recognizes that balanced couples and families are happier, engage in more positive communication, and can change their levels of cohesion and flexibility when faced with stressful situations (Olson et al., 2019). This study used the methodology of Moustakas as phenomenology seeks to understand everyday experience to gain an understanding of a phenomenon (Heppner et al., 2016). Data collection was achieved through in-depth, semi-

structured interviews that were conducted with eight long-term married couples.

Development and Organization of Findings

The data was collected via semi-structured interviews, and a journal was kept by the researcher to bracket out preconceived notions, thoughts, and feelings. Upon completion of the interviews, the audio recordings were transcribed and reviewed, and the participants were sent a copy of the transcript for member checking. The data analysis was conducted first using methods of horizontalization, which allowed the researcher to find statements of significance that the participants experienced (Creswell & Poth, 2018; Moustakas, 1994).

The transcripts were reviewed numerous times and then coded multiple times to promote the synthetization of the data to determine pattern recognition (Saldaña, 2021). Significant statements were identified and clustered together in nonrepetitive themes. An analysis of the themes of the data was accomplished using the assistive software MAXQDA and hand-coding. The transcripts were reviewed thoroughly, color-coded categories were created that described the lived experiences of the participants, and the researcher determined that saturation had been met. Through the extensive review of the data, four themes of the effect on long-term marriages of parenting a young adult with ASD were developed.

Theme 1 was the current challenges and future concerns regarding parenting a young adult with autism, and this was addressed by the couples discussing the difficulties they are currently facing with their young adult with ASD, as well as exposing their concerns regarding the challenges that their young adult with ASD will face in the future. Theme 2 was related to the setbacks and growth of the young adult with ASD and explained the couples' ability to move past disappointments and embrace positive movements in the trajectory of their young adult with ASD. Theme 3 discussed the upbringing and spirituality of the couples in long-term marriages as

they related whether their religious affiliation impacted their views on marriage and how their parents' marriages affected their own marriages. Theme 4 addressed the unification of long-term marriage, noting the roles that the couple played while raising their child with ASD that maintain themselves as they parent their autistic young adult (though with renewed vision). In addition, the couples revealed their relationships' prioritization and the components they attribute to their success.

Central Research Question Findings

The central research question, "How do long-term married couples describe their experiences of moving past the challenges of raising a child with ASD only to enter the new realm of challenges of parenting a young adult with ASD with mild to moderate symptoms that require some support?" sought to fill the gap in the literature by examining how couples who are now parenting a young adult with ASD remain bonded in their marriages. The central research question was supported by three research sub-questions; the resultant findings indicate that couples in enduring marriages experience challenges that are commensurate with age-related issues as their autistic young adult proceeds along the lifespan. The lack of ability to be self-supporting on the part of the young adult with ASD was worrisome for the participants in this study and impacts the couples' current financial situation, as well as creating a fear of future problems related to independence, friendships/relationships, vocational/financial stability, and overall happiness.

Research Sub-Question One Findings

Research Sub-Question One, "How do long-term married couples describe areas of their marriage that are stressed when parenting a young adult with autism?" sought to understand the significance of the challenges the couples face when parenting a young adult with ASD. The goal

of this research sub-question was to identify areas of the long-term marriage that experienced duress as the couple parents a young adult with ASD. Existing literature discussed the challenges of raising a child with autism; this research sub-question sought to identify the difficulties of this next phase of life for their autistic young adult and how it impacted the enduring marriage.

Themes 1 and 2 were applied to Research Sub-Question One.

Theme 1 explained that current challenges faced by couples in enduring marriages who are parenting a young adult with ASD are challenged by the inability of their autistic young adult to be self-sufficient, which is not only a financial concern but also leads to worries of a lack of purpose for their young adult with ASD. The couples also noted the financial impact that parenting a young adult with ASD has on their household income, and in some cases, delayed or did not permit the parents to feel like empty nesters, forbid the ability to travel, or enter retirement. Theme 1 also addressed the concerns that couples have as they consider the future of their young adult with ASD. None of the autistic young adults with ASD have solid next-step plans, and as such, the parental worry is linked specifically to what level of independence the young adult with ASD might be able to achieve, which includes concern over employment opportunities and financial viability. Additional worries were noted to be about the safety of the young adult with ASD, as well as friendships/relationships that would relieve them of loneliness and the overall happiness of their autistic young adult.

Theme 2 related to the setbacks and growth of the young adult with ASD as the participants discussed the “roller coaster” associated with the times of pessimism and optimism that are related to the trajectory of their autistic young adult. The parents recognized the need to be flexible in their expectations and to embrace any positive momentum that their young adults with ASD were experiencing.

Research Sub-Question Two Findings

Research Sub-Question Two, “How do long-term married couples describe the role of religiosity in sustaining their marriage through the difficulties of parenting a young adult with autism?” addressed the spiritual component in enduring marriage and its significance in supporting the couple through the challenges of parenting a young adult with ASD. The purpose of this question was to understand what impact religion has in helping the couple overcome adversity and whether faith in God supported the couple through the challenges of parenting a young adult with autism. Theme 3 addressed Research Sub-Question 2 as the participants highlighted spirituality as either traditional religious affiliation or spiritual guidance and recognized that faith and/or prayer sustained them during challenging times. Faith did not necessarily mean a faith in God; spirituality provided an understanding of something bigger than themselves, supporting service to others, selflessness, peace and unity. The participants stated that the foundation of their marriages could be directly linked to the role models that their parents’ marriages provided and that their upbringing contributed to sustaining their marriage.

Research Sub-Question Three Findings

Research Sub-Question Three, “How do long-term married couples describe the effects of hope and discouragement on marital discord or marital satisfaction, especially considering the concerns of the future of the young adult with ASD?” sought to understand how these two ends of the spectrum effect the marriage, negatively or positively. Theme 4 was applied to Research Sub-Question Three as the participants explained that hope equated to the personal growth and development of the young adult with ASD and the parents. The parents who have their young adult with ASD enrolled in the program in Florida discussed the improvement in their relationship with their autistic young adult as well as the positive steps that they have made while

being in the program. The parents who have their young adults in their homes are hopeful about their young adults with ASD either moving towards wanting to find a job or hoping to find a better job. The discouragement the parents experience is directly related to the “constant regurgitation” (statement by Couple 8-H) of situations, whether getting a job and losing a job, directives about hygiene, anticipation about next steps, and current or future financial expenses. Neither marital discord nor marital satisfaction were found to be particularly impacted by hope and discouragement given that the couples have experienced their own growth as they have matured in their communication skills, they have learned to prioritize their relationships, and they have gained an understanding that stress is inevitable; they do not allow it to disrupt their marriage.

Discussion

This section discusses the lived experiences of long-term married couples who are parenting a young person with ASD. It also provides an explanation of the study’s findings, which confirm and expand on existing literature. The study findings will also be discussed in the context of the study’s theoretical framework.

Empirical Literature Discussion

The exploration of the lived experiences of couples in enduring marriages who are parenting a young adult with ASD provided valuable insights that confirm and extend the existing literature on the challenges faced when parenting a young adult with ASD. The findings of this study align with previous research, which acknowledged the challenges associated with raising a child with ASD. Of note are three areas discussed in Chapter Two, which, when coupled with the findings of this study, indicate consistency in the transition to adulthood, including financial concerns, parental stress, and marital satisfaction.

Transition to Adulthood

The findings of Sosnowy et al. (2018) indicated that the transition from high school is particularly difficult for autistic youth and explained that from the parents' perspective, a desire for their young adult to reach sustainable independence might be a lengthy process. The participants of this study all shared the challenging journey that their young adult with ASD has been on since high school; none of the young adults with ASD aged between 23 and 31 has reached independence, and they are all reliant on their parents for support. The Sosnowy et al. study explained that achieving independence included the ability of young adults with ASD to make their own decisions, become gainfully employed, live independently, and negate the need for support from their parents. Yet, the study found that many autistic young adults received substantial support from their families and wanted help managing finances and job training. In other studies, young adults with ASD were found to face several obstacles that hinder their transition to adulthood, specifically employment, including social skills deficits and challenging behaviors (Chen et al., 2014; Chiang et al., 2012; Sosnowy et al., 2018). These findings were confirmed in the interviews with the participants of this study, wherein the parents discussed the challenges for their young adults in obtaining employment and the need for substantial support—directive and financial—as none of the young adults have been able to transition to independence.

The literature revealed that the families of young adults with ASD will be involved in their lives long into the future, which led to concerns about providing support beyond what is currently being provided (Herrema et al., 2017a). A study by Wisner-Carlson et al. (2020) affirmed that money management is a critical factor for an autistic young adult to function independently, and includes earning a living and budgeting, and further advised that this skill

may need to be monitored throughout the lifespan of the young adult with ASD. Participants supported this finding as discussed in Theme 1, wherein the parents explained that their future concerns focus on the employment of their young adult with ASD, even though two of the autistic young adults are currently employed full-time yet still need support. The parents whose autistic young adults are enrolled in the program in Florida have expressed that their young adult with ASD is receiving support in money management through the program, and several participants indicated a lack of understanding of the value of money nor how to spend it appropriately. All the participants are financially supporting their young adults with ASD and have notable concerns about the future earning potential of their autistic young adult as well as who will take over the care and support of the young adult with ASD when the parents are no longer able.

Studies conducted by Tillmann et al. (2019), Saulnier and Klaiman (2022), and Farley et al. (2009) discussed that the lack of EF skills impairs the mastery of DLS, which constricts the ability of young adults with ASD to become independent. The participants of this study, when referring to their young adults with ASD, noted that some of them lack mastery of hygiene skills (without reminders), some of them cannot master time management, they struggle with finances, and even when employed they cannot be self-supporting. These findings concur with studies by Bal et al. (2015) and Wisner-Carlson et al. (2020) that declared that children with ASD who are not able to perform ADL sufficiently will have difficulty transitioning to adulthood.

The lack of ability to transition to independence and become gainfully employed concerned the participants as they experience current financial expenses while supporting their young adults with ASD. A future concern of the participants of this study was that the lack of employment not only hinders self-sufficiency and independence but also inhibits the autistic

young adult's ability to find purpose and meaning in their lives. This finding supports the study by Solomon (2020), which stated that unemployment negatively affects autistic young adults not only economically but also excludes them from being a contributing member of society.

Parental Stress

The literature as it relates to parental stress revealed that raising a child with ASD can be stressful for parents as their child is more reliant on them for support given their unique needs (Allen et al., 2013). These results were highlighted in this study's findings of the participant data as parents mentioned the stress they endure given that the challenges that their young adult with ASD directly impact their household income due to the reliance on the couple for financial support. Additionally, several couples noted that although their young adult with ASD is away from home at a program in Florida, their return to their home is anticipated and likely to reintroduce stress within the family once again. A study by Corcoran et al. (2015) noted that parental stress is ongoing due to their concern for their child's future care and whether the child would be supported as necessary for them to have a productive life. Many of the study participants discussed their concern about placing the burden of caring for the autistic young adult on other family members, with one participant disclosing his fear that his young adult with ASD will be homeless.

Maternal stress, as expressed in existing literature, indicates that mothers are typically the primary caregivers and will leave employment to be home with their autistic child, which can result in feelings of resentment and isolation (Sim, Fristedt, et al., 2019). Mothers and fathers in this study corroborate the literature as they confirmed that mothers who were working shifted their careers to focus on their children with autism. Fathers recognized the amount of research that the mothers have conducted to find the most supportive environment for their autistic child

and now autistic young adult. “Research, research, research” was an oft-repeated phrase by mothers who felt responsible for finding post-secondary programs in which their young adult with ASD might find success. Further, research into another program would ensue when one program did not meet expectations. One mother in the study whose son is exhibiting manipulative behavior noted that she is losing her hair and experiencing stomach issues. Meanwhile, while acknowledging the duress that his wife is under, her husband takes a more “laid back approach.” A study by Bitsika et al. (2013) and another study by Di Renzo et al. (2021) confirmed that mothers bear the brunt of caring for children with autism and are pushed to their limits as compared to fathers, which leaves them vulnerable as they may feel incompetent and succumb to depression. Several mothers mentioned that they felt fortunate given that they had the resources to get professional help for their autistic young adults because the mothers did not believe that they were successful in effectively helping their young adult with ASD.

Previous studies conducted by Burrell et al. (2017) noted that fathers take on the responsibility of helping their children in their quest for independence and acceptance in society even, as they remain unsure of whether these are achievable goals. This study included a father who has provided a condominium and a car for his young adult son with ASD, who will complete his undergraduate degree in the fall, and the father is considering whether his autistic young adult should continue to get his Master of Arts in business administration because school is where he has found success. O’Halloran et al. (2013) emphasized that fathers accept that future support will be necessary and that they simply want their autistic child to attain a level of independent living, which includes a social life. Both mothers and fathers in this study expressed concern for the future of their autistic young adult’s social life, including friends and perhaps a

long-term relationship.

Marital Satisfaction

Literature on marital satisfaction focused on marriages wherein couples were raising a child with autism. A study by Easler et al. (2022) advised that the level of stress and marital satisfaction for parents raising a child with autism is in accordance with their perception of their children, their marital partner, and the demands on the family. As such, raising a child with autism does not necessarily have only negative implications for the marriage. A study by Romney et al. (2020) found that some couples with an autistic child reported stronger marriages because they endured the stress associated with the challenges. This study confirms that couples in enduring marriages in this study understand that their lives are richer for having parented a young adult with ASD as they have learned to be less judgmental and more accepting of others as well as being more empathic towards the problems that other people experience.

The Romney et al. (2020) study further advised that married couples have learned the benefit of prioritizing their marriage in ways that they might not have otherwise. One participant mentioned an autism conference that she attended while raising her autistic son and a speaker who advised the attendees to stay married because “children with autism need more than one parent, and autistic parents need more than one parent because it’s too much of a job for one person.” This comment impacted the participant as she explained that they have matured and learned to “curb their lesser basic instincts,” which was the theme of the long-term married couples in this study. The participants understand that love supersedes the challenges they have faced together and that they have adopted a team mentality over the years. The importance of this mentality is supported by a study by Romney et al. (2020), which emphasized that learning to rely on one another and working as a team leads to a sense of togetherness.

As suggested in previous studies, good communication is vital in keeping the marital relationship from experiencing turbulence. A study by Brisini & Solomon (2018) expressed that during times of upheaval, couples need to use good communication during times of transition of their autistic child's life. Solomon et al. (2016) found that proper communication during times of volatility can help the couple experience cohesion and the resultant growth in their bond. Rearing children has been found to permit a couple to garner a sense of shared responsibility, and the utilization of effective teamwork and togetherness fortifies the marriage (Karimi et al., 2019). The participants in this study have emphasized that through raising a child with ASD, they have become a unified team and have learned to appreciate the small successes of their young adult with autism, leading to a sense of accomplishment for what they have done together. The couples mention that they have sustained their marriage through communication, commitment, and understanding each other's strengths and weaknesses.

Marital Conflict

Previous literature revolved around the experience of raising a child with ASD and the negative impact that experience has on the parents' marriage. Romney et al. (2020) found that the marital relationship was challenged during the years of raising a child with autism because of a lack of financial resources and a lack of time for one another; Handley et al. (2020) noted that heightened parental stress hinders the maintenance of marriage. The research of Chan and Leung (2020) explained that the conflict between the parents of children with autism contributes to increased conflicts in the marriage, effectively lowering the loving bond between the married partners. Additionally, Forbes et al. (2022) and Anderson et al. (2020) specified that as the child grows to young adulthood, the stress experienced by parents can be exacerbated by the autistic young adult's inability to live an independent life. One couple mentioned the stress of having

their young adult son with ASD at home as well as the frustration of not being able to provide the help their son needed at home and that had their autistic young adult stayed home rather than attending the program in Florida, they are not sure how that would have affected their marital relationship.

Most of the participants in this study did not expressly state that they experienced marital discord as it relates to their young adult with ASD. While reflecting on times of marital discontent that occurred during the years of raising their children with ASD, given the mothers' high levels of responsibility and the fathers' absence while working, couples in an enduring marriage now appreciate that mothers can do the necessary research that affords their young adult children the opportunities to grow as the fathers recognize the value of the mother's efforts. Even as the couples explained that disappointments are inevitable while parenting a young adult with ASD, they expressed that they have been able to progress through the challenges and are optimistic about the growth of their autistic young adult. By recognizing even a modicum of success that their young adults with ASD are experiencing, the participants can alleviate some of the stress that is associated with parenting an autistic young adult. This, in conjunction with viewing themselves through the lens of teamwork, permits the couple to revere the years that they have been together as they understand that life is cyclical, and as one couple noted, "the good times far outweigh the bad times."

Religiosity and Spirituality

An unexpected finding was the lack of connection between the long-term marriages as it relates directly to the wedding vows. Fifteen of the 16 participants were raised with a religious affiliation; however, only two couples are regular church attendees—although several participants mentioned they intend to reintroduce regular church or synagogue attendance. One

couple observed that God was in the middle of everything and that when times were dark, a light always appeared. Another couple expressed that God is at the core of everything in their lives. Several participants noted that they pray and meditate. One couple has made a very conscious decision to abandon their religious upbringing altogether, specifically as it relates to the challenges that they have endured with their young adult with ASD. This couple has found relief from letting go of their Christianity. Regardless of their religious affiliation or lack thereof, all the couples are devoted to and express their love for one another. The overarching theme for the participants was that spirituality, whether through religious affiliation or spiritual guidance, contributes to their moral compass and leads them to seek peace and unity.

An additional unexpected finding was the marriages of the participants' parents in this study. Fourteen of the 16 participants in this study have witnessed the long-term marriages of their parents, one participant witnessed the successful long-term remarriages of his divorced parents, one participant whose mother passed away saw his father remarry and remain so until his death, and one participant's mother was divorced three times. The couples recognized that their upbringing was a significant contributing factor in their own marriages as they navigated the challenges associated with parenting a young adult with ASD. The examples provided by their parents' enduring marriages caused them to view their marriages with a longevity outlook from the start, and the participant, whose mother was divorced three times, avoided making the same mistake.

Theoretical Literature Discussion

The theory driving this study is the circumplex model of marital and family systems. This circumplex model is founded on basic concepts of systems theory and assists in understanding the couple and family systems (Olson et al., 2019). This theory posits that two dimensions help

determine the functioning of a family: cohesion (the emotional bonding between the couple and the family that affects variables such as boundaries, emotional bonding, and decision-making) and flexibility (how well systems can balance stability with change, including role relationships and rules of relationships); the third dimension is communication (Olson et al., 2019). The study findings include insights into how the lived experiences of parenting a young adult with ASD affect their enduring marriage, which aligns with the circumplex model. The study findings concur with the importance of communication, as outlined in the circumplex model, in identifying balanced family systems.

During the semi-structured interviews, the participants organically discussed the relevance of communication as it pertained to their long-term marriages. The couples varied from going into the marriage expecting communication with one another to shutting down when raising their autistic child was too demanding, and frustrations were high. The participants reflected on times when the roles of the mothers and the fathers raising an autistic child were separate, and the mothers experienced resentment as fathers confirmed that they prioritized their careers. This was a historical observation as the couples' communication has become elevated as the marital relationship has matured. The circumplex model allows for developmental change of the couple as they progress through different phases of marriage (Olson et al., 2019), which was recognized in the couples of this study who have a mastery of good communication skills, including active listening, speaking skills, empathy, and respect.

While the study aligns with Olsen's (Olson et al., 2019) circumplex model on the importance of communication and its effect on cohesion and flexibility throughout the years of marriage, it also seeks to extend an understanding of the significance of the inherent level of commitment that the couples have to each other and the marriage in the application of the

circumplex model. As an example, the participants described remaining married as having no concept of anything else, that they are oriented together, and how they were positively impacted by the examples set by their parents' long-term marriages. Specifically, the study queries whether entering a marriage without seeing divorce as an option plays a role in a couple's willingness to be cohesive and flexible while seeking effective communication.

Implications

This study produced findings that have theoretical, empirical, and practical implications. Theoretical implications extend current theory; empirical implications constitute further research that can be conducted based on insights gained from the collected data; and practical implications extract the study outcomes and apply them to real-world scenarios. This section will also discuss the implications of a Christian worldview as it pertains to the study's findings.

Theoretical Implications

This study was guided by the theoretical framework of Olson's circumplex model and demonstrated how cohesion, flexibility, and communication can positively or negatively impact a marriage and the family system. The model uses a 5 x 5 model, which differentiates balanced from unbalanced families and aids in understanding the function of appropriate levels of cohesion and flexibility (Olson et al., 2019). The findings of this study confirm that balanced couples who are structured (have stable roles and uses democratic leadership with some negotiations) or flexible (shared roles with fluid change permissible) are more functional over time. The circumplex model recognizes that good communication indicates balanced systems as listening and speaking skills contribute to respect and regard when applied to problem-solving skills. The study findings illustrate how marital and family functioning in the context of higher-order communication skills helps to maintain the longevity of the marriage and the family.

Empirical Implications

The empirical implications of this study reflect several areas that warrant further evaluation. The participants in this study have arrived at the stage of parenting a young adult with ASD while having nurtured their enduring marriage. The scope of the study did not include understanding whether these families were structured and balanced for many of the years that they spent raising their child with ASD. However, it is apparent that the couples have arrived at this stage of their marriage (25 years or longer) and identify themselves as being a team. Of interest is that 14 of the 16 participants in the study had the benefit of growing up in homes with intact marriages.

The problem that was addressed in this study was a lack of understanding of the effect on long-term marriage when parenting a young adult with autism. Previous research studies indicated a gap in the literature that focused on how couples sustained their marriage as they moved on to the next stage in their child's development. The study identified that the challenges of autism continue to require couples' involvement in the life of their young adult with ASD, and insights from this study provided information that helps to fill the existing gap. Specifically, the findings illustrate that long-term married couples respect and appreciate one another. They find opportunities for optimism based on small steps of forward momentum for their young adults with ASD.

Practical Implications

The practical implications of this study extend to professionals and practitioners engaged in marital or family counseling. Practical implications also extend to the development of team-building training and conflict resolution for parents who are raising a child with autism to help them avoid triangulation in their marital and family relationships; this training could also extend

to couples who are parenting a young adult with ASD. The vital importance of proper communication skills requires fervent focus on training couples in how to effectively speak to one another as well as how to speak to their young adult with ASD. Such training will aid in negating the stress associated with the manipulation that the autistic young adult has learned to employ as a strategy to create guilt or provide an excuse.

Another implication of this study is policy that would afford young adults with ASD access to affordable programs for long-term support, including mentoring, career training, and work modifications. Six of eight couples in this study had the resources to send their young adults with ASD to a program that was away from home. These couples spoke about the freedom they could experience due to the autistic young adult having professional assistance that went beyond the scope of their competence in providing direction. Further, the couples understood that because they had the resources to find a program that aided their young adults with ASD to experience a level of supported independence, they could enjoy their time together and were distant from much of the stress. Finally, this study is indicative of the need for policy to be written that will address the tsunami of young adults with ASD who will no longer be under the care of their parents, whether physically or financially, and will find themselves without any way to support themselves.

Christian Worldview Implication

A Christian worldview of this study identifies several interesting developments. The couples in this study were in enduring marriages despite the challenges associated with parenting a young adult with ASD. Fifteen of the 16 participants were raised in households with religious affiliations, and 14 of the 16 participants were from homes with intact marriages for their own parents. Given the circumstance of having an autistic young adult daughter, one couple made the

decision separately that they would dissociate themselves from their religious upbringing. The couple found peace and relief from letting go of God because they could not believe in a God who would allow harm to one of His children. On the contrary, several of the couples identified that God was at the helm of their lives and that they gave God the credit for bringing light when there was only darkness. All the couples took a spiritual stance in recognizing the importance of peace and unity and spoke of forgiveness, prayer, and meditation. When querying the ability of these couples to maintain long-term marriages, however, no one indicated they had taken a vow before God nor revered Matthew 19:6 which states, “Therefore what God has joined together, let no one separate.” (*Holy Bible, New International Version*, 2015).

Strengths and Weaknesses

Strengths

The strengths of this study were based on the central research question and three research sub-questions that provided solid answers and an interpretation of the lived experiences of long-term married couples who are parenting a young adult with autism. The semi-structured interviews with eight couples (16 participants) provided rich data that described their experiences and allowed the researcher to gain an understanding of the phenomenon from their viewpoints. Using a qualitative transcendental phenomenological method, the researcher bracketed out personal biases or notions, which permitted learning of the participants’ perspectives and resultant authentication of the study data and analysis.

The sample provided a wide range of ages of the participants, with the youngest participant being 46 and the eldest participant being 71. The length of the marriages ranged from 25 to 39 years. The ages of the young adults with autism fell between 23 and 31, providing a range along the development of the lifespan for young adults.

Weaknesses

While the study had several strengths, there were also notable weaknesses. The sample size of eight couples (16 participants) included six couples (14 participants) recruited from a program for young adults in Florida. If this study were conducted using a larger sample size that recruited participants from various geographic regions and more participants with their young adult with ASD living at home, the outcomes could differ, given a broader range of perspectives. This small sample size limited the transferability of the outcomes to larger populations of long-term married couples who are parenting a young adult with autism. Another weakness of the study was the underrepresentation of evangelical church participation relative to other denominations. Further, most of the couples in this study did not actively participate in weekly church services.

Another potential shortcoming of this study, although ameliorated by detailed manual sequential analyses, was the use of MAXQDA to code the interviews. The algorithm appears limited in its ability to associate and bundle different descriptors for the same category. Individuals often use substantial variability in the verbiage to describe the same categorical item. This carries across genders as well. Also embedded in these communications are non-verbal forms of expression, descriptors MAXQDA is incapable of recognizing. This study used repetitive manual overreads of each transcript to ensure these word groupings would be appreciated and coded. The previously mentioned truncation of conversation, based on a perceived stressor in the interview, was also an attribute MAXQDA would be incapable of detecting. In summation, the apparent redundancy of MAXQDA application and serial manual over-reads ameliorated this issue.

Delimitations and Limitations

Delimitations

Researchers make conscious decisions to place boundaries on a study, narrowing the scope and making the study feasible (Ross & Bibler Zaidi, 2019). This study was delimited to long-term married couples who are parenting their young adult with autism. This group was chosen because of the gap in the literature that discusses the ongoing challenges that parents of young adults with ASD experience as their child transitions to a new phase of life. However, to ensure that the recruitment of participants was feasible, most of the couples recruited were from a program for young adults with autism in Florida. The study was not controlled for educational level, socioeconomic status, and social support. The lack of control of demographic characteristics might have weakened this study.

Limitations

Limitations to a study represent areas that may weaken the study findings (Ross & Bibler Zaidi, 2019). The selection of participants for this study was limited to couples who have been married for more than 18 years and are parenting their young adult child with ASD between 18 and 35 years of age. Limitations to this study include the small sample size, with most couples having their children in a program that supports young adults with autism in Florida; two couples did not have their children outside of their homes. A study with equal representation from diverse socioeconomic statuses could be beneficial.

In this study, the couple participants were largely positive about their experiences, although when they were willing to focus on the challenges that they faced, some negative experiences emerged. Notably, some couples hesitated to divulge too much information about difficult situations, as evidenced by the truncating of their interactions when the conversation became uncomfortable. An apparent lack of willingness to expose the ongoing concerns could

result in a lack of accuracy in their current experience.

This study was limited to evaluating the situations of young adults with a designation of mild to moderate autism. Given the picture shown here among the eight couple participants, this population seems unable to achieve the essential milestones of independent living, and the stresses on these couples were significant. The study highlights that a couple dealing with a more impacted young adult with severe autism would have even greater stressors imparted upon their marriage. A parallel study of couples with severely impacted young adults on the autism spectrum would unmask these issues.

Another limitation is that there were only two female young adults with ASD. Future research could seek to have an equal number of female and male young adults with ASD. The same limitation was apparent in the parents of young adults with ASD, with only one parent identifying as other than White. Future research could seek to have other ethnicities represented in their studies. Additionally, there was a relative over-representation of mainlined Christian denominations. Given the dynamics of the evangelical movement in the United States, one would anticipate that spirituality would play a more significant role in the marriage of couples attending evangelical churches.

Recommendations for Future Research

Based on this study's findings, several recommendations for further research emerged. The first recommendation would be to determine a recruitment path that would encourage greater participation among married couples who are parenting a young adult with ASD. A qualitative study is an appropriate methodology as the study seeks to understand the lived experiences of these couples, yet some couples felt that the subject was too sensitive for them to participate, and others found finding the time for both to meet was complicated.

The study could be repeated by meeting separately with long-term married mothers and fathers of young adults with autism to override the apparent inclination to truncate the conversation when meeting as a couple, and the discussion became somewhat uncomfortable to permit absolute honesty. The study could also be repeated with parents of young adults with autism who have divorced, which would offer information about whether raising their autistic child contributed to their divorce or whether other obstacles, such as upbringing, contributed to the decision to divorce.

Another recommendation is to conduct a quantitative study from different regions across the country seeking information from multiple programs for young adults with autism, inquiring how many young adults could attain independence, maintain independence with support, or need to return home. Another inquiry in that study could be to determine how many of the young adults with autism could maintain employment. This could produce information that would show more insight into the trajectory of young adults with autism, especially as it relates to the future worries of long-term married couples.

Chapter Five Summary

The research presented in this study substantially contributes to the current body of literature about the parental management of young adult children with ASD by affirming the observations of the previous literature, namely Sosnowy et al. (2018), Chen et al. (2018), Chiang et al. (2012), Herrema et al. (2017a), and Wisner-Carlson et al. (2020). The extensive parental interview process used in this study highlighted and confirmed the continual challenges facing parents of young adults with ASD. These management issues continue from childhood into adulthood and represent a continuum of care issues that, although capable of some degree of modification and maturation, persist unabated. None of the couples in this study had young adult

children with ASD exhibiting authentic independent living. The development of the four themes extracted from the thorough interview process affirmed the commonality of the stressors facing parents of young adults with autism. Mild to moderate autism may be an adequate global description of the behavior status that allows a neurotypical population at large to quantify young adults with autism but grossly understates the profound performance shortcomings and challenges young adults with ASD and their parents face. This lack of understanding by society at large has immense policy and operational implications. The inability to effectively mainstream into society any of the young adults presented in this study, despite being labeled “mild to moderate autistic,” highlights the pressing need for local, regional, and national governmental agencies to develop cohesive, uninterrupted, and comprehensive programs to deal with this growing population. The couples interviewed in this study almost uniformly benefitted from a level of financial bandwidth to allow their young adults to be enrolled in long-term independent living programs or optimize their support in the home. This financial status is a form of “symptom-masking” that blinds society to the problems all would share if these familial efforts were not present. The parental interviews of this study highlighted the anxiety and uncertainty facing this population at-risk, clearly shown in the development of Themes 1 and 2. Despite the successful marital behaviors highlighted in Themes 3 and 4, the anxiety and concerns about financial security, safety, and life satisfaction persist.

The long-term married couples interviewed and analyzed in this study were uniform in their descriptions of why they felt their marriages were successful and steadfast despite the obvious stressors of raising and coping with a young adult child with autism. This uniformity perhaps highlights a potential flaw in the methodology or an understatement of the magnitude of the problem. Having been limited in the inclusion criteria of long-term marriages of a minimum

of 18 years, the parents in this study may have been “self-selected” for success. Divorce statistics are well-documented, and they indicate that the incidence of divorce decreases in all marriages over 7 to 9 years. The likelihood of a long-term successful marriage is likely predicated on the adaptation of behaviors in couples, such as enhanced communication and an emphasis on a collective team approach, which was the skillset highlighted by the couples in this study. It could be viewed as self-evident that adaptation of these positive marital skills and attributes would lead to successful and fulfilling marriages, regardless of familial pressures such as rearing an autistic child or young adult. A mirror analysis of divorced couples with a young adult with autism might shed further light on Themes 3 and 4 and the related research sub-questions. In addition, previously highlighted in the Discussion portion of this study was the apparent truncation of conversation by both parents when the line of questioning became more challenging or uncomfortable, thereby avoiding the potential for intra-marriage confrontation in the interview. Separate individual or round-table discussions with fathers and mothers separately may have highlighted a significantly higher degree of unresolved conflict and frustration among spouses. This information could be highly informative and valuable to those parents struggling with the management of their autistic young adult. This transparency could highlight additional stressors and help develop a framework for conflict resolution and mutually acceptable coping strategies for autistic young adults and their parents. The common relationship triangulation and reaction to skill regression in the autistic young adult could be better managed given an acceptance that even in well-functioning long-term marriages, these issues present themselves.

This study highlights the importance of several marital attributes essential to the optimized nurturing of the relationship in the face of the stressors inherent in the ongoing management of a young adult with ASD. Multiple implications were identified for further

research and discussion and a societal acknowledgment of the pressing need for local, regional, and national support for families dealing with autism. The inconvenient truth in the young adult with autism population is that autism cannot be compartmentalized into a pediatric issue; the issues do not go away as a child progresses into young adulthood. Autism spectrum disorder is not something that a person can grow out of with age. The insidious persistence of the challenges extends into full adult maturity and likely contributes to pernicious societal issues of mental health, unemployment, financial dependency, and even homelessness. A societal acceptance and acknowledgment that families cannot effectively deal with this problem long-term on their own could go a long way to helping proper support channels and efforts to be coordinated.

One of the significant contributions of this research is the codifying of both the attributes and skillsets of marriages successfully coping with the challenges of raising a young adult with ASD. These skills could be pre-emptively taught to the parents of children with autism aggressively in the early stages. Intuitively, just as the literature supports early interventions for basic skills in the autistic child, parental marriage coaching, and skillset acquisition will reap long-term benefits. Optimization of the function of a marriage in the face of the stressors of raising our children with autism into adulthood is the bedrock of successful societal management of this ever-pressing and growing challenge. In addition, regardless of the description of the component of spirituality and relationship with God, the necessity of the importance of that attribute in the marriage of parents raising a young adult autistic child is undeniable in this research. Just as the rope with three cords does not break (*Holy Bible, New International Version, 2015, Ecclesiastes 4:12*), a marriage, and by logical extension, a society, thrives given that life force.

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Appendix A**IRB Approval Letter****LIBERTY UNIVERSITY**
INSTITUTIONAL REVIEW BOARD

February 2, 2024

Tawnya Fabian Don Small

Re: IRB Exemption - IRB-FY23-24-915 Effects on the Enduring Marriage of Parenting a Young Adult with Autism Spectrum Disorder

Dear Tawnya Fabian, Don Small,

The Liberty University Institutional Review Board (IRB) has reviewed your application in accordance with the Office for Human Research Protections (OHRP) and Food and Drug Administration (FDA) regulations and finds your study to be exempt from further IRB review. This means you may begin your research with the data safeguarding methods mentioned in your approved application, and no further IRB oversight is required.

Your study falls under the following exemption category, which identifies specific situations in which human participants research is exempt from the policy set forth in 45 CFR 46:104(d):

Category 2.(ii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:

Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or

For a PDF of your exemption letter, click on your study number in the My Studies card on your Cayuse dashboard. Next, click the Submissions bar beside the Study Details bar on the Study details page. Finally, click Initial under Submission Type and choose the Letters tab toward the

bottom of the Submission Details page. Your information sheet and final versions of your study documents can also be found on the same page under the Attachments tab.

Please note that this exemption only applies to your current research application, and any modifications to your protocol must be reported to the Liberty University IRB for verification of continued exemption status. You may report these changes by completing a modification submission through your Cayuse IRB account.

If you have any questions about this exemption or need assistance in determining whether possible modifications to your protocol would change your exemption status, please email us at irb@liberty.edu.

Sincerely,

G. Michele Baker, PhD, CIP

Administrative Chair

Research Ethics Office

Appendix B

Research Participants Needed

The Effects on the Enduring Marriage of Parenting a Young Adult with Autism Spectrum Disorder

- Have you and your spouse been married for more than 18 years?
- Do you have a young adult with a formal diagnosis of autism spectrum disorder (ASD)?
 - Is our young adult with ASD between the ages of 18-35?

If you answered **yes** to all of the questions listed above, you may be eligible to participate in a research study.

The purpose of this research study is to examine the impact on your marriage as you transitioned from raising a child to parenting a young adult with ASD who is still dependent on you for support.

Participants will be asked to participate in a 60- to 90-minute online audio- and video-recorded interview. A potential for a follow-up interview for clarification purposes exists and will last approximately 30 minutes. Participants will also have the opportunity to review their interview transcripts for accuracy, which will also take approximately 30 minutes.

If you would like to participate, please contact the researcher at the phone number and address listed below. A participant recruitment letter will be sent to you at that time, which will contain a screening survey for you to complete and return.

If you are deemed eligible, a consent document for you to complete will be emailed to you. A copy of the signed consent document will be provided to at the time of the interview.

Tawnya Fabian, a doctoral candidate in the School of Behavioral Sciences, Department of Community Care & Counseling at Liberty University, is conducting this study.

Please contact Tawnya Fabian at [REDACTED] for more information.

Appendix C

Participant Recruitment Letter

Dear Potential Participant,

Thank you for your interest in participating in my study. As a doctoral candidate in the School of Behavioral Sciences, Department of Community Care & Counseling, at Liberty University, I am conducting research on couples who are parenting a young adult with autism spectrum disorder (ASD) to better understand the effect that the continued support of their young adult with ASD has on their marriage. The purpose of my research is to understand the challenges facing long-term married couples whose autistic child is now a young adult and seeks to describe how the couples have overcome their trials. I am writing to invite both of you to join my study.

Participants must be married for more than 18 years and are parenting a young adult with ASD who is between 18 and 35 years of age. Participants will be asked to take part in a video- and audio-recorded online interview. The interview should take approximately 60- to 90-minutes to complete, with the potential for one 30-minute follow-up interview. The participants will be asked to review their interview transcripts to check for accuracy which should take approximately 30 minutes to complete. Names and other identifying information will be requested as part of this study, but participant identities will not be disclosed.

To participate, please print and complete the attached survey, scan the completed survey, and return it to me by email at [REDACTED]. If you meet my participant criteria, you will be contacted to schedule an interview.

A consent document is attached to this email. The consent document contains additional information about my research.

If you choose to participate, you will need to sign the consent document and return it to me. Please print and sign the consent document, scan the completed document, and return to me via email along with the participant survey document.

Sincerely,

Tawnya Fabian
Doctoral Candidate

Phone Number: [REDACTED]

Email address: [REDACTED]

Pre-screening Questionnaire

1. Is your young adult with autism spectrum disorder (ASD) between 18–35 years of age?
 - Yes
 - No

2. Have you been married for longer than 18 years?
 - Yes
 - No

3. What is your racial identification? Check all that apply.
 - Black
 - African American
 - Latinx/Latin American
 - Native American
 - Asian American/Pacific Islander
 - Asian
 - White
 - Arab American
 - African
 - Not listed (please specify) _____
 - Prefer not to answer

Appendix D

Consent

Title of the Project: The Effects on the Long-Term Marriage of Parenting a Young Adult with Autism Spectrum Disorder

Principle Investigator: Tawnya Fabian, Doctoral Candidate, Liberty University

Invitation to be Part of a Research Study

You are being asked to take part in a research study. To participate, you must be in an enduring marriage (married more than 18 years) who have raised a child with autism spectrum disorder (ASD) and that child is now a young adult between the ages of 18 and 35. Taking part in this research project is voluntary.

Please take time to read this entire form and ask questions before deciding whether to take part in this research.

What is the study about and why is it being done?

The purpose of this study is to understand the impact on your long-term marriage in the years after raising a child with ASD as you continue to parent your young adult (ASD).

What will happen if you take part in this study?

If you agree to be in this study, I will ask you to do the following:

1. Your participation will include an audio/video recorded 60–90-minute interview with the two of you together via Zoom.
2. A follow-up interview for further information or clarification may be requested. This will take approximately 30 minutes.
3. Participants will have the opportunity to review their interview transcripts to ensure accuracy, which should also take approximately 30 minutes.

How could you or others benefit from this study?

The participants will gain insight into the pathways that they utilize in maintaining the sanctity of their marriage. They may also discern new or improved ways to communicate by participating in the interview process.

Benefits to society include guidance for mental health professionals who work with families and couples who are parenting a young adult with ASD.

What risks might you experience from being in this study?

The expected risks from participating in this study are minimal, which means they are equal to the risks you would encounter in everyday life.

How will personal information be protected?

The records of this study will be kept private. Published reports will not include any information that will make it possible to identify a subject. Research records will be stored securely, and only the researcher will have access to the records. Data collected from you may be shared for use in future research studies or with other researchers. If data collected from you is shared, any information that could identify you, if applicable, will be removed before the data is shared.

- Participant responses will be kept confidential by replacing names with pseudonyms.
- Interviews will be conducted in a location where others will not easily overhear the conversation.
- Data will be stored on a password-locked folder on a password-locked computer. Any hardcopy records will be stored in a locked file cabinet. After three years, all electronic records will be deleted, and all hardcopy records will be shredded.
- Participants will review and confirm the accuracy of the transcripts. Recordings will be stored on a password locked computer for three years and then deleted. Only the researcher will have access to these recordings.

How will you be compensated for being part of the study?

Participants will not be compensated for participating in this study.

Is study participation voluntary?

Participation in this study is voluntary. Your decision whether to participate will not affect your current or future relations with Liberty University. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

What should you do if you decide to withdraw from the study?

If you choose to withdraw from the study, please contact the researcher at the email address included in the next paragraph. Should you choose to withdraw, data collected from you will be destroyed immediately and will not be included in this study.

Whom do you contact if you have questions or concerns about the study?

The researcher conducting this study is Tawnya Fabian. You may ask questions you have now. If you have questions later, **you are encouraged** to contact her at [REDACTED]. You may also contact the researcher's faculty sponsor, Don K. Small, Ph.D. at [REDACTED].

Whom do you contact if you have questions about your rights as a research participant?

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, **you are encouraged** to contact the IRB. Our physical address is Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA, 24515; our phone number is 434-592-5530, and our email address is irb@liberty.edu.

Disclaimer: The Institutional Review Board (IRB) is tasked with ensuring that human subjects research will be conducted in an ethical manner as defined and required by federal regulations. The topics covered and viewpoints expressed or alluded to by student and faculty researchers are those of the researchers and do not necessarily reflect the official policies or positions of Liberty University.

Your Consent

By signing this document, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. You will be given a copy of this document for your records. The researcher will keep a copy with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

The researcher has my permission to audio-record/video-record me as part of my participation in this study.

Participant's signature _____ Date _____

Participant's printed name: _____

Participant's signature _____ Date _____

Participant's printed name: _____

Appendix E

Confirmation Email

Date:

Recipient Names:

Dear Prospective Participant,

Thank you for completing the prescreening information and signing the consent form. After reviewing your information, you have been selected to participate in this dissertation study.

Please use this link to access my calendar and select the day and time that works best for both of you to participate in a 60–90-minute audio- and video-recorded online interview:

Upon scheduling the interview, you will receive the link to join the interview in your confirmation email. At the time of our interview, you will click the link to join the interview.

Also attached, you will find a physical copy of the informed consent document to keep for your records. If you have any questions, please contact me.

Thank you for your time, and I look forward to meeting both of you soon.

Sincerely,

Tawnya Fabian
Doctoral Candidate

Appendix F

Interview Questions

1. Where would you like to go on vacation and why? (Icebreaker question.)
2. Please tell me a little about yourself and your family that you would share with someone you are meeting for the first time.
3. Tell me about your experience when your young adult with autism spectrum disorder (ASD) graduated high school.
4. Where is your young adult with ASD now and what are they doing?
5. Describe how the challenges of raising a young adult with ASD affect your marriage.
6. Describe how you anticipated your life would be at this point in your marriage.
7. Identify periods of hope and periods of despair that occur when raising your young adult with ASD.
8. Describe to me times of turbulence in your marriage that stemmed from raising a child with autism on the way to becoming a young adult with ASD.
9. What are your top three concerns right now about the future of your young adult with ASD?
10. How do you navigate the challenges that are brought into your marriage because of your young adult with ASD?
11. Explain your relationship with your young adult with ASD.
12. To what do you attribute the success of your long-term marriage through the challenges of raising a young adult with ASD?
13. Please describe how your faith has helped you cope with the challenges of raising a young adult with ASD.

14. What advice do you have for parents who have not yet arrived at the stage of young adult for their child with ASD?
15. Thank you for your time and for your willingness to participate in this study. I have gathered a lot of information today. I would like to know if you have anything to add that I may not have asked that will enable me to garner a pretty complete understanding of your experience of parenting of a young adult with ASD at this point in your marriage.

Appendix G

Interview Protocol

Participant Invitation Process: Participants for this research study will be invited to participate in a semi-structured interview via an online platform such as Zoom or Microsoft Teams with the researcher. Prior to officially beginning each interview, the researcher will reiterate with each participant that this is a voluntary research study and that they may decide to withdraw at any time.

- Interview Setup and Location
 - Interview Location: The interviews will occur online via Zoom or Microsoft Teams
 - Materials: A Word document of the interview questions for the researcher, the researcher's personal laptop to access Zoom or Microsoft Teams, and an iPad for the researcher to record notes during the interview.
 - Interviewer: Tawnya Fabian, the primary researcher
- Interview Overview
 - The Purpose of The Study: The purpose of this transcendental phenomenological research study is to explore the effects on the enduring marriage for couples who are parenting a young adult (between 18 and 35 years of age) with mild to moderate autism spectrum disorder (ASD) and will seek to understand the challenges to the marital union as well as factors that contributed to maintaining the marriage.
 - Consent Form: The participants each completed a consent form that was attached to the participant recruitment letter. A review of the consent form will occur prior to beginning the interviews.

- Sharing Study Results: The participants will be asked to review the transcript of the interview to confirm that the data that was collected is correct and interpreted accurately, and to ensure that researcher bias was not present.
- Length of Interview: The participants will be informed that the interview will last approximately 60-90 minutes. The participants will be advised of the possibility of a follow-up interview.
- Confidentiality: A pseudonym for each participant will be provided and all recordings of the interviews will be kept on the researcher's private, password-protected laptop. Any notes created on the researcher's iPad will be transferred to the researcher's private password-protected laptop and removed from the iPad. This data will be kept for 3 years and then destroyed.

Appendix H

Research Journal Excerpts

To conform with the requirements of a transcendental phenomenological qualitative research study, the researcher is expected to bracket out notions and biases to remain neutral when gathering information. The following are several entries that were entered in a journal to fulfill this expectation.

February 22, 2024

I am excited that names of potential participants are beginning to populate, and I have reached out and have heard back from three couples. I am hoping to receive their consent forms back shortly so that I can begin to schedule the interviews.

March 7, 2024

I am now in receipt of a few more couples who might be interested in participating. The consent forms have been sent to the five couples, but I have only received back the paperwork from two of the couples. I am feeling some nervousness as finding couples is taking longer than I had anticipated...

March 11, 2024

Just heard from one couple who no longer wants to participate given the association with Liberty University. This was an unexpected turn...

March 13, 2024

I am feeling encouraged today as another couple who was identified as possibly interested have received and turned around their paperwork quickly.

March 26, 2024

I have been working to gather participants for several weeks and am looking forward to

my first three interviews in the next few days. I need to open up the pathway to finding participants and will reach out to Dr. Small and the IRB to submit a modification.

March 27, 2024

While I am still struggling emotionally not hearing from potential participants, I am eager to begin interviews tomorrow and Friday. I am anxious that the participants might have issues with connecting to the virtual meetings. And I am acutely aware of my need to maintain separation from what I am hearing from these participants and relating the information to my situation with my husband...

March 28, 2024

Nerves and anxiety as I await tonight's interview with the first couple...

The interview went very well. The couple was engaging and forthright. During the course of the interview, I was impressed by how positive they were about their son and how united they were as a couple... I am anxious to conduct my next interviews and hopeful as this one went very well.

March 29, 2024

This morning, I was eager to conduct my second interview and it did not disappoint. This couple is quite optimistic about their son and were willing to be open about their struggles with their son. They appear to have a strong marriage and have reached a solid place in their lives, at least for the moment. They express a lot of growth for their son...

March 30, 2024

I am excited to meet with this third couple as these meetings have gone well and are leaving me eager to continue to learn about other couple's experiences...

The discussion focused a lot on separation of duties with the husband working and wife deciding to stay home to care for their autistic son. I felt a sense of knowing their experience as this was similar to how my husband and I dealt with our homelife. I needed to remember that I am a professional researcher as it could have been easy to slip into discussing our commonalities!

April 10, 2024

Thankfully finally received approval from the IRB to use email to recruit participants. I have becoming more upset at the length of time it is taking to get through this process. I am continuing to reach out to the couples whom I have attempted to contact before. One couple seems quite interested but delayed our meeting noting, “When you have kids with disabilities, life can be especially unpredictable.” At this point, I am in a holding pattern with three interviews completed, four more outstanding invitations, and will now reach out to acquaintances who know of people who fit the criteria for my study. And so I pray...

April 22, 2024

I continue to send out emails and while people appear to be interested, scheduling Teams meetings is proving difficult because people are not providing me with their choice of dates. Perhaps this is because I need to have both the husband and the wife in the meeting. But I will not give up! I have a meeting scheduled for later this week, am working to schedule one with the couple mentioned on April 10th, and now have two people whom I have reached out to whose names I was given with my new participant recruitment parameters.

April 25, 2024

Was waiting for the couple to join the Teams meeting and reached out when they did not get on the meeting. Ugh. The wife forgot to put the meeting in their calendar and her husband is

out walking their dog in the dog park. This is the husband who was not sure that he wanted to participate initially. However, she was very apologetic, and we rescheduled for April 29th...

While one of the original couples (who never returned her paperwork) backed out of the study because she “is concerned about video meetings and her husband is still working and she cannot commit his time,” I have been able to arrange a meeting with a new couple that is scheduled for Sunday, so I should have five completed interviews by the evening of April 29th...

April 28, 2024

I had a quick turnaround for a couple I recruited with my new IRB parameters. This couple was enthusiastic about meeting! The wife was quite optimistic about her son’s progress especially as it relates to his social life. The family travels quite a bit, and I understood a lot about their son’s ability to be able to get anywhere in the world given my daughter’s same talent. As much as I am connecting with the stories and I am hearing, I am pleased that I am able to remove myself emotionally and am hearing the lived experiences of the participants from their point of view.

April 29, 2024

Couple six’s interview completed! This process is frustrating as I wait and wait for couples to commit and actually give me a date for the interview, but then suddenly one or two appear and I am two interviews away. The interview tonight was difficult as this couple is older and upset with where their son is now in terms of stability because he often decided to sleep through his alarm rather than to go his job. I had to remind myself that I was not here as a therapist, rather just to learn their journey...

May 6, 2024

Making progress towards the eight required interviews. Met with couple seven today.

This process of interviewing couples has really been wonderful. I am happy that I started with an icebreaker question – every couple has chuckled and had fun answering the question. I am pleased that I am able to hear the stories of the journeys of the participants and confident that I have been able to push aside my biases...

May 9, 2024

I am so frustrated with the process of recruiting participants. In hindsight I guess it is difficult for some people to discuss their marriage and they are more hesitant than I would be. The unwillingness of people to participate has been more of a challenge for me to remove myself than it has been during the interview process. I have several people who did not want to participate after they were sent the consent forms. I still have invitations out to a few people, but I am not hearing back. I may have to use the seven couples that I have already interviewed and will email Dr. Small...

May 19, 2024

Had given up hope for an eighth couple and had a random encounter with someone who knows of a couple. Reached out and the couple agreed to be part of the study! This couple is on the younger side and have a young adult daughter with ASD who clearly challenges them. I realize how many different paths people can take, but also recognize the underlying challenges that couples face together.