EXPLORING PARENTAL RESILIENCE AND THE AUTISM SPECTRUM DISORDER USING THE 2011 NATIONAL SURVEY OF CHILDREN'S HEALTH

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DEDICATION

For my family I dedicate this dissertation to my family who always believed in me and could see my strengths despite times I doubted my abilities or lacked the clarity to finish this process. Without your support this would not be possible.

Thank you!

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ABSTRACT

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This study studied the relationship between parental perceptions of stressors and indicators of resilience in families with children diagnosed on the autism spectrum. The following parental perceptions were surveyed: (a) parental coping level, (b) parental stress level, (c) child's health, (d) child's social and emotional functioning, (e) spouse/partner relationship satisfaction, and (f) overall parental health as potential indicators of parental or family resilience. Secondary data from the 2011 National Survey of Children's Health were used to examine the parent respondents (n = 1376) who were raising at least one child (ages 6-17) currently diagnosed with autism spectrum disorder (ASD). The findings of this study suggest that parental stress is impacted by parental perceptions of their level of coping as an indicator of resilience. This study's findings suggest that a parent's perceptions of their level of coping is positively correlated with parental perception of the ASD child's health, parental perception of their child's social and emotional functioning, parental relationship satisfaction and parental health of families raising children with ASD.

In addition, parents accessing the formal external support of counseling for the child with ASD as an indicator of resilience was analyzed for this research. These results

specified counseling support to be negatively correlated with parental perception of the health of child with ASD as well as the mother's perception of her overall health. However, the formal support of counseling as an indicator of resilience positively correlated with parental perception of coping, child social, and emotional functioning, father's overall health, and parental relationship satisfaction. The final indicator of resilience analyzed in this study was the informal support of parents having an individual they could turn to in a time of need. This research indicated a relationship between the presence of an informal support system for the ASD parent and their perception of spousal relationship satisfaction and overall parental health.

The study emphasized the potential benefits of incorporating indicators of resilience to counter the impact of families parenting a child with autism. Implications and recommendations for future research are presented for mental health providers, school, or community professional who are in contact with ASD families.

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INTRODUCTION

Becoming a parent can be a fulfilling and stressful experience, yet research findings indicate parents and families generally adjust and adapt to this life event (Bluth, Roberson, Billen, & Sams, 2013). Equally, researchers have found evidence to support that families with a child diagnosed with a disability are adversely impacted and approach additional uncertainty and challenges than non-affected families (Karst & van Hecke, 2012). Algood, Harris, and Hong (2013) reported similar findings, while asserting their perspective focused on research with the families that included a child with an autism diagnosis. Algood et al., 2013 specifically focused on identifying the parenting challenges for families with an autistic child. Two of the most widely investigated topics related to families affected by autism is parental stress and identifying skills that empower parents to adopt indicators of resilience to help face the pressure of parenting a child with a disability (Bayat, 2007; Algood et al., 2013).

According to the Centers for Disease Control and Prevention, there has been a sharp increase in the number of children diagnosed with various forms of developmental disabilities such as autism born into American families in the past 20 years. Approximately, one in 88 children meet the criteria for a developmental disability (CDC, 2012). The work of Greeff and van der Walt (2010) reported that one particular developmental disability remains more identifiable than childhood cancer, cystic fibrosis, and multiple sclerosis combined. This particular developmental disability is

known as autism spectrum disorder (ASD), a lifelong, neurodevelopmental disorder that typically involves significant social, communication, and behavioral challenges (CDC, 2017). The broad term, ASD, is very complex and now incorporates the traditional and early definitions of autism as well as lesser forms of developmental delays (Greeff & van der Walt, 2010).

The rise in autism diagnoses is the impetus for researchers to produce (a) quality research findings and (b) to increase our knowledge of evidence-based interventions, services, and assistance for autistic individuals and their families (Karst & van Hecke, 2012). Part of producing more quality research findings and increasing our understanding of the impact on families with autistic members is to clearly define autism symptomology and prognoses for children and parents or caretakers.

In 2013, the American Psychiatric Association (APA) published the fifth edition of the Diagnostic and Statistical Manual of Mental Health Disorders (DSM-V). In this current edition, the APA altered the diagnostic criteria and standards used to describe and diagnose autism-like behaviors to the singular term of "autism" from the original three classification levels that included, asperger's syndrome, pervasive developmental disorder, and autistic disorder (APA, 2013).

Additionally, the DSM-V outlined autism using a spectrum of diagnosis with corresponding symptomology to differentiate between the severity levels of the disorder. The DSM-V defines criteria for those individuals who are diagnosed with autism to include observable discrepancies in communication and socialization, limitations of interests, and existence of repetitive behaviors (APA, 2013). The

communication and socialization deficiencies include a lack of social-emotional reciprocity, deficits with non-verbal communication and challenges with initiating and continuing relationships suitable to the autistic individual's developmental level (APA, 2013). Restrictive and repetitive interests are the second characteristic of autism defined in the DSM-V that includes stereotyped or repetitive speech, motor movements, or use of objects, topics, or interests (APA, 2013). Inclusive of the second characteristic of autism is the presence of inflexibility with rules and routines, fixated and limited interests, and an uncommon interest in sensory responses within the environment (APA, 2013). Additional characteristics that justify the spectrum perspective of autism is the range of criteria for intellect, expressive language abilities, level of support being received and level of interests (APA, 2013). The autism diagnosis defined by the DSM-V, identifies individuals using a three-level system of support (APA, 2013). Level 1 necessitates support that includes mild deficits and the need for minimal social supports. Level 2 necessitates substantial support with moderate deficits and receiving social supports. Level 3 requires very substantial support with pronounced deficits and the need to receive social supports. The initial symptomology occurs throughout early childhood and spans a lifetime with symptoms that are limiting with an impact on daily functioning (Boyle et al., 2011).

According to Karst and van Hecke (2012), the advancement of treatment for children with autism has progressed from institutionalization to living with their families. The integration of autistic members into the family system brings about the potential for increased challenges and increased demands on parents who must provide

daily care for a child with a pervasive diagnosis (Gray, 2002; Karst & van Hecke, 2012). Over the last two decades, researchers have identified challenges and stressors facing families with a child diagnosed with autism (Bayat, 2007). Researchers conclude that the stress of parenting a child with autism outweighs that of parenting a child who is neurotypical (Algood et al., 2013; Johnson, Frenn, Freetham, & Simpson, 2011). Additionally, one such coping mechanism, adaptation, has gained notoriety in research parenting a child with a disability specifically with autism (Bayat, 2007).

Research has shown a variety of ways parents and families tend to cope with the stress of raising children with autism. One such coping mechanism is resilience, which is defined by Walsh (2003) as the ability of an individual, family, or community to rebound or bounce back from an adverse situation. In addition, Walsh (2003) extended the definition of resilience to include the individuals within the family, the family unit as a whole, as well as the larger community and societal influences, each interacting together, linking to life's challenges, and hardships. Walsh concludes that resilient parents or caretakers have a positive psychological reaction and positive outlook despite significant struggles and challenges.

The research of Bayat (2007) concurred with Walsh's analysis regarding the impact of parental outlook. Bayat (2007) proposed that parents with a child with ASD seek to understand autism and its potential impact on the family. ASD parents hope to assimilate their knowledge of autism to develop a meaningful narrative of their plight while minimizing stress and enhancing family adaptability. Bayat (2007) projected that despite the stress associated with raising a child with autism, a positive outlook towards

the diagnosis and prognosis maximizes a parent's level of functioning thus maximizing a family's level of functioning. Bayat (2007) further focused on autism as experienced by parents facing the challenges of raising an ASD child while applying the fundamental of Walsh's resilience theory.

In addition to individual and family stress, parents of children with ASD often report lower levels of relationship satisfaction (Shur-Fen et al., 2012). In contrast, other parents report that marital satisfaction can counter the stress of having a child with ASD (Shur-Fen et al., 2012). When ASD parental coping is reported to be lower, relationship satisfaction among these couples remain lower than that of neurotypical families (Shur-Fen et al., 2012). Some researchers suggest that coping styles are not the only indicator to counter the stress of parenting an ASD child. The research of Higgins, Bailey, and Pearce (2005) indicated parenting stress directly affected the husband-wife relationship. The pressure of economic hardship, careers, and demanding parental roles has affected these relationships, level of coping and resilience (Higgins et al., 2005). For this current study, the researcher compared parents' perspectives related to the autism diagnosis with specific indicators of resilience that include parental belief systems or outlooks and use of external supports.

Statement of Problem

The problematic foundation of autism within the family system centers on the diagnosis' developmental and behavioral manifestations (King et al., 2006). The work of Knestrict and Kuchey (2009) proposed that childhood is a difficult and exciting period for all parents, and when a child has a developmental challenge, the demands and

trials are magnified. When a family is faced with parenting a child with autism it can be an experience associated with confusion, uncertainty and stress (King et al., 2006).

Research findings suggest that elevated stress levels are associated with the additional responsibilities of parenting a child with autism (Gray, 2012; Neff & Faso, 2014). This increase in stress has the potential to produce complex physical and mental health concerns that directly affect a parent's ability to adapt and remain resilient over the life course (Johnson, et al., 2011; King et al., 2006). The primary symptoms of ASD are evidenced by awkward verbal or nonverbal communication, irregular cognitive processing, diminished social interactions, and behavior difficulties (APA, 2013). Greeff and van der Walt (2010) reported that these symptoms have remained the primary sources of parental stress Secondary sources of parental stress remain the negative impact ASD has on the quality of relationships within the family, and the reduction of social and community resources that support family functioning (Greeff & van der Walt, 2010; Johnson & Simpson, 2013). Lastly, the uncertainty of the effects of the autism diagnosis on the family system and the ASD child contribute to the level of stress experienced by parents anticipating their future responsibilities (Greeff & van der Walt, 2010; Johnson & Simpson, 2013).

Family resilience theory is a way of better understanding ASD families experiencing stress and dysfunctionality. Walsh (1998) identified two indicators of family resilience that will be applied to this research: family belief system/outlook and organizational trends. Walsh (1998) stated, "belief systems are at the core of all family functioning and are powerful forces in resilience" (p. 49). Walsh's conceptual

framework suggests that how a family makes meaning of their adversity, what they see the future being, and their shared narratives as empowering beliefs of the family belief system. In addition, Walsh (1998) noted that organizational patterns in family functioning point to flexibility in the family structure, how connected family members are to others, and how the family uses the resources of the extended family and the community.

Over the last two decades, resiliency research has increased, and its theoretical presence has made its way into the disciplines of human ecology, social sciences, and education (Alvord & Grados, 2005). Consequently, resilience research has evolved from a focus on the individual, as reported in the early work of McCubbin and McCubbin (1997), to a broader lends that includes the family system as posited by Walsh (2002). The increasing number of children meeting the criteria for ASD has created the need to examine the effects of stress on families and challenge researchers to define essential family strengths and external supports that maximize family functioning and resilience (Hall, Neely-Barnes, Graff, Krcek, & Roberts, 2012; King et al., 2006; McCubbin, Thompson, Thompson, & Fromer, 1998). By utilizing a national dataset that contains responses from approximately 1,500 parents of children on the autism spectrum, this study will explore their stress, coping, and utilization of resources that may lead to understanding family resilience.

Statement of Purpose

The specific purpose of this study is to better comprehend the relationship between parental perceptions of stressors and indicators of resilience in parents and families with children diagnosed on the autism spectrum. This research focused on the responses of parents of school age children from 6-17, by understanding the experiences of the current parent group an opportunity emerges to equip parents and families that are adjusting to an initial autism diagnosis with indicators of coping and resilience.

The correlation between parents' concerns about their child's behaviors, their perceptions of their child's health, their own health and relationship satisfaction and indicators of family resilience were explored. Additionally, the correlations between having external (formal and informal) supports and parental and family coping levels were examined. Finally, the correlation between parental physical and mental health, parental relationship satisfaction, and indicators of parental and family resilience were also explored.

The 2011 National Survey of Children's Health (NSCS) served as primary source for this study, the NSCS data was prepared and managed by the Data Resource Center for Children and Adolescent Health, Child and Adolescent Health Measurement Initiative. The NSCH data set provided a parental perspective of having children with special health care needs, specifically ASD. This national survey provided data that had the potential to increase awareness of the experiences of ASD families who participated in the study. In addition, this data set revealed how ASD families engage with resources to support themselves and their children. In summary, this study provided a

more comprehensive understanding of parental experiences associated with an autism diagnosis and its influence on parental outlook.

Theoretical Framework

This study was grounded using theoretical constructs and themes established by Walsh's (2003) theory of family resilience and the relationship between maternal and paternal perceived experiences of coping and functional levels. The following indicators of resilience were examined from the lens of the parent: (a) belief system/outlook, (b) accessing informal support, and (c) accessing of formal support (Walsh, 2003). Hawley and DeHaan (1996) proposed a shift from a deficit view to a strength-based perspective on resilience. Hawley and DeHaan's (1996) view evolved to suggest that family resilience levels could be influenced and modified by either risk or vulnerability factors and protective factors. Pfeffer (2014) defined risk and vulnerability factors as the challenges that keep a family from functioning at maximum levels. In contrast, protective factors minimize or eliminate the challenges that keep the family from becoming fully functional (Pfeffer, 2014). Therefore, a family's overall functioning is highly influenced by their ability to overcome the challenges with the help of protective factors. This ability to function despite the challenges is due to the family's resilience (Walsh, 2003).

Walsh (2003) presented a theory of family resilience that focused on strengthening families in the context of adversity. Walsh suggested that rather than study invulnerable individuals, a shift in focus should include resilience-based approaches to strengthen and empower families. Walsh's (2003) family resilience theory proposes that strong and

robust families exhibit maximized functioning when confronting substantial adversity, stressors, and challenges. In addition, family resilience theory defines parental strengths and family protective factors such as communication, optimistic outlook, access to external supports, and a constructive personal narrative from the challenges of parenting a child with autism (Pfeffer, 2014). Family resilience theory comprises a broader scope, not only including individuals within the family unit, but in the larger community and resources that create a recognizable influence (Hall et al., 2012; Riggs & Riggs, 2011; Walsh, 2003). Lastly, the application of family resilience theory to families raising a child with ASD will encourage the analysis and defining of essential skills for adaptability and functionality.

Research Questions/ Hypotheses

RQ1. What is the relationship between parental stress and indicators of parental resilience in families raising a child on the autism spectrum?

Ho1. There will be a statistically significant increase in stress, decrease in coping, and decrease in the utilization/availability of formal support as parental concerns about their child's behavior increases.

RQ2. What is the relationship between parental perceptions of their child's health raising a child on the autism spectrum and indicators of parental resilience?

Ho1. There will be a statistically significant increase in stress, decrease in coping, and decrease in the utilization/availability of formal support as parental concerns of the child with ASD occurs.

RQ3. What is the relationship between parental perspective about their child's social and emotional functioning and indicators of parental resilience?

Ho1. There will be a statistically significant increase in stress, decrease in coping, and decrease in utilization/availability of formal support as parental perspectives about their child's social and emotional functioning deceases.

RQ4. What is the relationship between spousal/partner relationship satisfaction and indicators of parental resilience?

Ho1. There will be a statistically significant increase in stress, decrease in coping, and decrease in utilization/availability of formal and informal support as spousal/partner relationship satisfaction decreases.

RQ5. What is the relationship between mothers' mental, emotional, and physical health and indicators of parental resilience?

Ho1. There will be a statistically significant decrease in mothers' mental, emotional health, a decrease in mothers' physical health, a decrease in coping, and a decrease in utilization/availability of formal and informal support.

RQ6. What is the relationship between fathers' mental, emotional, and physical health and indicators of parental resilience?

Ho1. There will be a statistically significant decrease in fathers' mental health, a decrease in fathers' physical health, an increase in stress, and a decrease in utilization/availability of formal and informal support.

Definitions

- Autistic spectrum disorder (ASD). ASD is a condition outlined and specifically outlined by the DSM-V criteria (APA, 2013). ASD can be observed by obvious deficiencies or struggles in the areas of development related to communication skills and social exchanges. This diagnosis includes criteria and symptomology of observable impairments in social interactions and reciprocity (APA, 2013). Individuals with ASD may present with a limited scope of activities and interest to a range of perseveration on a specific topic or interest. Individual clinical characteristics are also observable for persons meeting the diagnosis criteria of ASD such as an intellectual capability that varies (APA, 2013). Lastly, the APA (2013) concluded that ASD individuals might present deficiencies in speech and language abilities and another neurodevelopmental, behavioral or emotional challenges.
- Belief system. Belief system is the lens that allows an individual to organize experiences in the social world. This lens defined by Walsh (2003) includes a positive outlook, spatiality, and meaningful orientation of experiences.
- Family. Family is defined as a social unit or system that includes at least two individuals that may be related by marriage, family, biological, or adoption (Patterson, 2002).
- Family resilience. Family resilience is defined by the characteristics of endurance and strength that a family demonstrates after a period of adversity and excessive challenge (Benzies & Mychasiuk, 2009).

- Family perception. Family perception is the frame of reference or lens to view a situation, environment, or circumstance (Walsh, 2003).
- Formal support. Formal support is the assistance from a professional, community, or state agency provided to individuals and families (Bayat, 2007).
- Informal support. Informal support is the assistance from immediate and extended family, friends, and neighbors provided to individuals and families (Bayat, 2007).
- Parental resilience. Parental resilience has been defined by Walsh (2003) as a caretaker, parent, or individual in a parenting role that successfully maneuvers the challenges or struggles of raising a child.
- Protective factors. Protective factors are characteristics or qualities of an individual or family that helps support or forecast positive outcomes under challenging or adverse situations, environments or conditions (Pfeffer, 2014).
- Risk factors. Risk factors are those features or challenges believed to contribute to higher probability of an undesirable outcome (Masten, 2001).
- Resilience. Resilience has been defined by Walsh (2002) as the strength and ability of an individual to recover or rebound post crisis, trauma, or a challenge. Walsh believed a resilient individual is more fortified to face adversity or challenges that come their way.

Assumptions

The theoretical and design assumptions for this study remained anchored in the family resilience theory using quantitative secondary data to investigate if the stress or

strain of parenting a child with autism influences or alters maternal, paternal, and family resilience. This study assumed an inferred relationship between parental stress and family resilience. It also assumed that family resilience does not cause or increase the stress level of parents who are raising a child with ASD.

Additional assumptions included the use of reliable, ethical research protocols by the national survey, and efficient data collection from study participants. The research survey and demographic survey include self-report data that depend on participants' capacity to recall and provide truthful and accurate self-reflection. This self-report survey also relied on participants' ability to comprehend the questions, and their inclination to share responses or personal information accurately.

This study also assumes that each participant gave consent at the onset, fully understood the purpose of the surveys, and fully comprehended the survey questions provided throughout the demographic survey. Each respondent was informed of the confidentiality of his or her responses and the procedure to ensure privacy. It was assumed all participants had a telephone available to them for access and completion of the telephone survey or ability to receive and return mailed surveys. It is also assumed that each participant understood the English language. It is assumed that the protocols followed for the national survey reached a diverse population, representative of various age ranges, regions, and socioeconomic levels.

Delimitations

The first delimitation of this study necessitated the meeting of the first participant criteria: (a) female and male caretakers, (b) biological/adoptive parents, (c) step/foster

parents, or (d) extended family members who assumed the parenting role of a child with ASD. The second delimitation relates to the age range of the child who held the primary diagnosis of autism. Currently, the age range of the child for this study spans from 6-17 years. Lastly, the NSCH data source was integrated into this study. The NSCH was selected in hopes to gain insight into autism, family resilience, individual stress, and parental resilience.

Summary

As autism diagnoses have increased, there has been a rapidly growing group of parents seeking effective services, resources and evidence-based interventions to help ensure a brighter future for their children (Greeff & van der Walt, 2010; Solomon & Chung, 2012). With the increase in families seeking support, resiliency researchers have begun to explore the impact of receiving an ASD diagnosis and various coping strategies that may serve to effectively circumnavigate the autism pathway with a resilient spirit (Firth & Dryer, 2013). As mentioned previously, stress is consistently linked with parenting a child with a disability, and ASD in particular. Parents living with an autistic family member must find ways to regulate their stress levels and adjust effectively to meet their child's needs.

Within families parenting a child with ASD, researchers suggested there is a varying relationship between stress and the indicators of resilience (Bayat, 2007). Depending on this relationship, there remains the potential for families to achieve maximum functional levels or block optimal functional levels (Watt & Wagner, 2013). Therefore, it is possible to maximize functional levels in families with an autistic child by

enhancing or building parental strength and resilience. This study used the family resilience theory, quantitative method, and a non-experimental design to extend the current research literature on parental and family resilience. This task was be supported by exploring the relationship among various indicators of parental resilience and families impacted by ASD. In addition, data results indicated if parental perceptions of stressor adversely affect individual and family resilience. The results of this study may affect future research by defining characteristics of family resilience and commonalities of family outlook regarding the prognosis, and adaptability of the child with ASD.

CHAPTER II

REVIEW OF LITERATURE

Introduction

The anticipation of a pending birth or adoption can result in a range of emotions of excitement and often the process of adapting is lost in the eagerness or uncertainty facing the responsibilities of being a parent (Bluth et al., 2013; Condon, Boyce, & Corkindale, 2004). A child born with a disability can result in a change in parental dreams for the future of the child, but also a loss of many significant relationships in the lives of the parent, leading to feelings of grief and loneliness (Bluth et al., 2013; Gray, 2002; Obrien, 2007).

Knestrict and Kuchey (2009) contributed to the research on the impact of parenting a child with a disability. These researchers work proposed that parenting a non-disabled child can be challenging but in contrast, the demands of parents caring for a disabled child are significantly augmented. The severity or range of symptomologies such as physical limitations, developmental disabilities, behavioral challenges, and chronic medical conditions increase the stress of parenting a child with a disability (Knestrict & Kuchey, 2009; Simon-Tov & Kaniel, 2011). The increased demands and challenges of caring for a disabled child require an increased level of resilience, coping, and adaptability for parents that exceed that of families with healthy or non-affected children (Knestrict & Kuchey, 2009). Parental depression, anxiety, marriage problems, financial stress, family functioning difficulties, and reduced parental physical and

mental health were found to be predictive symptomology of parenting a child with a disability (Obrien, 2007; Johnson et al., 2011). The autism diagnosis results in a maximum level of parental stress as compared to neurotypical children and those with other disabilities (Dabrowska & Pisula, 2010; Daire, Munyon, Carlson, Kimemia, & Mitcham, 2011; Simon-Tov & Kaniel, 2011). There are pervasive, persistent, and unescapable stressors inherent in parenting a child with ASD (Obrien, 2007; Pisula, 2006; Simon-Tov & Kaniel, 2011).

This literature reviews defined variables that encourage family resilience and adaptability of parenting a child with ASD. This chapter will include an overview of the prevalence, diagnosis and various issues associated with living with ASD, and the construct of resilience and the impact of ASD symptomology and on parenting stress. By probing the affect autism has on parents who are a vital part of the family system, the necessary factors for these families to build or maintain their resilience will be determined. By conceptualizing the narrative of parents raising a child with ASD, mental health professionals, educators, and community and government entities can begin to offer social and emotional supports that build resilience.

Prevalence of Autism

Nationwide research conducted in 2012 by the CDC concluded that one in 88 children are diagnosed with ASD. In addition to the 2012 findings the CDC funded the Autism and Developmental Disabilities Monitoring Network (ADDM), which followed the number and characteristics of children with ASD and other developmental disabilities in 14 states: Alabama, Arizona, Arkansas, Colorado, Florida, Georgia,

Maryland, Missouri, New Jersey, North and South Carolina, Pennsylvania, Utah, and Wisconsin. Baio (2008) reviewed the findings of the ADDM and the CDC research indicated that the diagnosis remained higher in boys at a rate of one in 54 to a rate of one in 252 in girls. In addition, Baio (2008) supported prior research findings that indicated white children were more often identified with ASD than any other minority group. The ADDM also concluded that ASD is one of the few developmental disabilities that a positive correlation exists between prevalence of the condition or symptomology and socioeconomic status (SES) (CDC, 2012). Lastly, Baio (2008) concluded that ASD was identified as the fastest growing developmental disability in the United Stated with an annual growth rate of 10% to 17% with an average of 67 children diagnosed a day. From a global perspective, Baxter et al. (2015) concluded that the rate of the ASD diagnosis has increased on a worldwide scale with an approximation of 52 million reported occurrences internationally.

Autism Evaluation

The initial diagnosis for autism follows a set of assessment and evaluation protocols (CDC, 2012). A complete observation of the child, parent and child interviews, self-report surveys inclusive of educators, and analysis of a developmental history constitutes the qualitative and quantitative diagnostic process for diagnosis (CDC, 2012). Autism researchers recommended that earlier behavioral intervention and diagnosis of ASD will optimize the effectiveness of treatment modalities and programs designed for the child, parents and family system (Eikeseth, Smith, Jahr, & Eldevik, 2007). The evaluation of autism signs and symptoms can become evident as

early as 18 months in children, but treatment for the diagnosis is not typically available until age four (Eikeseth et al., 2007). In contrast, Mandel, Novak, and Zubritsky (2005) concluded that children in rural areas exhibited an even later diagnosis age. In 2012, the CDC suggested that during regular checkups, pediatricians should complete a full developmental assessment on infants, toddlers, and children who profile for a developmental delay. Children who meet this criterion would then be referred by the pediatrician to local child development and intervention programs. Additionally, the need for a comprehensive assessment for ASD would possibly make it necessary for the pediatrician to make a recommendation to a developmental pediatrician or psychologist (CDC, 2012).

Autism Diagnosis

Since the origins of autism in 1943, an evolution of the definition and understanding of this phenomenon has continued. Leo Kanner (1943) an Austrian-American psychiatrist and physician was the first to diagnose early infantile autism in children in 1943 (Qian, 2011). He initially believed this disorder to be defined by speech deficits, specific speech patterns, need for predictability and uniformity, limited adaptability to change and astonishing recall capabilities. In 1943, Leo Kanner published an early article of autism entitled *Autistic Disturbances of Affective Contact*, in which he conducted qualitative research providing context of the family experience of 11 children presenting with autism symptomology (Qian, 2011). Kanner's (1943) research determined that children with autism exhibited consistencies with socialization challenges that included a trend of limited interest in social play with peers and deficits

with social reciprocity (Firth, 1991; Qian, 2011). In addition, Kanner determined the potential of additional deficits in communication, sensory responsiveness, prevalence of stereotypical behaviors that included hand flapping or concentrated body rocking, and limited interests and activities (Blancher & Christensen, 2011; Qian, 2011).

Additionally, Kanner's qualitative research determined the presence of coexisting symptomologies in children with ASD such as emotional disturbances, anxiety, frustration and anger dysregulation (Blancher & Christensen, 2011; Qian, 2011). Early researchers proposed that autism was a spectrum of symptomology marked by communication deficits that range from a more developed functioning level to a lesser level of functioning to include non-verbal abilities (Firth, 1991; Ganz, Kaylor, Bourgeois, & Hadden, 2008; Siller & Sigman, 2002). Kanner concluded from his years of extensive research that many children and young adults were misdiagnosed with schizophrenia as opposed to a more accurate diagnosis of autism (Qian, 2011). There remains a presence of Kanner's research findings in a majority of current research on autism (Blancher & Christensen, 2011).

In addition to Kanner's work, the evolution of autism diagnosis can be traced to the work of Austrian pediatrician, professor, medical researcher, and theorist, Hans Asperger who authored *Autistic Psychopathology in Childhood* in 1944 (Blancher & Christensen, 2011; Firth, 1991). Asperger and Kanner independently described the exact same kind of child while agreeing on the identifying diagnostic criteria that included moderately normal IQ, deficient speech abilities, and challenge with social communication and nonverbal skills (Blancher & Christensen, 2011; Firth, 1991).

Asperger's research findings on diagnosis, prognosis, and treatment outcome helped to extend the body of research and knowledge of autism. In addition, Asperger identified autism as a spectrum of ranging abilities and deficits with contributing symptoms of attention deficits and associated learning disabilities (Blancher & Christensen, 2011). Qian (2011), a researcher of Kanner's and Asperger's works and philosophy of autism symptomology, concluded that ASD remains one of the most studied and researched issues in child disorders and special education.

The earliest study of autism diagnosis and research progressed resulting in the 1980 recognition and initial criteria outlined by the APA for Infantile Autism in the DSM-III. The revision to the DSM-III autism diagnosis included new areas of diagnostic criteria that encompassed deficits in socialization and communication, repetitive behaviors, and limited interests. Later in 2000, the APA published another change to the measures of autism in the DSM-IV-TR to include pervasive developmental disorder (PDD). The PDD criteria provided an inclusive grouping of disorders that included autistic disorder, asperger's disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), rhett's disorder and childhood disintegrative disorder (APA, 2013).

In 2013, the most recent publication of the DSM-V, the APA voted to eliminate the Asperger's classification and included a three-point severity scale and two criteria areas to define a new diagnosis for autism. The graduated severity scale specifies a progressive level of support: (a) Level One for an individual requiring support, (b) Level Two for an individual requiring substantial support, and (c) Level Three for an

individual requiring very substantial support. The revised criteria included persistent discrepancies in social communication and social interactions across various settings. These subsequent criteria included motor movements, inflexibility on routines, restricted/fixed interests, reactive to sensory input, or uncommon interested in sensory features of the environment (APA, 2013).

Symptomology

The term *spectrum* in ASD means that every individual can be impacted in diverse ways, and symptoms can range from minimal to extensive limitations as well as abilities (Baio, 2008; Ben-Itzchak & Zachor, 2007). Despite multiple symptoms of an individual with ASD, how the symptoms affect a person's or family's functioning is contingent on the intensity and grouping of those symptoms (Ben-Itzchak & Zachor, 2007; Hayes & Watson, 2013). ASD is a developmental disability that is distinguished by variances in how the brain functions and tests a person's understanding of their surroundings and interaction to changes within an environment (Baio, 2008; Hayes & Watson, 2013). From the origins of the diagnosis, to the core elements of the symptomology and behaviors, clinical manifestations, and developmental dimensions can be observed across the lifespan (Baio, 2008; Ben-Itzchak & Zachor, 2007).

Researchers have used the term *triad criteria* for an ASD diagnosis when social interaction skills and reciprocal social communication are diminished and repetitive behaviors or restrictive interests are detected (Hobson, Tarver, Beurkens, & Hobson, 2015). These features or symptoms, according to the DSM-V, must first be presented during the early development of a child with recognizable deficits in social,

occupational, and other areas of functioning (APA, 2013). It has been determined that children with ASD demonstrate communication discrepancies and challenges with social reciprocity as well as struggles with cognitive processing and adaptability (Ganz et al., 2008; Huang et al., 2014). The children with ASD developmental skills have been observed to be frequently unpredictable, while their responses to interventions fluctuate, and they may participate in self-injurious, aggressive, or inflexible behaviors that may affect the entire family's functioning (Huang et al., 2014). Children with ASD have often demonstrated various discrepancies related to ASD symptoms that might have an influence on family functionality and well-being (Benson, 2006; Huang et al., 2014).

A variety of common or fundamental symptoms are presented with a child with ASD, each symptom presenting differently in each individual with varying degrees of intensity (Hayes & Watson, 2013). Parents or primary caretakers are challenged with addressing the behaviors that originate from these fundamental symptoms (Hayes & Watson, 2013; Huang et al., 2104). Researchers (Hobson et al., 2015; Huang et al., 2014; Rao & Beidel, 2009) determined that the intensity and severity of ASD symptomology could be associated with the amount of stress parents report. It was concluded that as core autism symptoms and behaviors increase, parents' self-reported stress also increased (Benson, 2006; Rao & Beidel, 2009).

Beurkens, Hobson, and Hobson (2013) and Huang et al. (2014) concluded that children with ASD display a lack of connectedness or attachment as observed by interactions that are void of affection to their parents, caretakers or other individuals.

The early work of Asperger (1944) and Huang et al. (2014) posited that children with ASD do not characteristically express affection to other people. Hans Asperger and the research of Serta (2012) concluded the children with ASD demonstrated a comfort in relating or connecting to objects that they have an exceeding interest. In addition, researchers reported children with ASD demonstrated challenges with understanding social norms, communicating emotions and connecting socially to others effectively (Beurkens et al., 2013; Huang et al., 2014).

Social Communication

Deficits in verbal communication skills remain a major area of parental concern and a constant symptom of ASD specific to social communication skills and functional language (Bianco et al., 2018; Ganz et al., 2008; Siller & Sigman, 2002). The child with ASD demonstrates a range of communication levels from extensive verbal abilities and potentially unlimited vocabulary to a non-verbal response (Bianco et al., 2018; Ganz et al., 2008; Siller & Sigman, 2002). Researchers indicated that both extremes of communication from the child with ASD could elevate parental stress levels (Siller & Sigman, 2002). The acquisition of verbal communication skills remained delayed and progressed at a slower pace than neurotypical children (Siller & Sigman, 2002). Many children with ASD struggle with the ability to effectively communicate needs or desires with regulated inflection, speech tone or word choice (Bianco et al., 2018; Siller & Sigman, 2002). Earlier research addressed Echolalia, a communication pattern of repeated or echoed words or phrases that were previously heard were observed by children with ASD with limited verbal abilities as a means of communication (Firth,

1991). Researchers defined that interaction and cooperative interaction levels between children with ASD and parent or caretaker remained a predictor of language development (Bianco et al., 2018; Siller & Sigman, 2002).

The impaired interpretation of non-verbal facial expressions and misinterpretation of messages received in communication affected receptive language skills in children with ASD (Ingersoll, Dvortcsak, Whalen, & Sikora, 2005; Siller & Sigman, 2002). Language and communication challenges were central to ASD including challenges with processing verbal and nonverbal input and generating verbal communication/output (APA, 2013) The exchange of input or communication can improve by mastering social or pragmatic language (Ingersoll et al., 2005). This challenge with pragmatic language included understanding tone and inflection in voice and nonverbal language such as body language and gestures (Ganz et al., 2008; Ingersoll et al., 2005; Siller & Sigman, 2007). Earlier research indicated that figurative language and making inferences in communication and written scripts of children with ASD can be a challenge due to a trend toward rigid or concrete cognitions among the individuals with ASD (Ingersoll et al., 2005). Speech and language challenges directly affected the child's capacity to comprehend reading, and express himself or herself when writing and speaking (Bianco et al., 2018; Ganz et al., 2008; Ingersoll et al., 2005). As indicated by earlier researchers, a deficit in communication skills leads to increased emotional dysregulation and problematic behaviors in a child with ASD resulting in elevated parental and caretaker stress (Bianco et al., 2018; Ingersoll et al., 2005).

Sensory Processing

One of the most common co-existing behaviors in children with ASD was the presence of sensory processing challenges and concerns specific to auditory input (Tomcheck & Dunn, 2007). Schaaf, Toth-Cohen, Johnson, Qutten, and Benevides (2011) supported prior research (Ben-Sasson, Hen, Fluss, Cermak, & Engel-Yeger, 2009) that 80% of children with ASD experienced a form of sensory processing challenges. The original work of Kanner (1943) determined that when an aversive stimulus was presented to many children with ASD, an aversive emotional or behavioral reaction such as screaming or pushing others to escape the loud noise could be observed. Schaaf et al. (2011) reported resistant or aversive responses from children with ASD could also be observed with sensitivity to texture, odor, or color of foods when eating. Researchers (Ben-Sasson et al., 2009; Schaaf et al., 2011) reported that sensory challenges negatively affected the day-to-day lives of ASD children and their families by reducing the opportunities for normalized socialization. These individuals and families were confronted with purposefully planning around or avoiding specific activities (cooking, cleaning, eating, bathing, and sleeping) while establishing and maintaining routines for minimizing sensory input and maximizing sensory regulation (Schaaf et al., 2011). It remained evident that numerous adjustments to the home, school, or social routine can elevate the stress level of parents and caretakers of children with ASD resulting in minimizing or withdrawal from social events and activities (Ben-Sasson et al., 2009; Schaaf et al., 2011). This withdrawal or avoidance of family or

community social opportunities have led parents or caretakers to feel isolated and segregated from family and friends (Ben-Sasson et al., 2009).

Restricted Repetitive and Stimming Behaviors

There remained a range of repetitive behaviors, from the very noticeable to the subtler and more difficult to detect, such as eye rolling or blinking, body movements, finger tapping, arm flapping and hair pulling (APA, 2013; Qian, 2011; Serta, 2012). According to the DSM-V (APA, 2013), restrictive repetitive behaviors include repetitive speech or physical movements, insistence on the maintaining of patterns or routines, restrictive interests on objects or activities, and abnormal sensory interests. These non-functional behaviors, including stereotyped and repetitive movements, and impulsive outbursts, have been seen in children with ASD (APA, 2013; Serta, 2012). Qian (2011) referred to these repetitive behavioral reactions as stimming, a self-stimulating behavior employed to block out the stimuli or overwhelming demands while offering the ASD child calming sensory input and relief. These stereotyped reactions to stimuli often resulted when the ASD individual experienced frustration, excitement, stress, anxiety, pleasure, or escape, and avoidance from a task (Kennedy, Meyer, Knowles, & Shukla, 2000; Qian, 2011; Serta, 2012).

In addition to repetitive or stereotyped behaviors, children with ASD may exhibit an overwhelming interest in objects and rigidity faced with a change to a schedule, plan, or routine (Firth, 1991; Qian, 2011; Serta, 2012; Schaaf et al., 2011). These repetitive behaviors and perseverations on interests or specific topics are restrictive in nature by negatively affecting a child's educational and social

opportunities (Kennedy et al., 2000; Qian, 2011; Schaaf et al., 2011). Children with ASD are typically found to have a single specific interest at a time (Schaaf et al., 2011). As they developed and experienced more exposure to alternatives, changes in interest were likely to occur (Serta et al., 2012). These repetitive behaviors and limited or narrowed interests remain a challenge for children with ASD and parents, possibly limiting family activities or social opportunities (Qian, 2011; Schaaf et al., 2011; Serta et al., 2012).

Comorbidity Behaviors and Emotional Issues

Nearly three quarters of children with ASD have been found to have another medical or psychiatric condition, referenced as comorbidity or co-occurring (Joshi et al., 2010; Mannion & Leader, 2013). Researchers report co-occurring or comorbid conditions are found to appear at any time during an individual's development (Mannion & Leader, 2013). Researchers (Joshi et al., 2010; Mannion & Leader, 2013) determined that children with autism experienced and responded to externalizing triggers of behaviors, atypical sensory responses, erratic sleep patterns, self-injurious behavior, and displays of emotional dysregulation. Co-occurring behavioral outbursts challenged the parents and caretakers of children with ASD presenting with a range from regulated to impulsive and non-compliant aggression (Joshi et al., 2010). These responses for a child with ASD adversely affected the parent and caretaker relationship, peer relations, and potentially minimized social interactions and learning opportunities (Joshi et al., 2010; Mannion & Leader, 2013).

Children with ASD often have problematic behaviors and emotional challenges along with the core symptoms of autism (Leyfer et al., 2006). These disturbances of attention, cognitions, and emotions remain prevalent in children with ASD of all ages (Leyfer et al., 2006). Dawson and Burner (2011), Joshi et al. (2010), Rao and Beidel (2009) reported that approximately half of all children with ASD engaged in some form of self-harm or self-injurious behavior that included hitting, kicking, biting, scratching, and hair pulling. Physical and verbal aggression or frustration can be observed by children with ASD in the form of physical aggression towards others correlated to complications with social and pragmatic communication (Joshi et al., 2010). Parents of children with ASD are challenged with the stress of ensuring safety for their children, in addition to providing costly behavior, social, and psychological treatments to minimize the potential for self-injury (Joshi et al., 2010). In addition to self-injurious or aggressive behaviors, Leyfer et al. (2006), Mannion and Leader (2013), Rao and Beidel (2009) indicated a trend towards more outward aggression from ASD children is directly linked to the inability to effectively relate or communicate with others.

The aggressive actions of children with ASD produce heighten stress and fear in parents or caretakers, often restricting the inclusion of family and child in social, community, and academic opportunities (Leyfer et al., 2006; Rao & Beidel, 2009). In addition to the challenges of parents managing aggressive behaviors, parents are required to face the challenges of ensuring and advocating for services, academics accommodations, social opportunities, and evidence-based treatments (Rao & Beidel 2009). The child with ASD lacks self-regulation skills and demonstrates aggressive

behaviors to others will limit the opportunities to interact appropriately with others without training for the child and advocacy skills by the parents (Leyfer et al., 2006).

The child with ASD will likely experience the co-occurring internalizing behaviors of emotional disturbances evidenced by attention deficit hyperactively disorder, anxiety, withdrawal, disobedience, and depression (Hartley et al., 2011; Leyfer et al., 2006). Children with ASD that profile with a higher level of functioning are reported to be an elevated risk for mood disorders, social anxiety, depression, and suicidal behaviors (Chalfant, Rapee, & Carroll, 2007; Rao & Beidel, 2009).

Due to the challenges of children mastering social rules and norms as well as understanding the world around them, the pervasiveness of social anxiety and autism remain prevalent (Rao & Beidel, 2009). Researchers indicate that 80% of individuals with ASD have anxiety symptoms (Leyfer et al., 2006; Rao & Beidel, 2009). The origins of the child's anxiety has the potential to be numerous and difficult for parents and caretakers to identify and provide specific interventions or solutions (Leyfer et al., 2006; Sofronoff, Attwood, & Hinton, 2005). Among the many reasons for anxiety for children with ASD include change in routines and schedules, new activities, unfamiliar people or environments, sensory concerns, decision making, and transitions of activities or events (Leyfer et al., 2006). It was reported that parents of children with ASD often face oppositional and challenging behaviors, increase in daily demands, elevated emotional, physical, and financial stress (Algood et al., 2013).

The research of Benson (2006) indicated that the associated behaviors of a child with ASD would place parents or caretakers at greater physical risk and emotional

distress. The results of co-existing behaviors such as unregulated coping and noncompliance are associated with heightened parental stress beyond that of core autism symptomology (Huang et al., 2014). Benson (2006) concurred with other researchers that there remains a trend in increase of parental stress with a proportional increasing emotional dysregulation and problematic behaviors of children with ASD.

Other ASD Issues

Sleep pattern disturbances for children with ASD also remained elevated as the increase in core symptoms of autism became more prevalent (Moss, Gordon, & O'Connell, 2014). The direct impact of the child's sleep disturbance resulted in challenges for the entire family, including difficulty falling and staying asleep and waking early, resulting in sleep deprivation, irritability, and emotional and physical fatigue (Giallo, Wood, Jellett, & Porter, 2016; Kuhaneck, Madonna, Novak, & Pearson, 2015; Moss et al., 2014). Additionally, researchers (Giallo et al., 2016; Kuhaneck et al., 2015) reported that many parents reported that being emotionally and physically fatigued from sleep deprivation directly affected their ability to meet the daily demands of parenting a child with ASD. The child who experiences an irregular sleep pattern may display challenges with emotional regulation due to extreme fatigue or lack of sleep at night. Johnson, Giannotti, and Cortesi (2009) reported that children with ASD have a significantly greater chance to experience chronic insomnia than neurotypical children, and the impact on quality of life and general happiness of parents and children can be felt.

Gastrointestinal (GI) challenges for children with ASD can include a range of symptoms from minor stomach pain, nausea, reflux, constipation to diarrhea (Kuhaneck et al., 2015; Peters, 2014). These GI problems may have been associated with anxiety, social issues, behavioral responses, and dysregulated sleep (Mazurek et al., 2013; Peters, 2014). Researchers indicated that parents and caretakers of children with ASD attempted to reduce the GI symptoms with costly and time-consuming diets (Kuhaneck et al., 2015; Mazurek et al., 2013). Coury et al. (2012) challenged researchers and clinical practitioners to acknowledge the role of GI comorbid conditions in children with ASD and the impact on parents.

Prognosis

Researchers have publicly proclaimed that the variations of symptomology and prognosis of autism are numerous and unique to the many individuals diagnosed with ASD (Ben-Itzchak & Zachor, 2007; Grandin, 1992). Dr. Temple Grandin, a professor with ASD and autism spokesperson, has stated, when you meet a person with autism, you have only met one person with autism (Grandin, 1992). Dr. Grandin often speaks from her own life experience with ASD to parents and caretakers who are concerned about the outlook or prognosis after the ASD diagnosis. Parents and caretakers desire a better understanding of the symptomology and necessary treatment interventions to optimize the prognosis across the lifespan of the individual with ASD (Ben-Itzchak & Zachor, 2007).

No finite response or answer from a medical professional or researcher has been suggested to parents or caretakers who have apprehensions about the future of their

child with ASD (Coplan, 2000; Grandin, 1992). However, Dawson and Burner (2011) concluded that the presence of other conditions or comorbid symptomologies were coincided with autism and can affect the prognosis of the individual with ASD. According to researchers, individuals with ASD who possessed a cognitive level of an intellectual quotient (IQ) above 70, language skills and presence of verbal communicative speech before the age of 6, predicted a more optimistic outlook and prognosis (Ben-Itzchak & Zachor, 2007).

Regardless of the absence of an irrefutable cure for autism, Zachor and Ben-Itzchak (2010) suggested that early diagnosis and implementation of evidence-based treatment methods and interventions will result in the closing of developmental gaps and other challenges associated with an ASD. Recommended treatment modalities outlined by the National Institutes of Health (NIH) included the following: behavioral management therapy, cognitive therapy, education and school-based therapies, medication treatment, occupational therapy, parent training, physical therapy, social skills training, and speech-language therapy. Zachor and Ben-Itzchak (2010) suggested the earliest development of a treatment plan that collaborates unique treatment methods to the unique needs of the individual with ASD and family will optimize the ASD prognosis.

Woodman, Smith, Greensburg, and Mailick (2015) proposed the life expectancy of the child with ASD remains normal, but functional level of individuals with ASD range from independent and autonomous to required lifelong support. The majority of individuals identified in childhood continued to meet the conditions for ASD diagnosed

in adulthood (Woodman et al., 2015; Gray, 2002). The individuals with ASD functional level was contingent on the symptom severity, development of daily living skills as well as access to treatment (Woodman et al., 2015). Individuals with ASD commonly demonstrated improvements in daily living skills across the life span with effective training and support. The progression of daily living skills, adaptability, social skills and effective communication, maintaining employment was found to be likely among individuals with ASD (Gray, 2002; Woodman et al., 2015). However, adults with ASD who have a reduced level of mastery with the prior skills resulted in a negative impact on functional level and quality of life (Woodman et al., 2015).

Researchers proposed that a parent's belief, attitude and behavior towards their child's autism played a pivotal role in the prognosis and outlook for the future and family interaction level (Thomas, King, Mendelson, Nelson, & Gray, 2017; Zhou & Yi, 2014). Thomas et al. (2017) concluded that parent expectation and outlook for children with ASD in secondary school predicted future employment more than supportive resource accessibility, autonomy skills, and social communication skills. The relationship between a child with ASD and parent was contingent on positive parental belief of their child's future, parental emotional coping abilities, and severity of autism symptomology (Hobson et al., 2015; Sikora et al., 2013). The finding of Thomas et al., (2017) supported prior research findings (Hobson et al., 2015; Sikora et al., 2013) indicating that the emotional regulation of the parent and the symptomology severity of the ASD influenced 51% of parent expectations of their child with ASD. Research encouraged parents and caretakers to counter the emotional reactions to depression,

anxiety and frustration as an essential intervention to increase a vision of optimism for the future for their child with ASD (Hobson et al., 2015; Sikora et al., 2013; Thomas et al., 2017).

Child Development

Children with ASD do not follow a typical profile child development (Szatmari, et al., 2009). In some children with ASD, foreshadowing of imminent difficulties may be apparent from birth (Szatmari et al., 2009). The difficulties become more visible during early childhood through adolescence as the child with ASD may demonstrate gaps in development from neurotypical children the same age (Szatmari et al., 2009). These developmental gaps in children and adolescents with ASD who attend school are often initially recognized by parents and teachers that request an evaluation by the school's special education team (Szatmari et al., 2009). Parents and teachers may agree on the social difficulties and communication challenges characteristic in early diagnosis of school age children. Older children and adolescents may have trouble with social communication and forming friendships with peers (Szatmari et al., 2009).

The indicators of autism in the young child and adolescent are often observed as developmental deficits when compared to non ASD individuals (Smith, Maenner, & Mailick, 2009). There has been a limited amount of research describing the life course indicators of autism. However, some researchers specify a modest improvement of symptoms is apparent in some individuals from childhood to adolescence and into adulthood (Smith et al., 2009). Despite the improvements, results infrequently reach a level of functioning in the typical range (Smith et al., 2009). This belief strengthens the

theory that autism is commonly a lifelong issue. In addition, ASD improvement is not observed for all behaviors and not all individuals with ASD flourish (Smith et al., 2009).

The lack of essential life, communication and self-regulation skills of children with ASD have been determined to have a negative impact on parent and family functioning (Anderson, Maye, & Lord, 2011). Families are overcome by the challenges associated with rearing and supporting family members with autism (Anderson et al., 2011). Currently, there is an emphasis on initial discovery so that interventions can be applied that minimize ASD challenges while building adaptability for families facing these life circumstances (Anderson et al., 2011). This study attempted to determine the impact of autism on specific indicators of resilience of parents rearing a child with ASD between the ages 6-17. By taking account from the parental experience with school age children with ASD, families that are early in the diagnosis phase may be empowered to face the impending challenges of autism.

Resilience Theory and Indicators of Resilience

Greef and van der Walt (2010) reported that due to the severity of the ASD, several families have reported that parenting a child with autism can challenge understanding of the diagnosis, as well as acquiring essential skills to cope with the needed changes in the home for stability (Bekhet, Johnson, & Zauszniewski, 2012). It becomes vital for families living with an ASD to determine the key factors of resilience that support adaptability resulting in a stronger family outcome (Bekhet et al., 2012). The central position of resilience theory was to identify specific characteristics and

resources that individuals and families have that shape and maintain adaptation even with the presence of a crisis (Simon, Murphy, & Smith, 2005). Resilience has been defined by the pioneers of research and construct development as, "The process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances" (Masten, Best, & Garmezy, 1990, p. 426). It has also been defined as, "A dynamic process encompassing positive adaptation within the context of significant adversity" (Luthar, Cicchetti, & Becker, 2000, p. 543). Masten (2001, p. 228) defines, resilience as "a class of phenomena characterized by good outcomes in spite of serious threats to adaptation or development," and Walsh (2002, p. 130), described, it as the "capacity to rebound from adversity strengthened and more resourceful."

It is essential for researchers to understand why some families faced with the challenge of autism vary from adaptable to adverse reactions (Bayat, 2007; Bekhet et al., 2012). When a child is first diagnosed with ASD, it can have a less than favorable impact on relationships in the family, family routines and roles, while increasing stress, and require psychological adjustments for everyone (Rao & Beidel, 2009). Bayat (2007), Rao and Beidel (2009) determined that resilience is influenced by factors that combine to support growth and empowerment for adaptability in the family system.

The resilient family facing an ASD establishes beliefs and practices that allow them to navigate the most difficult challenges while providing increased family cohesion (Greef & van der Walt, 2010). There are many variations of resilience definitions mostly focusing on children who have demonstrated adaptive tendencies in less than ideal environments. The concept of resilience has transitioned from a

viewpoint of internal personality trait to more of a process within the individual. The research of Luthar et al., (2000) proposed that resilience is not a construct that is immobile or motionless, but may be variable and moving over the course of an individual's life or continuation of a family. This fluidity of resilience has been noted by researchers of ASD (Bekhet et al., 2012; Greef & van der Walt, 2010; Luthar et al., 2000).

Trends emerged from researchers of resilience indicating that there is not one homogenous formula to guarantee resilience. Both the presence of risk and protective factors may have an impact on families and individuals with ASD throughout their developmental stages or life course (Robledillo, Garcia, De-Andre, Blasco, Bono, & Albiol, 2014). Masten (2001) concluded that defining characteristics of adaptability and strategies at developmentally appropriate levels for an individual with ASD is an essential step in resilience formation. Luthar et al. (2000) added that parents may demonstrate resilience from an external view via behaviors or verbalizations, but they may also be experiencing internal stress related to the environment. In addition, Luthar et al. (2000) proposed that parents may face trials balancing the internal and external characteristics. This conflict may surface in community or school settings while signifying challenges in emotional regulation and coping.

Cicchetti's (2010) research suggested that resilience could be seen as a process with variation between families, community and individual risk and protective factors. Research findings provided initial insight and identification of these strengths or factors to include self-determination, emotional self-regulation, and self-efficacy. In addition,

Cicchetti (2010) determined that the view of healthy, productive, or positive, functioning might appear to be a more normal response to adversity than what was defined by earlier researchers. Masten (2001) suggested that "resilience is common and that it usually arises from the normative functions of human adaptational systems, with the greatest threats to human development being those that compromise these protective systems" (p. 235).

Family resilience is a construct defined by Walsh (2002) as the coping process within the family system. There are various crises and relentless stressors that have potential to affect the whole family (Walsh, 2002). The threat or risks of marital conflict, family discourse, and financial hardship have the potential to impact or render the family dysfunctional. Walsh (2002) determined the construct of family resilience includes protective factors that counter the effects of the turmoil or stress. These protective factors within the family system minimize the impact of the stressor or allow adaptation to counter the negative effects of adversity (Walsh, 2002). Walsh (2002) identified three essential elements to increase and maintain family resilience: a family belief system, organizational patterns, and communication processes.

Parental Outlook

Walsh (2002) also posited that the family having a defined and shared belief system or outlook could promote resilience by making meaning of adversity. This unified outlook can create a feeling of cohesion, and offer a positive view of the future. Walsh (2007) reported, "a resilience-based stance in family therapy is founded on a set of convictions about family potential that shapes all interventions" (p. 25). This

strength-based perspective encourages collaboration, communication, mutual support, and shared outlooks among family members. The research findings from Armstrong, Birnie-Lefcovitch, and Ungar (2005) determined that an increase in positive parental perception of the child and a positive outlook towards informal/formal supports increase resilience. This parental perspective has a direct impact on parental stress by enhancing the parent's coping resources (Armstrong et al., 2005).

Bayat (2007) determined a family's optimistic view of their child's prognosis could result in positive adaptation. In addition to Bayat's (2007) research findings, it was believed that families who can verbalize a positive perception and narrative of the autism diagnosis reinforced a higher level of family functioning. Walsh (2007) stated, "Belief systems are at the core of all family functioning and are powerful forces in resilience" (p. 49). This theoretical framework defines how a family makes meaning of their adversity and how they see the future. Walsh (2002) and Bayat's (2007) research help to understand how shared meanings and beliefs in a family can lead to, or detract from, family resilience. When examining shared meanings and beliefs of the impact of ASD, parental perception is an important element as parents are a core piece of the family unit.

Research on parental perception suggests a correlation exists between the level of positive parental perception and adaptive functioning of the parents and the entire family system (Deal, Haverson, & Wampler, 1989; Simon, McCluskey, & Mullett, 1985). Additionally, Block, Block, and Morrison (1981) concluded that a more positive outlook on child rearing resulted in a more stable and predictable home environment for

children. Later research (Belsky, Crnic, & Gable, 1995) emphasized the direct impact of positive parental perceptions on the functional level, intellectual development, emotional/behavioral adaptability and ego-resilience of the child. Belsky et al. (1995) further stressed the importance of co-parenting and positive parental outlook in divorced families with similar results of adaptability and growth in children from a nuclear family.

Although the extant literature on parental perception discusses the relationship between optimistic outlook and positive outcomes for families, the research primarily includes mothers as study participants (omitting fathers' perspectives) and focuses on outcomes for children, not the parents. As illustrated in the previous paragraphs, the bulk of the research literature regarding parental perception focuses on the level of perceptions parents have about their children's behaviors and how the perceptions affect outcomes for the children. Additionally, some research has focused on marital quality and parental perception, but there is no specific research that focuses on the experiences of agreement/disagreement when parenting a child with ASD. As such, this study sought to determine the potential impact of parental perceptions of numerous factors linked with parenting a child with ASD.

Parental Stress

Researchers concluded that how parents perceived and responded to stressors remains more significant than the actual stressor in determining the impact and outcome for themselves and their children (Benson, 2006; Sikora et al., 2013; Siman-Tov et al., 2011). Parents of children with ASD were more likely to attain mental and physical

health, and maintain a positive outlook of the future if they are resilient (Kavaoliotis, 2017; Knestric & Kuchey, 2009; Kuhaneck et al., 2015). Researchers of parental stress have provided evidence that parents of children with ASD are at increased risk of facing the results of child related stressors of poor social skills, behavior or attention problems, withdrawal or emotional dysregulation (Tervo, 2011).

Research findings indicated that mothers of children with ASD experienced more challenges to their emotional and mental strength than fathers (Dabrowska & Pisula 2010). It has been concluded that mothers remained more stressed due to the level of direct care provided to the child with ASD while fathers remained more preoccupied with social acceptance, financial strain, and outlook for the child's future (Dabrowska & Pisula 2010; Kuhaneck et al., 2015). The economic impact of having a child with autism is extensive, with many specialized resources needed for treatment including medical specialist, respite care, speech pathologist, and behavior therapies (Dabrowska & Pisula 2010; Daire et al., 2011). Therefore, these resources create additional financial strain, increasing the emotional stress of parents, and resulting in a less than favorable impact on the mental health of the parent (Benson, 2006; Lee, Harrington, Louie, & Newschaffer, 2008). The CDC in 2017 determined that the average cost of facing an autism diagnosis ranges from $17,000 to $20,000 more per year than a neurotypical family.

Parental Coping

Many of the stressors linked with raising a child with autism are inescapable, as they are directly related to the symptomology experienced (Hobson et al., 2015; Olsson & Hwang, 2008). In an attempt to maximize the potential for quality of life, parents must identify the ineffective coping responses or risk factors within the family system and counter with evidence-based strategies (Hobson et al., 2015; Lee et al., 2008). Smith, Seltzer, Tager-Flusberg, Greenburg, and Cater (2008) determined that problem solving, or problem focused coping strategies are predictive of less psychological distress in parents of children with ASD along with closer parent and child relationships. In addition, the research of McConnell and Savage (2015) determined that parents might benefit from interventions such as parent training and cognitive behavioral therapy, to build adaptability, effective coping strategies, establishing a positive outlook and solution finding skills.

Giallo (2016), Smith et al. (2008) proposed that parents who engaged in problem focused coping and solution seeking in order to help their child resulted in maximized adaptability and coping. This solution focused perspective suggested by Giallo et al. (2016) included researching treatment opportunities, seeking respite, and engaging in social supports and support groups. In contrast, Smith et al. (2008) concluded that emotion focused coping and problem solving foretold the likelihood of elevated stress levels in parents of children with ASD. Implementation of the emotion focused coping can often result in withdrawal, blaming, and escape-avoidance strategies by both parents and children (Smith et al., 2008). Parents experiencing the associated stressors

of raising a child with ASD while maintaining a pattern of emotion focused coping require the most support from family, peer, and professionals to counter the risk of developing mental illness due to associated stressors (Giallo et al., 2016; Olsson & Hwang, 2008; Smith et al., 2008; Kavaoliotis, 2017).

Parental Mental and Physical Health

Parenting a child with ASD is often associated with impaired mental health, higher levels of stress, and impaired physical functioning in mothers and fathers (Hastings & Brown, 2002; Johnson et al., 2011; Pisula, 2006). Research indicates that parents with children with ASD often report psychosomatic problems associated with internalized feelings of anger, depression, grief, and anxiety (Johnson et al., 2011). Parental stress and health outcome are related to ASD characteristics such as severity of the symptoms, coexisting behaviors, age of the child, and the extent of adaptive functioning (Hastings & Brown, 2002; Johnson et al., 2011).

Researchers report the mental and physical health of parents can be negatively or positively associated with the stress level of providing care for a child with ASD (Hastings & Brown, 2002; Johnson et al., 2011). In addition, the severity of the ASD symptoms and duration for caring for the child are mediating factors to parental physical and mental wellness (Hastings & Brown, 2002; Johnson et al., 2011; Sawyer et al., 2010). The research of Allike, Larson, and Smedje (2006) suggested that changes to daily life and reduced social support systems decreased parental physical and mental health. These changes and level of resources directly affect parental health while

longitudinally demonstrating an upward trend from early childhood through adolescence (Allike et al., 2006).

Parental Support

Walsh (2007) noted that family functioning includes flexibility in the family structure, how connected family members are to others, and how the family uses the resources of the community. The growth in availability of familial, social (informal) and community (formal) supports/resources and the depth of understanding of autism by these support systems improve the coping and resilience level of families facing an ASD (Bayat, 2007; Bitsika, Sharpley, & Bell, 2013; Kavaoliotis, 2017). Gottlieb (1983, p. 28) defined social support as "verbal and nonverbal information or advice, tangible aid, or action that is offered by social intimates or inferred by their presence and has beneficial emotional or behavioral effects on the recipient." Social (informal) supports and community (formal) support is one of the most frequently analyzed variables related to resilience in parents and families of children with ASD (Baker, Seltzer, & Greenburg, 2011; Chalfant et al., 2007; Robledillo et al., 2014; Solomon & Chung, 2012; Zablotsky, Bradshaw, & Stewart, 2013). The process of accessing formal community supports for the family with an ASD aligns with indicators of resilience such as coping and lowered stress (Bayat, 2007; Bitsika et al., 2013; Cridland, Jones, Magee, & Caputi, 2014; Kavaoliotis, 2017).

Marital Satisfaction/Relationship Satisfaction

The research of Santamaria, Cuzzocrea, Gugliandolo, and Larcan (2012) reported that marital satisfaction could be viewed as the protective factor that supports a

parent's coping and adaptability while raising a child with a disability. Numerous researchers have indicated that parents of children with ASD report lower levels of marital satisfaction as compared to neurotypical families (Garcia-Lopez, Sarria, Pozo, & Recio, 2016; Patterson, 2002; Santamaria et al., 2012; Shtayermman, 2013). Marital satisfaction and mutual support remain variables that predict parental adaptability and support psychological wellbeing while reducing stress levels and building family resilience (Garcia-Lopez et al., 2016; Hartley, Barker, Seltzer, & Greenburg, 2011; Searing, Graham, & Grainger, 2013).

Interestingly, some researchers conclude that parents report higher levels of marital satisfaction or bonding as a result of parenting their child with ASD (Marciano, Drasgow, & Carson, 2015; Risdal & Singer, 2004). These parents report that by focusing on the positive impact of ASD on the family, their coping and overall marital relationship satisfaction are enhanced (Langley, Totsika, & Hastings, 2017; Risdal & Singer, 2004). In addition, those with a heightened level of marital satisfaction report fewer symptoms of depression and anxiety, less severe ASD symptoms and increased availability of social/treatment supports (Lovisotto, Caltabiano, & Hajhashemi, 2015; Shtayermman, 2013). In contrast, those with lower levels of martial satisfaction report increased mental health problems and higher divorce rates and decreased social/treatment supports (Risdal & Singer, 2004; Shtayermman, 2013).

As evidenced in the above-mentioned studies, most of the research on parenting children with ASD and relationship satisfaction has primarily focused on married partnerships. So much focus on married parents leaves a gap in understanding what

might be happening with relationship satisfaction among unmarried or divorced parents who are raising a child with ASD (Hartley et al., 2011). Some researchers of marital satisfaction exclude single or divorced individuals.

Summary

Numerous families parenting a child with ASD cope effectively with problematic situations and can adjust according to their situations (Baker et al., 2011; Bitsika et al., 2013; Boyle et al., 2011). This research examined the capacity of parents to respond to the many challenges of parenting a child with ASD. A resilience method encompasses the discovering of protective factors and resources that allow families to adjust when confronted with adversity (Baker et al., 2011; Benzies & Mychasiuk, 2009; Hartley et al., 2011).

Suggestions from resiliency research recommend families develop a strong sense of their own shared, belief system and the capability and confidence to make good decisions for the child with ASD (Benzies & Mychasiuk, 2009). Benzie and Mychasiuk (2009) determined that establishing a positive perspective of autism, vision of hope for the future and connectedness to others help parents moderate the effects of an ASD. Challenges facing all parents are abundant, but challenges facing parents of ASD children are massive. Parents of a child with ASD typically hope interventions, programs and resources will lessen symptoms of autism and offer an optimistic prognosis (Bitsika et al., 2013; Greeff & Nolting, 2013; Hartley et al., 2011).

This literature review has provided a foundational explanation of ASD research and the way ASD affects children and families. The growth of resilience within

families impacted by autism can provide a defense against the adversities of loss, lack of social support, family stress and associated challenges parenting a child with ASD. Formal or informal support systems have the potential to lessen the stressors of autism by implementing strategies that promote resilience (Bayat, 2007; Bitsika et al., 2013; Cridland et al., 2014; Solomon & Chung, 2012).

The literature regarding the prevalence, evaluation, and diagnosis of ASD shows how pervasive this disability is and primarily focuses on the individuals being diagnosed. Additionally, this current study sought to explore ways ASD affects families, and to provide a better understanding of how parental coping and accessing of formal and informal support adaptability and resilience in parents facing an ASD diagnosis.

CHAPTER III

METHODOLOGY

Introduction

When a family is faced with parenting a child with autism it can be an experience associated with confusion, uncertainty and stress (King et al., 2006). Research findings suggest that elevated stress levels are associated with the additional responsibilities of parenting a child with autism (Neff & Faso, 2014). This increase in stress has the potential to produce complex physical and mental health concerns that directly affect a parent's ability to adapt and remain resilient over the life course (Johnson et al., 2011; King et al., 2006).

The purpose of this study was to examine the relationships between specific indicators of resilience that include parental coping, accessing of informal and formal supports with paternal perspectives of parental stress, ASD symptomology, relationship satisfaction, and parental health. This chapter outlines the methodology used to examine the research questions and hypotheses. Additionally, Chapter III provides descriptions of the participants, sampling techniques and measures used in this research. Lastly, this chapter concludes with discussions on the protection of human subjects, specific research procedures, and data analysis strategies.

Procedures

This study used quantitative methods in a non-experimental design. This study used secondary data from the 2011 National Survey of Children's Health (NSCH). The data set is available from the NSCH website and contains a national sample of parents

of a child with a diagnosed disability. These self-reported data focused on the quality of health care and treatments for children with a multitude of needs related to health care. The NSCH results were prepared and disseminated by the Data Resource Center for Children and Adolescent Health, Child and Adolescent Health Measurement Initiative. This data set was created to help increase awareness of the increase in children with health care needs and those with a diagnosis of ASD while identifying central characteristics of families with children that maintain an ASD.

The NSCH data source was chosen for this study because it seems distinctively matched to help identify how families with child with ASD view diagnosis and symptomology and how they engage in resources and support services. The NSCH data collection was conducted by RDD sample and Computer-Assisted Telephone Interview (CATI) technology. This methodology provided a well-organized, nationally representative data set that allows for straightforward hypothesis testing.

The 2011/12 NSCH represents a third attempt of data collection that began in February of 2011 and concluded in June of 2012. Previous attempts of data collection occurred in 2003 and 2007. Each collection of data by the NSCH was completed by telephone with multiple translation options in English, Spanish, Mandarin, Cantonese, Vietnamese, and Korean. Researchers at the National Center for Health Statistics at the CDC managed the sampling and telephone interviews for the survey. Randomly selected telephone numbers were called to identify households with one or more children under 18 years old. In each household with two or more children, one child was randomly selected to be the focus of the parent interview. In addition, the NSCH's

data concerning children's well-being and health were assembled using a process that supports comparisons among states as well as nationwide. A total of 1,624 of the 95,677 NSCH respondents were from a family with a child with ASD between the ages of 0-17 years.

As mentioned previously, the NSCH data set was used in this study to answer research questions and hypotheses focusing on parents with children diagnosed with ASD. It was determined that this national survey might provide insight into the relationships between parental perceptions of stressors and resilience in families with children diagnosed on the autism spectrum. In this current study, specific perceptions were gathered from mother and father respondents of the NSCH regarding their child's ASD symptomology, relationship satisfaction and self-reported health. Also, in this current study, comparisons and relationships were determined between parental perceptions with the following indicators of resilience: parental coping, assessments of informal and formal supports.

Protection of Human Subjects

This study followed and complied with the policies and procedures of Texas Woman's University (TWU) research guidelines as conducted by TWU faculty, staff, or students using human subjects. An exempt application was submitted to the TWU Institutional Review Board (IRB). Exempt applications are reserved for studies that pose little-to-no risks to human subjects. In using this pre-existing de-identified data from the NSCH data set, this study posed no risks to participants. With regard to human subjects' protections in the original data gathering procedures, participation in

the survey conducted by the NCHS was strictly voluntary and confidentiality of all identifiable data or information collected was maintained. For this national survey of CSHCN, commitment to discretion and confidentiality was given to potential participants as part of the informed consent procedures. All consent and data collection procedures for the 2010-2011 NSCH were approved by the NCHS Research Ethics Review Board, with participants giving informed consent prior to inclusion in the study. The NCHS Research Ethics Review Board and the National Operation Research Center Institution Review Board approved all study procedures.

Subjects

The 2011-2012 NSCH was a cross-sectional telephone survey that included interviews with 95,242 families with children with special health care needs (CSHCN) across the United States. Families meeting the initial criteria for the 2009-2010 NS-CSHCN had one or more CSHCN ages 2-17 years. The criteria for CSHCN included children who have one or more diagnoses of chronic developmental, physical, or emotional conditions that require health and related services supports. Only one child with special health care needs was sampled from each eligible family. In the event that one or more children remained eligible, one child was randomly selected to be the focus of the 2011-2012 NSCH parent interview. For the 2011 NSCH, 68.6% of the respondents were mothers, 24.2%, were fathers, and 7.2% were other relatives or guardians.

Measures

This study selected items from the 2011-12 NSCH to address the research questions. The 2011-2012 NSCH survey includes items that indicate levels of parental stress, how well a child is flourishing, and indicators of a positive home environment. This study focused on specific variables related to parental perceptions and their child's experiences living with ASD. The first set of constructs examined was parental perceptions of their children. Specifically, this study examined parental perceptions of their child's behaviors, health, self-regulation, and parental physical, social, and emotional functionality. The next set of constructs included parental perceptions of their own stress, coping, and access to/utilization of informal/formal support and resources.

Independent Variables-Indicators of Parental Resilience

Specific items from the 2011 NSCS were selected to represent this study's indicators of resilience that included three variables: parental coping (K4Q30_rev), accessing formal supports (K4Q38), and informal supports (K8Q35). Parental coping was the first indicator of resilience used in this analysis represented by item-K4Q30_rev. The second indicator of resilience- K4Q38, focused on assessing formal support of counseling for the child with ASD. Lastly, an additional independent dichotomous variable was added indicating the availability of a trusted individual for support to the parents of the child with ASD.

Parental coping. The specific item taken from the NSCH for the purposes of assessing parental perceptions of their own coping abilities is represented as an ordinal variable, measured by a reverse coded 4-point Likert scale (see Table 1).

Table 1

Parental Perception of Parental Coping Indicator (NSCH, 2011)

Item	Question	Responses
K8Q30_rev	In general, how well do you feel you are coping with day-to-day demands of parenthood or raising children?	1-not well at all, 2-not very well, 3- somewhat well, 4-very well

Note. Responses reverse coded

Child's utilization of formal support of counseling. The specific item taken from the 2011 NSCH was selected to determine the utilization of formal support was indicated by participation of the child with ASD in therapy support (see Table 2). This variable is represented as dichotomous based on the two parental response options.

Table 2

Child with ASD Accessing the Formal Support of Therapy (NSCH, 2011)

Item	Question	Response
K4Q38	Is [S.C.] currently receiving therapy services?	0-no, 1-yes

Parental utilization of informal support. For the purposes of this study, additional questions have been taken from the 2011 NSCH to determine parental utilization of the informal support of someone to turn to for support (see Table 3). This variable is represented as dichotomous based on the two parental response options.

Table 3

Parental Perception of Informal Support Indicator (NSCH, 2011)

Item	Question	Responses
K8Q35_rev	Is there someone that you can turn to for day-to-day emotional help with [parenthood/raising children]?	0-no, 1-yes

Dependent Variables

The first dependent variable analyzed in this study indicating parent stress or concern was represented by item K4Q30_rev. The second dependent variable analyzed in this study indicating parental perception of the child's health was represented by item K2Q01_rev. The item socemotfunctioning_mean remained the third dependent variable analyzed in this study indicating parental perception of their child's social and emotional functioning. The item K9Q18_rev remained the fourth dependent variable analyzed in this study that indicated relationship satisfaction as reported by the adult respondent. The final two dependent variables analyzed in this study indicated the physical and mental health of the mother (mother_health) and father (father_health) respondents.

Parental perception of their stress. Additional questions were taken from the 2011 NSCH for the purposes of assessing parental perceptions of their own stress while raising a child with ASD (see Table 4). Parental stress was represented by item K4Q30_rev that was created from a mean of scores of the following coping items:

K8Q31, K8Q32 and K8Q34. These ordinal variables were measured by a 5-point Likert scale that was represented by five parental response options.

Table 4

Parental Stress Indicators (NSCH, 2011)

Item	Question	Responses
K8Q31	During the past month, how often have you felt [S.C.] is much harder to care for than most children [his/her] age?	1-never, 2-rarely, 3- sometimes, 4-usually, 5- always
K8Q32	During the past month, how often have you felt [he/she does things that really bother you a lot?	1-never, 2-rarely, 3- sometimes, 4-usually, 5- always
K8Q34	During the past month, how often have you felt angry with [him/her]?	1-never, 2-rarely, 3- sometimes, 4-usually, 5- always

Parental perceptions about their child's health. A specific question was taken from the 2011 NSCH for the purposes of assessing parental perceptions of their child's health while raising a child with ASD (see Table 5). The child health item K2Q01_rev was represented as an ordinal variable, measured by a 5-point Likert scale that was recoded to represent five parent response options.

Table 5

Parental Perception of Child's Health Indicator (NSCH, 2011)

Item	Question	Responses
K2Q01	In general, how would you describe [S.C]'s health?	1-poor, 2-fair, 3- good, 4-very good, 5- excellent

Parental perceptions about their child's social and emotional functioning.

The specific items chosen represent indicators of how well a child is functioning socially and emotionally (see Table 6). The item socemotfunctioning_mean was created from a mean of scores of the following child functioning items: K7Q84_rev, K7Q85_rev, K7Q79_rev, K7Q70_rev, and K7Q71_rev. All of the social emotional functioning items were measured by a 5-point Likert scale that was recoded to represent five parent response options.

Table 6

Parental Perception of Child's Social and Emotional Functioning Indicator (NSCH, 2011)

Item	Question	Responses
K7Q84_rev	[He/She] finishes tasks [he/she]starts and follows through with what [he/she] says [he'll/she'll] do.	1-always , 2-usually, 3- sometimes, 4-rarely, 5- never
K7Q85_rev	[He/She] stays calm and in control when faced with a challenge.	1-always , 2-usually, 3- sometimes, 4-rarely, 5- never
K7Q79_rev	[He/She] is unhappy, sad, or depressed.	1-always , 2-usually, 3- sometimes, 4-rarely, 5- never
K7Q70_rev	[He/She] argues too much.	1-always , 2-usually, 3- sometimes, 4-rarely, 5- never
K7Q71_rev	[He/She] bullies or is cruel or mean to others.	1-always , 2-usually, 3- sometimes, 4-rarely, 5- never

Note. Responses reverse coded

Spousal/relationship satisfaction. To determine the potential relationship between perception of spousal relationship satisfaction and parental resilience a single

item was selected from the 2011 NSCH (see Table 7). The relationship satisfaction item K9Q18_rev asked parents to rate their relationship with another adult on a 4-point Likert scale. This ordinal item was recoded to represent four parental response options.

Table 7

Parental Perception of Relationship Satisfaction Indicator (NSCH, 2011)

Item	Question	Responses
K9Q18_rev	Would you say that your relationship is completely happy, very happy, fairly happy, or not too happy?	1-not too happy, 2-fairly happy, 3- very happy, 4-completly happy

Note. Responses reverse coded

Maternal self-report of health. To determine the potential relationship between perception of maternal health and indicators of parental resilience multiple items were selected from the 2011 NSCH. A mean of maternal physical health and mental and emotional health (mother_health) was created with the following items: K9Q20_rev and K9Q23_rev. (see Table 8). All of the maternal health ordinal items were measured by a 5-point Likert scale that was recoded to represent five parent response options.

Table 8

Maternal Health Indicator (NSCH, 2011)

Item	Question	Response
K9Q20_rev	Would you say that, in general, [[S.C.]'s [MOTHER TYPE]'s/your] health is excellent, very good, fair, or poor?	1-poor, 2-fair, 3- good, 4-very good, 5-excellent
K9Q23_rev	Would you say that, in general, [[S.C.]'s [MOTHER TYPE]'s/your] mental and emotional health is excellent, very good, fair, or poor?	1-poor, 2-fair, 3- good, 4-very good, 5-excellent

Note. Responses reverse coded

Paternal self-report of health. To determine the potential relationship between perception of paternal health and indicators of parental resilience multiple items were selected from the 2011 NSCH. A mean of paternal physical health and mental and emotional health (father_health) was created with the following items K9Q24_rev and K9Q21_rev (see Table 9). All of the paternal health ordinal items were measured by a 5-point Likert scale that was recoded to represent five parent response options.

Table 9

Paternal Health Indicators (NSCH, 2011)

Item	Question	Responses
K9Q24_rev	Would you say that, in general, [[S.C.]'s [FATHER TYPE]'s/your] health is excellent, very good, fair, or poor?	1-poor, 2-fair, 3- good, 4-very good, 5-excellent
K9Q21_rev	Would you say that, in general, [[S.C.]'s [FATHER TYPE]'s/your] mental and emotional health is excellent, very good, fair, or poor?	1-poor, 2-fair, 3- good, 4-very good, 5-excellent

Note. Responses reverse coded

Plan of Analyses

The analysis for each hypothesis within this study remained focused on applying a multiple regression analysis to determine how each of the independent variables as represented as indicators of parental resilience (i.e., coping, access to formal support, and informal support) predicted each dependent variable (i.e., parental stress, child health, child social/emotional functioning, parental relationship satisfaction and parental health). A separate regression was used for each outcome. To identify variable importance, beta weights and corresponding significance tests were inspected. Correlational analysis was used to examine bivariate relationships between the independent-predictor variables and dependent variable. This analysis identified dependent and independent variables for each research question and corresponding hypotheses are outlined below.

RQ1. What is the relationship between parental stress and indicators of parental resilience in families raising a child on the autism spectrum?

> Ho1. There will be a statistically significant increase in stress, decrease in coping, and decrease in the utilization/availability of support as parental concerns about their child's behavior increases.

This hypothesis required the implementation of a regression analysis between each of the independent variables (parental coping and accessing formal support) and the dependent variable (parental stress). Beta weights and corresponding significance tests identified variable importance between each of the independent variables (parental coping and accessing formal supports) and the dependent variable (parental stress).

Correlational analyses between each of the independent variables (parental coping and accessing formal support) and the dependent variable (parental stress) provided analysis of bivariate relationships.

RQ2. What is the relationship between parental perception of child's health raising a child on the autism spectrum and indicators of parental resilience?

Ho1. There will be a statistically significant increase in stress, decrease in coping, and decrease in the utilization/availability of support as parental acceptance occurs.

This hypothesis required the implementation of a regression analysis between each of the independent variables (parental coping and accessing formal support) and the dependent variable (parental perception of child's health). Beta weights and corresponding significance tests identified variable importance between each of the independent variables (parental coping and accessing formal supports) and the dependent variable (parental perception of child's health). Correlational analyses between each of the independent variables (parental coping and accessing formal support) and the dependent variable (parental perception of child's health) provided analysis of bivariate relationships.

RQ3. What is the relationship between parental perspective about their child's social and emotional functioning and indicators of parent resilience?

Ho1. There will be a statistically significant increase in stress, decrease in coping, and decrease in utilization/availability of support as parental perspectives about their child's social and emotional functioning deceases.

This hypothesis required the implementation of a regression analysis between each of the independent variables (parental coping and accessing formal support) and the dependent variable (parental perception of child's social and emotional functioning). Beta weights and corresponding significance tests identified variable importance between each of the independent variables (parental coping and accessing formal supports) and the dependent variable (parental perception of child's social and emotional functioning). Correlational analyses between each of the independent variables (parental coping and accessing formal support) and the dependent variable (parental perception of child's social and emotional functioning) provided an analysis of bivariate relationships.

RQ4. What is the relationship between spousal/partner relationship satisfaction and indicators of parental resilience?

Ho1. There will be a statistically significant increase in stress, decrease in coping, and decrease in utilization/availability of support as spousal/partner relationship satisfaction decreases.

This hypothesis required the implementation of a regression analysis between each of the independent variables (parental coping, accessing formal and informal support) and the dependent variable (spousal/partner relationship satisfaction). Beta weights and corresponding significance tests identified variable importance between each of the independent variables (parental coping and accessing formal and informal supports) and the dependent variable (spousal/partner relationship satisfaction). Correlational analyses between each of the independent variables (parental coping and accessing formal and

informal support) and the dependent variable (spousal/partner relationship satisfaction) provided analyses of bivariate relationships.

RQ5. What is the relationship between maternal mental and physical health and in indicators of parental resilience?

Ho1. There will be a statistically significant increase in stress, decrease in coping, and decrease in the utilization/availability of formal and informal support as maternal health decreases

This hypothesis required the implementation of a regression analysis between each of the independent variables (parental coping, accessing formal and informal support) and the dependent variable (maternal health). Beta weights and corresponding significance tests identified variable importance between each of the independent variables (parental coping and accessing formal and informal supports) and the dependent variable (maternal health). Correlational analyses between each of the independent variables (parental coping and accessing formal and informal support) and the dependent variable (maternal health) provided analyses of bivariate relationships.

RQ6. What is the relationship between paternal mental and physical health and indicators of parental resilience?

Ho1. There is a statistically significant decrease in fathers' mental health, a decrease in fathers' physical health, and a decrease in utilization/availability of formal and informal support.

This hypothesis required the implementation of a regression analysis between each of the independent variables (parental coping, accessing formal and informal support) and

the dependent variable (paternal health). Beta weights and corresponding significance tests identified variable importance between each of the independent variables (parental coping and accessing formal and informal supports) and the dependent variable (paternal health). Correlational analyses between each of the independent variables (parental coping and accessing formal and informal support) and the dependent variable (paternal health) provided analyses of bivariate relationships.

Summary

In summary, the NSCH dataset was used in this study to answer research questions and hypotheses focusing on parent perceptions with children diagnosed with ASD. Data were used to determine the relationships between parental perceptions of stressors, outlook of their child's health and behavior, parental relationship satisfaction, and health with the indicators of resilience of families with children diagnosed on the autism spectrum. Lastly, this chapter provided this study's methodology, descriptions of the parental participants, sampling techniques, and measures applied.

CHAPTER IV

FINDINGS

Introduction

The purpose of this study was to investigate relationships between parental perspective of parental stress, child health and behavior, relationship satisfaction and overall health and indicators of resilience that include parental coping and accessing formal and informal supports in families with a child diagnosed with autism. More specifically, the focus was to determine the relationships among parents' perceptions of their child's behavior and whether indicators of resilience facilitated parental coping. The study's research questions were answered through regression and correlation analysis. This chapter will begin with an overview of the descriptive statistics of the sample followed by a discussion of the results related to the study's research questions and hypotheses. This chapter concludes with an evaluation of the study results and chapter summary.

Description of the Sample

Descriptive analyses were included to gain an understanding of the demographic information of the parents who completed the survey questionnaire. Frequency analysis for age of children with autism, gender of children, ethnicity of children and parents, gross income, and household composition was included. A total of 1,376 parental responses of children with ASD were collected from archival data from the 2011-2012 National Survey of Children's Health (n = 95,667). Tables 10 and 11 depicted the demographic data based on parent feedback according to child and parent

characteristics. The characteristics presented in Table 11 include descriptions of family income, parents' educational levels, family structure, and descriptions of ethnicity.

Descriptive statistics of the current sample of children with ASD (see Table 10) indicated that the sample was primarily male, non-Hispanic white (81.8%, *n* = 1140). The prevalence of ASD in the children of this sample, six years or older is higher than in younger children, perhaps reflecting the later onset of ASD symptoms or later recognition of those symptoms.

Table 10

Children Demographic Information

	Frequency	Percent
Gender of selected child		
Male	1140	81.0
Female	235	18.2
Race/Ethnicity		
Hispanic	116	8.3
White, non-Hispanic	1009	72.4
Black, non-Hispanic	104	7.5
Multi-racial	140	10.1

Note. *n* = 1,376

The current sample indicated a greater proportion of children with ASD come from a family where a parent has earned more than a high school degree (48.3%, *n* = 673). Additionally, this sample indicated a greater proportion of children with ASD come from higher income homes. At least 62% of these children with ASD live in a household earning 200% or more of the federal poverty level (FPL) and 14% come from families living below the poverty level. The current study provided the predominant demographic picture of children with ASD within this sample as a non-

Hispanic white, school-age boy with educated parents in a middle or upper middle-class home.

Table 11

Parent Demographic Information

	Frequency	Percent
Race/Ethnicity		
White only	1082	77.7
Black only	112	8.0
Other	177	12.9
Educational Level		
Less than High School	191	13.7
High School Graduate	465	33.4
More than High School	673	48.3
Family Yearly Income		
Below 100% of poverty	199	14.3
Above 100% to at or below 133% poverty level	117	8.4
Above 133% to at or below 150% poverty level	26	1.9
Above 150% to at or below 185% poverty level	102	7.3
Above 185% to at or below 200% poverty level	28	2.0
Above 200% to at or below 300% poverty level	247	17.7
Above 300% to at or below 400% poverty level	170	12.2
Above 400% poverty level	398	28.6
Relationship to child		
2 parent-Biological or Adoptive	835	59.9
2 parent-Step Family	117	8.4
Single mother-no father	308	22.1
Other family type	116	8.3

Note. n = 1,376

Analysis Overview

SPSS was used to perform the statistical analysis for this study. A multiple regression analysis was used to examine how indicators of parental resilience (i.e., coping, access to support, and social support) predicted each DV (parental stress, child

health, child social/emotional functioning, parental relationship satisfaction, and parental health; see Figure 1).

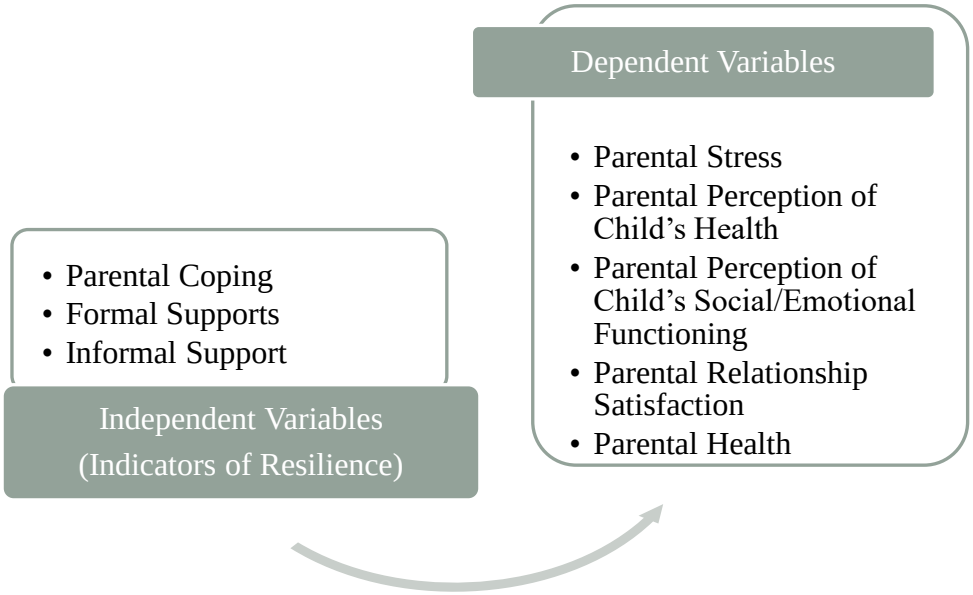

Figure 1. Independent and dependent variables

A separate regression was used for each outcome. To identify variable importance, beta weights and corresponding significance tests were inspected. Correlational analyses were used to examine bivariate relationships between the predictor variables and dependent variable. Table 12 provides the mean and standard deviation for each of the variables analyzed for this study. In addition, Table 12 provides the correlations for each the variables analyzed for this study.

Table 12

Means, Standard Deviations and Bivariate Correlations of all Variables

	M	*SD*	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Parental Coping- IV	3.35	.62	-								
2. Formal Support - IV	.72	.45	-								
3. Informal Support-IV	.87	.34	-								
4. Parental Stress- DV	2.74	.86	-.52**	.16**	-						
5. Child Health-DV	3.87	1.0	.27**	-.15	-						
6. Social/Emotional Functioning-DV	3.37	.47	.062**	.099**	-						
7. Relationship Satisfaction-DV	3.02	.91	.29**	.015	.39**	-					
8. Maternal Health-DV	3.56	.91	.50**	-.037	.42**	-					
9. Paternal Health-DV	3.70	.83	.33**	.007	.25*	-					

Note. ***p*<.01, **p*<.05.

Research Question One

RQ1. What is the relationship between parental concerns about their child's behaviors and indicators of parental resilience in families raising a child on the autism spectrum?

A multiple regression analysis was used to examine how parental coping and use of formal supports (IVs) related to parental stress (DV). The results of the multiple regression analysis indicated the two IVs were able to explain a significant amount of variance in parental stress (R^2 = .15, F(2, 1285) = 113.18, p < . 001). Inspection of each IV indicated that parental coping and accessing formal support were both significant predictors. The negative regression coefficient for coping indicated that, as coping increased, parental stress decreased (β = -.52, p < .01). The regression coefficient for accessing external supports (β = .16, p < .01) was positive indicating that as use of formal support of therapy increased, parental stress also increased.

Research Question Two

RQ2. What is the relationship between parental acceptance of their child's prognosis raising a child on the autism spectrum and indicators of parental resilience?

A multiple regression analysis was used to examine how parental resilience (IVs) related to parental perception of their child's health (DV). The results of the regression analysis indicated that the overall model was significant, (R^2 = .03, F(2, 1285) = 20.7, p < . 001). Thus, results indicated that parental coping and accessing formal support could explain a small effect of 3 % of variance in parental perception of their child's

health. Inspection of each of IV indicated that parental coping was a significant predictor in the model while accessing formal support was not a significant predictor. The positive regression coefficient for parental coping (IV) indicated that, as parental coping increased parental perception of their child's health (DV) increased ($\beta = .27$, $p < .01$). In contrast, the regression coefficient for accessing formal support (IV) was not significant, ($\beta = -.15$, $p = .017$).

Research Question Three

RQ3**.** What is the relationship between parental perspectives about their child's social and emotional functioning and indicators of parental resilience?

A multiple regression analysis was used to examine how parental coping and formal support (IVs) related to parental perception of social/emotional functioning (DV). The results of the multiple regression analysis indicated the two IVs were able to explain a minimal significant amount of variance in parental perception of their child's level of social and emotional functioning, ($R^2 = .01$, $F(2, 1287) = 10.12$, $p < .001$). Inspection of each IV indicated that coping and assessing formal support were both significant predictors. The regression coefficient for coping ($\beta = .062$, $p < .01$) indicated that, as coping increased, parental perception of child's social/emotional functioning increased. The regression coefficient for accessing formal supports ($\beta = .099$, $p < .01$) indicated that, as parental resilience increased, parental perception of their child's social/emotional functioning increased.

Research Question Four

RQ4. What is the relationship between spousal/partner relationship satisfaction and indicators of parental resilience?

A multiple regression analysis was used to examine how parental coping, formal and informal support (IVs) related to spousal/partner relationship satisfaction (DV). The results of the regression analysis indicated that the overall model was significant, (R^2 = .07, $F(3, 943) = 25.4$, p < .001). While the model indicated that parental coping, formal and informal support could explain (R^2 = .07) 7 % of variance in spousal/partner relationship satisfaction. The positive coefficients (IV's) of parental coping (β = .29, p = .00) and informal support (β = .39, p = .01) were significant predictors in the model. In contrast, the coefficient (IV) formal support was not a significant predictor, (β = .015, p = .787). The results of this sample indicated that as parental coping and accessing informal supports increased so did the levels of spousal/partner relationship satisfaction.

Research Question Five

RQ5. What is the relationship between mothers' mental, emotional, and physical health and indicators of parental resilience?

A multiple regression analysis was used to examine how parental coping, formal and informal support (IVs) related to maternal and paternal health (DV). The results of the regression analysis of mothers indicated that the overall model was significant, (R^2 = .15, $F(3, 1179) = 70.5$, p < .001). While the model indicated that parental coping,

formal support informal support could explain (R^2 = .15) 15 % of variance in maternal health. The positive regression coefficients (IV's) of parental coping (β = .50, p = .00) and informal support (β = .42, p = .01) were significant predictors in the model. In contrast, the negative regression coefficient of (IV) formal support was not a significant predictor, (β = -.037, p = .492). The results of this sample indicated that as parental coping and informal supports increased so did the levels of maternal health. Also, as accessing formal support increased, maternal health decreased.

Research Question Six

RQ6. What is the relationship between fathers' mental, emotional, and physical health and indicators of parental resilience?

The results of the regression analysis of fathers indicated that the overall model was significant, (R^2 = .07, F(3, 923) = 24.4, p < .001). While the model indicated that parental coping, formal support and informal support could explain (R^2 = .07) 7 % of variance in paternal health. The positive regression coefficients (IV's) of parental coping (β = .33, p = .00) and informal support (β = .25, p = .05) was significant predictors in the model. In contrast, the positive regression coefficient (IV) of formal support was not a significant predictor, (β = .007, p = .908). The significant results of this sample indicated that as parental coping and informal supports increased so did the levels of paternal health.

Summary of Findings

The focus of this study investigated the mediational effects of parental stress, parental coping, and the accessing of external supports (formal/informal) as indicators of parental resilience while raising a child with ASD. This study analyzed the relationship between indicators of resilience and the parental perceptions of the child's health, behavior and parental relationship satisfaction and overall parental health. Archival data from the 2011-2012 NSCH provided 1,376 specific parental respondents for this study. A multiple regression analysis was used to determine relationships using SPSS. Data analyses revealed the following research conclusions.

1. The results of the multiple regression analysis indicated that parental coping and utilization of external support explained a significant amount of variance in parental stress. A negative regression coefficient for parental coping (IV) indicated that, as coping increased, parental stress (DV) decreased. In addition, the regression coefficient for accessing formal supports indicated that as use of formal support increased, parental stress also increased.
2. The results of the multiple regression analysis indicated that parental coping and utilization of formal support explained a significant amount of variance in parental perception of the ASD child's health. The positive regression coefficient for parental coping (IV) indicated that, as parental coping increased parental perceptions of their child's health (DV) increased. In contrast, the regression coefficient for accessing formal supports (IV) was not significant.

3. The results of this multiple regression analysis indicated that parental coping and utilization of formal supports (IVs) explained a significant amount of variance in parental perception of the child's social/emotional functioning (DV). The regression coefficient for parental coping indicated that, as parental coping increased, parental perception of the child with ASD social/emotional functioning increased. Additionally, the regression coefficient for utilization of formal supports indicated that, as participation of the child in the formal support of counseling increased, parental perception of the child's social/emotional functioning increased.
4. The results of this multiple regression analysis indicated that parental coping, utilization of formal and informal support explained a significant amount of variance in spousal/partner relationship satisfaction. The positive coefficients (IV's) of parental coping and informal support were significant predictors of spousal/partner relationship satisfaction.
5. The results of this multiple regression analysis indicated that maternal coping, utilization of formal support, and informal support explained a significant amount of variance in maternal health. The positive regression coefficients (IV's) of maternal coping and informal support were significant predictors of maternal health. In contrast, the positive regression coefficient of (IV) utilization of formal support was not a significant predictor of maternal health. The results of additional regression analysis indicated that paternal coping, utilization of formal supports and informal support explained significant amount

of variance in paternal health. The positive regression coefficients (IV's) of paternal coping and informal support were significant predictors of paternal health. In contrast, the positive regression coefficient (IV) of utilization of formal supports was not a significant predictor of paternal health.

CHAPTER V

SUMMARY, DISCUSSION, AND RECOMMENDATIONS

Overview

This study examined the relationships between the indicators of resilience that includes parental coping, accessing of informal and formal supports with the paternal perspectives that include, parental stress, ASD symptomology, relationship satisfaction, parental health. The findings of this study suggested that parental stress is impacted by parental perceptions of their level of coping as the first indicator of resilience. Equally, this study's findings suggest that a parent's perceptions of their level of coping is positively correlated with parental perception of the child's health, parental perception of their child's social and emotional functioning, parental relationship satisfaction and parental health of families raising a child with ASD.

In addition, parents accessing the formal support of therapy for the child with ASD is the second indicator of resilience analyzed for this research. These results indicated that therapy support was found to be negatively correlated with parental perception of the child's health as well as the mother's perception of her overall health. However, therapy support as an indicator of resilience positively correlated with parental perception of coping, child's social and emotional functioning, parental relationship satisfaction, and father's overall health. The third indicator of resilience analyzed in this study was the informal support of parents having an individual they could turn to in a time of need. This chapter will discuss these findings. Study limitations will be presented and implications of findings to mental health providers and

family services organizations will be explored. Lastly, recommendations for further inquiry will be presented.

Summary of Findings

RQ1. What is the relationship between parental stress about their child's behaviors and indicators of parental resilience in families raising a child on the autism spectrum? The results of this study aligned with a review of literature that reported as parental coping and resiliency levels increased, parenting stress of a child with ASD decreased (Hobson et al., 2015; Rao & Beidel, 2009). The respondent parents in this current study indicated that as a positive perspective in their coping level increased, and the child with ASD participated in therapy services, a decrease in self-reported parental stress was detected.

RQ2. What is the relationship between parental perception of their child's health on the autism spectrum and indicators of parental resilience? The results of this study indicated a relationship existed between parental perceptions of their child's health with parental coping as an indicator of parental resilience. Other researchers reported similar findings indicating a relationship between parental outlook of their child's health and self-reported coping abilities (Bayat, 2007; Rao & Beidel, 2009). In contrast, this study's results on parental perception of their child's health were not positively correlated with the child's participation in the external and formal support of therapy.

RQ3. What is the relationship between parental perception of their child's social and emotional functioning raising a child on the autism spectrum and indicators of parental resilience? The results of this study indicated a relationship between a

positive parental perception of the child's social and emotional functioning with parental coping as well as involvement of the child with ASD in therapy support. Other researchers indicated stronger correlational findings associating parental outlook of the child's functioning level with parental coping (Bayat et al., 2007; Rao & Beidel, 2009). Despite the limited historical research on the impact of therapy support and the child with ASD, some researchers supported the findings on the relationship between parental coping level and the child with ASD involved in therapy services (Chalfant et al., 2007).

RQ4. What is the relationship between spousal/partner relationship satisfaction and indicators of parental resilience? The results of this study indicated a moderate relationship exists between parental perception of spousal/partner satisfaction and parental coping. Hartley et al. (2011) indicated similar findings between the relationship of parental coping and marital or relationship satisfaction. In addition, this study and earlier researcher findings indicated a relationship existed between parental perception of relationship satisfaction and the presence of an informal parental support system (Hartley et al., 2011). Lastly, this study indicated a weaker relationship between parental relationship satisfaction and the engagement of the child with ASD in therapy. Historical research on the impact of therapy support for the child with ASD and the relationship satisfaction of parents was not available at the time of this current study.

RQ5. What is the relationship between mother's mental, emotional and physical health with indicators of parental resilience? The results of this study indicated a

relationship between a mother's positive perception of her overall health with indicators of resilience; maternal coping and presence of formal and informal support systems. Prior research indicated similar findings regarding the relationship between maternal health and coping with the availability of informal supports (Hastings & Brown, 2002; Johnson et al., 2011; Kavaoliotis, 2017). In contrast, this study result indicated there was a negative relationship between the mothers' perception of her overall health and the involvement of the child in therapy support.

RQ6. What is the relationship between father's mental, emotional and physical health with indicators of parental resilience? Further analysis of this study indicated a relationship existed between paternal self-perception of overall health with all three indicators of resilience: paternal coping level, presence of the formal support system and informal supports. Earlier researchers indicated similar findings regarding the relationship between parental health and parental coping and availability of support systems (Hastings & Brown, 2002; Johnson et al., 2011; Kavaoliotis, 2017).

Discussion of the Findings

Parental Coping

Parental coping was the first of three independent variables correlated in this study. The relationship between parental coping and the dependent variables of parental stress, parental perception of the child's functioning, parental perception of spousal or partner support and parental perception of their own health will be interpreted in the following sections.

Parental Stress

The parental stress results of this study aligned with the literature regarding the relationship between parental coping and parental stress level (Rao & Beidel, 2009). This current study finding on stress indicated that possessing parental coping mechanisms while parenting a child with ASD correlates with parental stress. Some researchers reported parental stress to be a result from the care of a child with ASD (Gray, 2006; Hobson et al., 2015). The research of Knestric and Kuchey (2009) and Kuhaneck et al. (2015) specified that an elevated level of parental coping had the potential to counter the level of parental stress associated with ASD symptomology. By understanding the relationship that exists between parental coping mechanisms and parental stress level, families and various service providers can better understand the pivotal role of parental coping strategies. It is posited by this study that by increasing understanding of the impact of ASD on families, community support agencies, service providers and educators can develop comprehensive and best practice interventions to reduce the symptomologies associated with ASD while building resilient family systems.

Parental Perspective

Despite the minimal correlation from this study finding on parental perspectives alignment remained with the literature on the relationship between parental coping and parental perception of the child's health and social/emotional functioning. Earlier researchers indicated that a relationship existed between parental coping and an optimistic parental perspective of the child's health, prognosis, and functioning (Bayat, 2007; Rao & Beidel, 2009). The importance of supporting parental coping as a means

of improving parental perception of their child's health and functionality remained evident in this current research. Likewise, prior researchers reported the most important predictor of parental stress is a negative definition of the situation while increased parental coping correlated with a more positive perspective of the child with ASD and the family (Kavaoliotis, 2017; Knestric & Kuchey, 2009; Kuhaneck et al., 2015). Lastly, the result of this study emphasized the importance of facilitating parental coping as means of increasing parent capacity towards a positive perspective of their child's health and overall functionality. By heightening the awareness of the associations between parental coping and parental perspective, metal health providers, community agencies, and educators can minimize the impact of autism by developing specific programing for families and children with ASD.

Relationship Satisfaction

The result of this study specific to relationship satisfaction indicated a moderate and positive association between parental coping and spousal relationship satisfaction. This study finding aligned with the work of Searing et al. (2013), who proposed that parents who reported a positive perceptive of their relationship reported a positive view of their coping ability. Additionally, Langley et al. (2017) indicated that a more complimentary relationship reported between spouses increased the level of parental coping and optimism. This current study result emphasized the influence that parental coping has on relationship satisfaction. It is likely that parents with a child with ASD may benefit from teachings, resources, or supports that facilitate satisfaction with their

relationship, while in turn maximizing parental coping while parenting a child with autism.

Maternal and Paternal Health

The results of this study ~~i~~ndicated that a positive relationship existed between parental coping and maternal and paternal perception of their overall health. The literature would agree with this current analysis that as parents report positive coping levels they also self-report a positive perception of their wellbeing (Hastings & Brown, 2002; Johnson et al., 2011). Similarly, Dabrowska and Pinsula (2010) indicated a relationship exists between maternal and paternal stresses with parental health concerns. Based on the analysis of the respondent parents in this study and the current literature on parental health, it could be posited that building parental capacity for coping will result in a more positive self-perception of health and wellbeing. The respondent mothers in this current study indicated a lesser but still positive relationship between coping level and perception of their overall health. The respondent fathers in this study indicated a moderately positive relationship between coping level and perception of their overall health. Based on these findings, it is likely that parents with a child with ASD may benefit from mental health and community resources that facilitate programing and interventions that support parental physical and mental health, while in turn maximizing parental coping and resilience.

Utilization of Formal Supports

The utilization of the formal support of therapy for the child with ASD remained the second of three independent variables correlated in this study. The relationship between utilization of formal supports and the dependent variables of parental stress, perception of child's functioning, parental perception of spousal or partner support, and parental perception of their own health will be interpreted in the following findings.

Parental Stress

This current study finding indicated a low but positive relationship between the participation in therapy support for the child with ASD and parental stress. The result of this study agreed with the literature on therapy for the child, parents whose child participated in therapy reported reduced parental stress. Sofronoff et al. (2005) indicated that therapy interventions reduced the symptomology of autism for the child while reducing the anxiety and stress level of the parents. The accessing of therapy support has been proven effective to reduce stress levels of families that include a child with ASD (McConnell & Savage, 2015). This current study result emphasized the relationship between therapy support and parental coping. Based on this finding, it is likely that parents of a child with ASD may benefit from effective mental health, community services, and school mental health resources. Many of these resources can enhance individual or family resilience by providing individual or group counseling, family therapy, behavioral support, and parent training. Based on this current study, it was posited that effective mental health resources for the child could build parent capacity for coping, improve parental outlook while enhancing parental resilience.

Parental Perspective

The results of the current study indicated a negative inverse relationship between the child with ASD in therapy and parental perception of the child's health. In this study, as a child's inclusion in therapy reduced, parental perception of the child's health increased. While historical research on the relationship between therapy supports and the parental perception of the child's health was not available, historical research remained available on the functioning level of the child with ASD (Chalfant et al., 2007).

Findings from this current study aligned with other researchers who reported a relationship between the involvement of the child with ASD in therapy and parental perception of the child's level of functioning (Chalfant et al., 2007; Sofronoff et al., 2005). Based on this study finding, as parents engaged their child in therapy services a more positive perception of their child's functioning level emerged. This current study remains consistent with the limited historical research that proposed families with a child involved in therapy experience a reduction of negative ASD symptomology. Researchers posited that therapy for the child with ASD assisted in applying strategies to minimize atypical behavior while in turn building parental coping and optimism (Chalfant et al., 2007; Sofronoff et al., 2005). This current study result emphasized the relationship between therapy support and parental perception of their child with ASD. It is likely that parents of a child with ASD may benefit from mental health professionals, community support, or educators that facilitate therapy supports while in turn maximizing parental outlook.

Relationship Satisfaction

Despite the lack of historical research available regarding the impact of the child with ASD in therapy on parental relationship satisfaction, this current study concluded that a positive correlation exists between these two variables. Despite this current study's lower level of correlations, it was determined that as the child with ASD participated in therapy services the relationship satisfaction of the respondent parents slightly increased. Previous literature cited a correlation between the ASD child's involvement in behavioral support services and the parent's favorable perception of their relationships (Garcia-Lopez et al., 2016; Hartley et al., 2011). Based on these finding, it is possible that parents with a child with ASD could benefit from relationship resources or supports that facilitate positive relationship mediation. Mental health providers, community support, and educators can provide individual, group and family therapy, parent training or respite services to maximize parental coping as a means of increasing parental resilience.

Parent Health

Historical research findings specific to the relationship between therapy services for the child and the impact on parental health remain limited. Differences between the participation of the child with ASD in therapy services and the impact on maternal and paternal perception of their health existed in this current study and among other researchers (Langley et al., 2017; Risdal & Singer, 2004). A negative inverse relationship between the child's involvement in therapy and maternal perceptions of her

health was reported in the current research findings. In contrast, a positive relationship between participation of the child with ASD in therapy and paternal perceptions of paternal health was reported in this study and by earlier research (Langley et al., 2017). The final analysis of this current study concluded that the involvement of child with ASD in therapy positively correlated with positive self-perception of paternal health. In conclusion, based on these findings it is likely that therapy improves the self-regulation of the ASD child in turn improving parental self-reported coping and self-perception of overall physical and mental health. It is possible that mental health providers and community agencies who support ASD families could support parental coping and health by facilitating counseling and behavioral supports for the ASD child.

Utilization of Informal Support System

The presence of an informal support system remained the last of three independent variables correlated in this study. The relationship between an informal support system of having an individual to turn to and the dependent variables of parental perception of relationship satisfaction and parental perceptions of their own health will be interpreted in the following findings.

Spousal/Partner Relationship Satisfaction

This current study findings on informal support systems indicated a relationship between parents who have a supportive individual in their life and spousal/partner relationship satisfaction. This current study's moderate relationship result aligns with other researchers results that indicated a relationship between parents' perceptions of unmet support needs and relationship satisfaction (Langley et al., 2017). Historically,

researchers reported that mothers of children with ASD sought the support of friends while facing the challenges of parenting (Shtayermman, 2013; Lovisotto et al., 2015). When a discrepancy between the perceptions of unmet social support needs occurred, spouses reported conflicted relationships and poor communication (Langley et al., 2017). It is apparent in this study finding that parents could benefit from community support resources that enhance the quality of the spousal relationships in an effort to establish essential coping for families raising a child with ASD.

Parent Health

In this current study, a moderate and positive correlation existed between both parents having someone to turn to for support and the impact on parental overall health. Researchers indicated that an increase in access to a support system for the parent resulted in improved mental and physical health while reducing parental stress (Johnson et al., 2011; Zablotsky et al., 2012). In addition, Johnson et al. (2011) reported that an increased involvement of a support system manifested a reduction in physical problems, as well as depression symptoms in parents. Physical and mental health problems in parents have been linked to the level of symptomology exhibited by the child (Kuhaneck et al., 2015). The work of Kavaoliotis (2017) further extended the research on symptomology and the family as well posited that a mothers' health was impacted the most by the effects of autism. Kavaoliotis (2017) further suggested that involvement of social support or nonstandard support (family and friends) can directly affect the parents' stress levels as well as increase resilience.

In summary, the impact of parents possessing a support system or individual for respite, emotional or social support improve parental perspective towards their relationships as well as their overall health (Kavaoliotis, 2017). Resilience researchers contend that parental access to informal supports and resources remains a pivotal protective factor capable of countering the adversities of parenting a child with ASD (Kuhaneck et al., 2015). Based on the analysis of this study and the current literature on parental health, it is likely that parents could benefit from community support services or mental health providers that encourage physical and mental health in an effort to maintain essential coping and resilience mechanism to counter the effects of ASD.

Limitations

NSCH self-report data could present biases and limitations of honesty, interpretation of the question, rating scales and response bias. Self-reported data remains vulnerable to the participant's desire to be socially acceptable rather than offer honest responses. Self-report data can limit participants understanding of the survey questions and associated rating scales.

The results of this study should be interpreted in light of the following methodological limitations. First, this study investigated cross-sectional data from archival data of the 2011-2012 NSCH. Therefore, data was limited, cause and effect were not quantifiable, and changes made over time could not be determined. Another limitation that resulted from using NSCH archival data was the limitation of clearly stated survey items used for analysis. An absence of strong measures of parental perception of relationship satisfaction, stress, and coping remained a limitation of this

current study. This study reported on the results of parents with children between the ages of 6-17. The inability to differentiate between parent responses of a specific age range of the child remains an additional limitation of this study.

Direction for Future Research

There are several recommendations for future research based on the present study's findings and the limitations identified. The specific areas of population, services, and research were used to outline future research directives.

Population

Future studies should involve a larger and more diverse group of families, including the fathers as well as a more ethnically and racially varied sample. This would allow further study of the ways that paternal influence, culture, and ethnicity play a role in parental perspective, parental coping level, and impact of external supports in relation to ASD. The ability to analyze and generalize the impact of ASD on these populations as a whole is not possible without adequate research.

Services and Supports

Future researchers also need to provide the prospective of the families who are challenged with barriers to access of services for early diagnosis and effective interventions, resources and supports. Further outcome research is needed to fully understand the impact of specific external supports and interventions accessed by the family. It would be useful to further explore the parental satisfaction of specific types of external supports utilized by these families. Research should include a more accurate way of describing the behavioral profile and autism symptomology related to the child

with ASD, and its influence on parental coping and access to formal and informal supports.

Research Areas

Future research is recommended on the topic of family resilience. A better understanding of the role that risk and protective factors play in the family is also needed. Additionally, research should include a qualitative and longitudinal component, which would provide mental health professionals and community agencies an opportunity to learn more about the lived experiences of families over the lifespan. Longitudinal research methods could offer insight to the varying points on the developmental trajectory of families with a child with ASD. In addition, data collection from more than one family member, specific developmental stages of the child and specific research from the father's perspective would be useful. A wider data circle would provide a greater in depth look into the impact of ASD on family systems as a whole.

Implications for Practice and Families

This research may inform mental health professionals, educators, and community support organizations to better understand the complexity of the adaptation of resilient families and their child with ASD. Mental health providers (counselors, psychologists, and social workers), educators (public/private, primary, secondary, and higher education), and community support organizations (i.e., faith-based organization, non-profit organizations, state and federal programs) play a critical role in the development of resources, education, and implementation of best practice interventions

that support healthy family functioning. The results from this current study may be directly applicable to the planning of treatment goals, interventions, and education for professionals and organizations assisting families with a child with ASD to build resilience. Mental health providers, educators and community support organizations can be enablers of parental coping and resilience by facilitating the protective role of (a) positive parental outlook, (b) paternal and maternal emotional and physical health, and (c) access to informal and formal supports as a means of reducing stress and adversity in the family.

Mental Health Providers

Mental health providers can be essential change makers for the parent and family with a child with ASD. The types of mental health providers that can be instrumental in resilience building include counselors, social workers, and psychologist. Solomon and Chung (2012) indicated that mental health providers might take on the role of family counselor to facilitate emotional coping, connectedness, and adaptability while families face the adversity and stress of autism. The role of the mental health provider can help families and individuals impacted by autism to create and accept a new narrative that will guide their belief system with hope, acceptance, self-efficiency, and empowerment.

Mental health providers are charged with the goal to encourage parents to counter social isolation through involvement in autism support groups, as well as seeking assistance from community and government organizations as well as school systems (Solomon & Chung, 2012). In addition, Solomon and Chung (2012) indicated

that mental health providers need to be willing to expand their role as an advocate and part of a multi-disciplinary team that includes school professionals, medical professionals, and community resource representatives. As mental health providers increase their understanding of autism, and their level of effectiveness providing essential systemic support to the parents and families affected by autism is maximized.

Educators

All levels of educators providing instruction and care to students with an autism diagnosis can benefit from increasing their knowledge of the impact of diagnosis on the family system. Educators from early childhood programs to post-secondary educators can benefit from understanding the student with ASD and their family system. This understanding of how parents are impacted by their child with ASD will help educators better comprehend individual caretaker and familial needs. As educators on all academic levels increase their awareness of the impact of autism on the family system, more precise assessment of academic/social needs and use of effective interventions can minimize the symptomologies associated with autism.

Public school students with ASD remain eligible for a variety of support services that range from academic to social support. School districts that are active in minimizing the impact of the ASD on the student and family offer parent education, in-home behavioral supports, student social skills groups, psychological and related services support, parent groups, and post high school transition supports. Post-secondary or college and university campuses offer academic supports for students with ASD through the office of disabilities.

Additionally, educators who include parents in key decision making and promote a sense of teamwork increase the likelihood of successfully transitioning students and delivering effective services to students and their families. Parents remain a vital resource for educators working with students with ASD. A collaborative relationship between parents and their child's educators results in a positive parental perception of the school staffs understanding of autism and their child's academic and behavior concerns and growth.

Community Support Agencies

Community support agencies that affect families with a child having ASD include faith-based organizations, nonprofit groups, and state or federally funded systems of government. These organization types can be essential change makers for the child and the family system associated. The support provided by these organizations can include respite, social supports, life transition, and future planning.

Faith based organizations seek to understand and meet the needs of their parishioners and community by offering various outreach programs to families impacted by a variety of disabilities such as autism. These services can function as a relief for families and caregivers, which can potentially reduce family stress and improve family adaptability and inclusion into the community. Through supporting the caregivers of these children, faith-based organizations offering respite and educational services have the potential to create feelings of inclusion and normalcy for families living with ASD.

Non-profit organizations can often offer support groups for parents and siblings, as well as socialization groups for child with ASD. Various non-profit organizations

catering to the ASD population can offer support groups and training opportunities for families seeking connections to others facing the diagnosis and uncertainty of the future. These types of groups facilitate feelings of parental connectedness that supports a more optimistic outlook from the parents and caretakers of children with ASD (Eikeseth et al, 2007). Additionally, these groups can build family resilience and adaptation by offering education on accessing supports and treatment that support essential coping and transition planning across a variety of life stages.

State and federally funded community organizations have the potential to impact individuals with ASD and their families by reducing stress and increasing adaptability. Services provided by these organizations include respite care, life skills training, behavior supports, transition planning, supportive employment, and supportive/group home living. The relevant community organizations that provide support and resources to these individuals and their parents or caretakers reduce the impact of ASD. By understanding the impact of autism on the individual and family, the development of effective community resources and treatment opportunities remain essential to improving the quality of life, future outlook, and connectedness for the individual with ASD and their family during each transition of life.

It is imperative that mental health providers, educators, and community support organizations understand the effects of autism so that families can be equipped with effective strategies and interventions to reduce the challenges associated with ASD. The challenges facing families of children with ASD remain as varied as the interventions and supports that build family strength and resilience. Mental health

providers, educators, and community support organizations need to be aware of how to best match individual needs with effective resources that build parental and child capacity for resilience. These essential resources are necessary to maintain hope for the parent and child with ASD.

Conclusions

This study focused on a parental perspective while raising a child with ASD. Conclusive results indicated that the parental perspectives of self and the child with ASD were impacted by three indicators of resilience selected for this study: (a) parental coping, (b) engagement of formal supports, and (c) availability of informal supports.

Research on resilience theory recommends parents to identify risk and protective factors associated with adversity (Walsh, 2003). In this current study, the correlational process proved suitable for identifying potential relationships between risks and protective factors associated with parents with children with ASD. The risk factors identified in this study indicated parental stress, parental perspective, spousal/partner relationship satisfaction, and parental health. The protective factors evidenced in this study supporting resilience theory remained parental coping and utilization of formal and informal supports to counter the impact of ASD. This study concluded with a correlational analysis that provided explanations into the relationship that existed between the factors that indicate characteristics of resilience in parents that parenting a child diagnosed with autism.

The conclusive results of this study indicated that parental coping, and formal and informal supports served as protective factors while reducing the challenges of

parenting a child with ASD. For these families, formal support strengthened parental coping, especially when mental health support was a utilized intervention for the ASD child. Also, informal (familial/peer) support remained a critical mediator of parental stress and relationship satisfaction.

As the number of children with ASD increases so will the needs of individuals and parents who will face a lifetime of challenges associated with the diagnosis. It is paramount that mental health professionals, educators, and community organizations who support the ASD population remain educated on assessing needs and making recommendations for evidence-based interventions and supports that reduce the challenges of autism on the child, parent, or family.

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