

ABSTRACT

STRESS AND COPING AMONG PARENTS OR CAREGIVERS RAISING A CHILD WITH AN AUTISM SPECTRUM DISORDER (ASD)

Children with Autism Spectrum Disorder (ASD) lack social, emotional, and communication skills which can last throughout their life (Centers for Disease Control and Prevention, 2014). There is limited research that pertains to the influence that children with ASD have on the family functioning. This qualitative phenomenological study used a semi-structured interview that examined the psychological well-being and coping in 10 parents of children with ASD. Two central questions guided this study: What type of stressors are linked to parents who are raising a child diagnosed with autism spectrum disorder? What coping mechanism(s) if any are parents utilizing when raising a child with ASD? These questions focused on the daily challenges faced by parents of children diagnosed with ASD and looked at the different coping strategies the parents used. This researcher asked ten open-ended questions. The use of scribing and audio-recording was used to collect data and was transcribed into written form and then analyzed using thematic analysis. Findings of this study may contribute to the existing literature and emphasizes the need to inform social workers and other professionals to implement or improve support programs and appropriate services to families who have a child with an autism diagnosis. The stigma observed in the community toward families and persons with disability must also be focused when advocating for those in the ASD community.

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STRESS AND COPING AMONG PARENTS OR CAREGIVERS
RAISING A CHILD WITH AN AUTISM SPECTRUM
DISORDER (ASD)

by
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CHAPTER 1: INTRODUCTION

Problem Statement

Autism spectrum disorder (ASD) is a developmental disability that represent challenges in communication, social interaction, and restricted behaviors. ASD is a spectrum disorder which depending on the person with ASD, experience a range to mild to severe symptoms (American Psychiatric Association, 2013). Autism is much more common in boys than in girls and can occur in all racial, ethnic and socioeconomic groups (Centers for Disease Control and Prevention, 2014). Parents of children diagnosed with ASD exhibit more stress than parents of typically developing children and parents of children with non-ASD developmental concerns (DesChamps, 2019). It is of grave importance that parents use appropriate coping strategies that can reduce stress and build parental resilience. The mental health of the parent is essential in order to be the best caregiver to their child with ASD.

Much of the previous research shows raising a child with ASD gives numerous and unique challenges in different aspects in the parent's life such as feelings of isolation, seeking support and coping strategies (Ludlow et al., 2012). Although there is numerous research suggesting that raising a child with ASD is challenging, there are also positive reactions when receiving a diagnosis (Mansell & Morris, 2004). In many different studies, parents have been accepting of the diagnosis and severity of the child's autism (Da Paz et al., 2018; Wachtel & Carter, 2008). Many parents reported an increase of protection, had a better relationship with their child and enhanced understanding by teachers and therapists (Jacobs et al., 2020). In addition to having a better relationship with their child with ASD, mothers have reported a sense of competence, social and marital support, and focusing on the present (Navot et al., 2016).

While many parents report a positive outlook of having a child diagnosed with ASD, parents have also reported higher levels of stress than parents of typically developing child (Pisula & Porębowicz-Dörsmann, 2017). In addition to stress, parents have expressed feelings of denial, loss, depression, guilt, and devastation, while extended families felt emotional distress by the news of the child's diagnosis (Lopez et al., 2018).

When raising a child with ASD, it is vital that parents develop some type of coping strategy to reduce stress levels or challenges that they may face. Finding acceptance of the diagnosis of their child, can enable parents to push forward on focusing on their goals and deal with their situation (Blackledge & Hayes, 2006). Parents with children with high-functioning autism spectrum disorders (HFASDs) report lower levels of adapting coping compared to parents of children with typical development and struggle for services for their children (Lee et al., 2009). A coping strategy that parents use is social supports. Parents who were motivated to participate in support groups reported having better insight on their child's needs, empowered, and were engaged by expert panels of professionals and parents during times of uncertainty (Banach et al., 2010).

Purpose of the Study

The purpose of this phenomenological study is to examine the parental stress and coping in a sample of parents or caregivers with a child with ASD. Two central questions guided this study: What type of stressors are linked to parents who are raising a child diagnosed with autism spectrum disorder?, What coping mechanism(s) if any are parents utilizing when raising a child with ASD? The goals of this study is to review the stressors that some parents may be facing when raising a child with ASD while looking at the different types of coping strategies that parents have may be using. Findings from the current study may help to inform social workers and other professionals who are studying

children and diagnosing ASD as well as enhancing social support networks and services that are useful depending on their individual situation.

Implications for Social Work Practice

The mission of the social work profession is to provide opportunity for all especially the vulnerable population and focus on the well-being of individuals and society. The results of this study can allow professionals to be more sensitive and aware of autism and find suitable services to tailor to the parent and their child's individual needs. Social workers are equipped to engage in social and economic justice for individuals with autism and their families. Social workers need to be knowledgeable on how to interact and provide appropriate services with this vulnerable population as this diagnosis not only affects the individual but the family system as well as policies put in place in agencies working with this population. This study can be useful in order to look at current systems in place in Fresno that may need to be implemented that assist children with ASD. In the micro level, the results of this study will help inform social workers, pediatric therapists, and other professionals on how to provide effective services to this population. The mezzo level is the relationship between the child that can get therapy at their school as well supporting parents being involved in the treatment. Lastly, the macro level will be the laws, and policies put in place that affects systems. The issue affects the population since there may be no coping mechanisms or programs to assist parents to relieve the challenges they may be dealing with when raising a child with ASD. It is vital to find professionals to serve the child with ASD to formulate objectives on how to alleviate the child's symptoms in result relieve any stressors the family may be facing. It is with the effort of the family members to take an approach of the child's treatment that can influence the progress of the child to get the best outcomes.

Summary

Receiving a diagnosis of ASD brings in strong emotions from parents of the diagnosed child. Parenting a child with ASD can be tremendously challenging and can increase stress depending on their child's behavior and symptoms. As they raise their child, many parents forget about their own mental health. Appropriate coping strategies and services are needed to improve the well-being for both mothers and fathers. The intention of this research is to study parental stress when raising a child with ASD; especially the coping strategies that they may be using to cope.

CHAPTER 2: LITERATURE REVIEW

Introduction

Autism spectrum disorder (ASD) describes a variety of lifelong and pervasive developmental disorders that affect individuals and their families in a variety of ways (Cridland et al., 2014). This section is an examination of the research literature on the impact children diagnosed with ASD have on the family functioning. Information was gathered from academic library searches using online resources, dissertations, peer reviewed articles, the DSM-5, as well as textbooks that focus on autism spectrum disorder and the theoretical framework that applies to this research. The review of the literature is organized in the following sections: historical overview that traces the origin of ASD, autism prevalence that aims to focus on the prevalence of ASD through a table, and the review of academic literature which includes information from numerous studies that provide context for this research study. The literature review discusses what is being said about the stress levels parents are going through depending on the symptom severity of their child, level of support by either formal or informal, and the coping strategies used by parents when raising their child with ASD. This chapter concludes with a discussion of gaps in the current literature and the need for more research to be done to assist parents of children with ASD.

Historical Context

The term autism was first used by Eugen Bleuler in 1911, to refer to a symptom of schizophrenia (Evans, 2013). A psychiatrist named Leo Kanner, was known to be the first to report about autism in 1943, when he observed children with “autistic disturbances of affective contact,” thus naming their condition, infantile autism (Mintz, 2017). Hans Asperger, a pediatrician, would name autism as Asperger’s Syndrome in 1944, on his observation on patients that showed signs of intelligence but difficulty in

socializing with peers (Mintz, 2017). For Kanner, his cases would be recognized as childhood schizophrenia, although by 1980, the Diagnostic and Statistical Manual of Mental Disorders, third edition (DSM-III) recognized infantile autism as a diagnosis, describing it as “pervasive development disorder” distinct from schizophrenia (Harris, 2016). There have been changes in the concept and definition of the disorder over the years. The ideas that were once held in the 1950s through the 1960’s about autism were proved to be unfounded. One inaccurate research was by psychologist Bruno Bettelheim who publicized the idea that autism was rooted by uncaring mothers which he termed them as “refrigerator mothers” (Mintz, 2017).

While the diagnostic criteria for autism has evolved, societies view on ASD has changed as well. The Americans with Disabilities Act of 1990 acknowledged that those with a disability face stigmatization as well as social and economic disadvantages (Schriner, 2001). This finally acknowledged children on the spectrum which prompted services to be put in place. The changes implemented in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) placed ASD as a single spectrum that falls into two categories: affects social communication and interaction, and restricted and/or repetitive behaviors (Deconinck et al., 2013). According to data by the government agency, Centers for Disease Control and Prevention (CDC) (2014), at this time there are no medications that can cure autism which can occur in any family regardless of race, ethnicity, or socioeconomic status. There are several risk factors in which autism can be traced through such as genetics, environmental, and biological factors and observing the behavior and development of the child—as well as these factors—can help understand what causes these disorders (CDC, 2014).

Autism Prevalence

About 1 in 54 children in the United States has a diagnosis of autism spectrum disorder (ASD). ASD is more common in males than females, and autism can be diagnosed as early as 18 months (Autism Speaks, 2014). Table 1 from the Center for Disease Control and Prevention (CDC) (2014) presents the prevalence of ASD in the U.S. per 1,000 children. It displays the increase in ASD diagnosis from the year 2000 to 2016. The prevalence in 2000 was 6.7, having 1 in 150 children diagnosed with ASD, while in 2016 it was 18.5, having 1 in 54 children diagnosed of ASD (CDC, 2014). The speculation on why there is an increase in prevalence of ASD might be the influence on wider screening, the increased awareness and intervention services, changes in diagnostic criteria, and lowering the age to diagnose a child with any disorders (Neggers, 2014).

Table 1

Prevalence of ASD in the U.S. per 1,000 Children

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Combined Prevalence per 1,000 Children (Range Across ADDM Sites)	This is about 1 in X children...
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88
2010	2002	11	14.7 (5.7-21.9)	1 in 68
2012	2004	11	14.5 (8.2-24.6)	1 in 69
2014	2006	11	16.8 (13.1-29.3)	1 in 59
2016	2008	11	18.5 (18.0-19.1)	1 in 54

Parental Reactions to their Child's Diagnosis of an ASD

A majority of parents have often noticed problems in their child's development before 24 months (Baranek, 1999; Howlin & Moore, 1997), with language delay and communication concerning the parents the most (De Giacomo & Fombonne, 1998; Howlin & Moore, 1997; Hess & Landa, 2012). Parents have reported adapting appropriately to their child's ASD diagnosis while other parents have struggled to respond appropriately. When families receive an ASD diagnosis it brings in feelings of loss of their ideal child (Randall & Parker, 1999; Mansell & Morris, 2004; Heiman, 2002; Altieri & von Kluge, 2009). Although, other parents may feel a sense of relief after prolonged periods of uncertainty (Abbott et al., 2013) and are eager to utilize resources to help their child (Altieri & von Kluge, 2009).

Poslawsky et al. (2014) conducted a study using Reaction to Diagnosis Interview (RDI), which classifies caregivers as "resolved" or "unresolved" to assess their parental reactions subsequent to receiving their child's autism spectrum disorder diagnosis. It found that a majority of parents were accepting and had active adaption to their child's diagnosis and moved beyond the crisis of the diagnosis (Poslawsky et al., 2014). Most interestingly, Poslawsky et al. (2014) found that small majority of parents whose child had severe autistic symptoms, were classified as being unresolved and had difficulties in moving past the crisis of the child's diagnosis. The unresolved parents felt, "emotionally overwhelmed, depressive, passive, neutralizing and angrily preoccupied" (p.299).

When focusing on the diagnostic process and how it impacts parental satisfaction and stress, Moh & Magiati (2012) obtained 102 parents of children with a diagnosis of autism, ASD, Asperger's syndrome or Pervasive Development Disorders-Not Otherwise Specified and 17 professionals for the study. This study is consistent with other studies, (Harstad et al., 2013), that parents with higher educational and socioeconomic background are more likely to raise concern and seek services (Moh & Magiati, 2012).

When understanding the factors that predict parental stress during the diagnostic process, effective and positive collaboration with fewer professionals had lower levels of stress for parents. Parents reported that when they obtained information following the diagnosis, they were sent off with very helpful information and experienced less stress during the process. Although longer diagnosis period and consulting with more professionals has led to higher stress for parents (Moh & Magiati, 2012).

In another study, focusing specifically on mothers with the first born being diagnosed with ASD, Navot et al. (2016) used a semi-structured interview to explore family planning decisions after the child's diagnosis and any future childbearing plans. It concluded that some mothers had fear of the future and the unknown, and some mothers educated themselves to the world of autism to get a better understanding of their child's diagnosis. When focusing on family planning decisions after acknowledging their child's diagnosis, a majority of mothers were flexible on future expectations and were focused on present decisions while continuing their family vision to reproduce. The mothers who had lower flexibility on future expectations, were contemplating whether to reproduce and felt lack of control as well as feelings of isolation rather than support by family or friends. Emotional and physical assistance were shown to be helpful for mothers during demanding situations (Navot et al., 2016). Based on their findings, Navot et al., (2016) offered recommendations for service providers who work with the parents of the child with ASD such as providing interventions, improving service delivery that will suit the family situation, and discussing the challenges that may come from family vision to current circumstances. These findings are essential to see what type of parental support programs are needed for parents with unresolved reactions to their child's ASD diagnosis.

Raising a Child with ASD

Individuals with autism have challenging behaviors of aggression, tantrums, self-injury, disruptions and noncompliance (Horner et al., 2002), and for these reasons, many parents of children with ASD find themselves to develop a daily family routine around meeting the demands of the child with autism. DeGrace (2004) interviewed five family units on their daily routines and how the presence of a child with severe autism impacted their life. The results reported that developing a routine had families robbed because of the personal sacrifices that costs them their own well-being. Common feelings of frustration, anger, and sadness were expressed by the families. Although the use of routines was meant to control the behavior of the child with autism, it might conflict with the functioning of the family unit. The results of this study are useful for professionals to provide ongoing support to families who are dealing with stressful experiences when raising a child with severe autism.

It is reported that parents who raise a child with ASD show high level of stress (Singer & Powers, 1993). They can also become socially isolated from the time of diagnosis from family and friends (Huws et al., 2001). A sample of 52 parents were interviewed by Altieri & von Kluge (2009) that admitted that family and friends have disconnected from them upon their child being diagnosed with ASD. They reported that this was a struggle to cope, particularly when family members lose touch with the child and the family. Although, the distance from family members may be due to the lack of understanding about ASD, since one couple interviewed by Altieri & von Kluge (2009), realized their extended family are not supportive since they are not educated about autism. Although the study indicated that parents had lack of support from family and friends, many couples reported after receiving a diagnosis of ASD for their child, were able to recover quickly, control their emotions and seek out assistance to help them with their well-being and with their child with autism.

Parents of children with autism struggle with the stigma of the diagnosis of autism for their child, and how it brings negative emotional and social consequences for them (Green, 2003). Woodgate et al. (2008) explained that some parents felt isolated because of societies view on autism as well as disconnection from spouse and extended family members. The families also emphasized the lack of understanding from professionals within the system. (Woodgate et al., 2008). The Kinnear et al. (2016) investigated the factors contributing to stigma and how it impacts the 502 families raising a child with autism in the study. The parents of the children reported that their child showed autism-related behavior such as lack of eye contact, meltdowns, and bowel or bladder problems. The study reported that many parents (40.4%) isolated themselves from family and friends because of these behaviors and some parents (31.7%) were excluded from gathering events by others (Kinnear et al, 2016). The lack of social outings and emotional quality of interaction from family members has led parents to perceive their family life as abnormal due to the impact of their child's autism (Gray, 1997). It is important to have social support since it has been seen as effective to lower psychological distress for mothers of children with ASD (Boyd, 2002) but be aware that negative social support can play a role in increasing stress and decrease well-being (Benson, 2012).

Maternal Stress

Several studies indicate that mothers experience more stress compared to fathers when raising a child diagnosed with autism spectrum disorder (ASD) (Bebko et al., 1987; Davis & Carter, 2008; Rivard et al., 2014). A quantitative study by Ekas & Whitman (2011) whose population was 46 mothers whose children are diagnosed with ASD, gathered data for 30 consecutive days. The Positive and Negative Affect Schedule is a 7-point Likert-type scale to measure positive and negative mood. The study also used other 7-point Likert-type scales to determine how frustrating the event was for the

parent and to examine frustrating experiences by mothers from each type of symptoms. It reported extreme levels of maternal stress were linked with decreased negative affect and positive affect diminishes the continuous negative effects of stress on negative affect but only during times of none or one type of stress that is raised (Ekas & Whitman, 2011). While the findings focus on how life stress and child stress were above average, there was a decrease in negative affect the following day because maternal parents seek support and resources to cope with that stress.

A contributor towards maternal stress can be the amount of depression a parent may be receiving because of the child's symptom severity. The use of daily diaries on mothers with a child who has ASD, are useful to show the parenting interactions on consecutive days such as the study by Pruitt et al. (2016) which concluded that the rise of depressive symptoms were linked with less daily positive affect and an increase in child social motivation impairment were linked to higher daily positive affect. In addition, high levels of depression in mothers and a rise in negative family functions is associated with greater frustrating parenting interactions.

Davis & Carter (2008) found that mothers (33%) reported higher levels of depression in the clinical range compared to fathers (17%). This quantitative study consisted of 108 parents of young-newly diagnosed children and used regression analysis to look at the variables of four domains: autism spectrum symptoms, child problem behaviors and competencies, child cognitive functioning, and parental affective symptoms. The study used cross-sectional data as well as stepwise linear regression method to determine the contributions of each domain. Findings from the study were in line with other studies about the negative effects of ASD has on the mother's mental health.

Paternal Stress

Unlike like other studies, a study conducted by Rivard et al. (2014) had fathers (61%) having a higher level of stress compared to their counterpart, (54%) when raising a child with ASD. It focused on 118 families (118 fathers and 118 mothers) which had more males (92) than females (26) (Rivard et al., 2014). This can contribute to the fact that ASD is much more common in males than females (Autism Speaks, 2014). The study required both parents to contribute to the study and the child diagnosed had to be 2 to 5 years of age. Rivard et al. (2014) stated two important hypotheses for reasons as to why fathers in the study had higher stress than previous studies with results having mothers having the higher stress level. The first hypothesis would be that the sample size in this study had a better representation for fathers compared to other studies. According to the literature shown, fathers are perceived as an “invisible parent” compared to their counterparts (Rivard et al., 2014 citing Ballard, Bray, Shelton, & Clarkson, 1997). The second hypothesis concludes the time spent with the child and at work determines the difference between mothers’ and fathers’ stress level (Rivard et al., 2014). The study reveals fathers who work full-time dictates their time away from supportive services that focus on the child’s diagnosis and may be the reason behind the excessive stress that accumulates. (Rivard et al., 2014).

Parental Stress and Psychological Issues

According to Pisula (2011):

There are three major group factors that contribute to elevated stress in parental of children with autism: (1) child characteristics, in particular behavioral symptoms associated with autism and behavioural problems; (2) lack of adequate professional support and unsatisfactory relationships between parents and professionals from the stage of autism diagnosis to limited access to medical and educational services for the child; (3) social attitudes towards individuals with

autism and lack of understanding for problems they and their families experience.
(p. 88)

Most literature highlights on how raising a child with ASD experience high stress levels than parents of children with typical development or other development disabilities (Hartley et al., 2012; Dykens et al., 2014; Padden & James, 2017). A study investigated parental stress and psychological stress in mothers of toddlers with ASD, developmental delay without ASD (DD), and typical development (TYP) (Estes et al., 2013). The mothers of children with ASD had a higher parenting stress score and higher levels of problem behavior compared to mothers of children in the DD and the TYP group. The psychological distress did not diff for mothers of ASD, DD, or typically developing children (Estes et al., 2013). In this result, the current findings replicate much of the previous literature that parents of children with ASD exhibit higher levels of parenting stress than parents of children with any other type of disability problem (Koegel et al., 1992; Weiss, 2002). Although it should be noted that there are other factors of autism, beyond behavior problems that is linked to maternal stress (Eisenhower et al., 2005). These findings are inconsistent with Estes et al. (2009) other work which found mothers of children with ASD had higher levels of parenting stress and psychological distress compared to mothers of children with DD.

There is numerous literature that has been focused on managing parents' stress on families of children with autism (Davis & Carter, 2008). The problems of children with ASD seem to affect different domains on parental stress. A study conducted by Bebko et al. (1987) applied the Childhood Autism Rating Scale (CARS), using a 4-point scale for parents to rate their child's behaviors from normal to severe. The study incorporated professionals to also rate the severity of the child's symptoms and observe how stressful they thought the parents found each symptom. Many parents reported cognitive and communication impairment to be the most stressful and nonverbal communication for

professionals from all other symptoms in severity. This study indicated that it is important to understand ASD from not only the perspective of professionals but parents as well.

Brobst (2009) investigated how parenting children with special needs influences couples' relationships among couples whose children have ASD with couples whose children do not have developmental disorders. Results based on the Parenting Stress Index-Short Form (PSI-SF), Eyeberg Child Behavior Inventory (ECBI), Social Support Scale (SSQ6), Respect Toward Parent Scale, and Commitment Scale, indicated that the parents of children with ASD reported more parental stress, social support, marital satisfaction, and greater trouble with child behavior problems than the comparison group. The study by Brobst et al. (2009) has several limitations. The participants in the study were mostly Caucasian with higher education and above-average income. Therefore, this study may not provide realistic results on parents stress level other than wealthy Caucasian couples since they may not have access to professional services. Couples from other cultures and individuals from other socioeconomic levels were not represented in this study (Brobst et al., 2009). Additionally, parents reported their children's diagnosis without confirmation from medical records or physician. The sample size of the study and bias from parents needs to be considered as well.

Coping Strategies

Coping is best described as the efforts one makes to manage stressful situations, in order to minimize their effect on ones' well-being (Carroll et al., 2013). Many of the available studies about parents of children with ASD show how useful coping mechanisms can decrease or increase their stress levels and reduce risk for mental health problems. The use of coping mechanisms can assist in reducing the parent's risk of depression and other forms of psychological issues (Coyne & Downey, 1991).

For example, the Dunn et al. (2001) study included 39 mothers and 19 fathers of children with an autistic child and were asked to respond to questions related to social support using the Inventory of Socially Supportive Behavior (ISSB); coping style using Ways of Coping Questionnaire-Revised (WOC); parental stress using Parenting Stress Index (PSI); and the Life Experience Survey (LES) to assess desirability and impact of events that have transpired over the previous year. The results concluded that the use of escape and avoidance as coping mechanisms corresponded to increase in depression and spousal problems. Distancing, an emotion-focused style was also a factor to increased depression (Dunn et al., 2001). The use of escape-avoidance, the decrease use of positive reappraisal and less seeking of social support has led to spousal relationship problems (Dunn et al., 2001). The spouse is an important emotional support for mothers of children with autism and without it, can lead to feelings of isolation (Navot et al., 2016). These findings correlate with other studies that show that positive reappraisal which refers to attributing a positive attitude to the stressful event (Rusu et al., 2019) has been shown to reduce depression and anxiety (Rayan & Ahmad, 2017) and lead to positive marital quality (Finkel et al., 2013). This study can assist parents of children with autism how to choose appropriate coping styles to reduce depression and spousal problems.

When focusing on the fathers' and mothers' ways of coping with their child's problems and diagnosis, Ludlow et al. (2012) used a qualitative study when exploring 20 parents on what has helped them cope. The fathers of the child with autism stated that it was the mothers who are typically more stressful because they are often the child's primary caregiver (Ludlow et al., 2012). Mothers reported that their husband or the father of the child had feelings of denial and were less patient or tolerant of the child's behaviors since they spend less time interacting with their child with autism. Denial and avoidant coping skills are styles of coping that many tend to adopt (Lee, 2009). Many parents in the study felt the support of other parents of children with autism has helped

them cope, since they are a source of support who are experiencing similar issues (Ludlow et al., 2012). Although this was a thorough study, it lacked any information regarding how the fathers of these children can contribute to decreasing the mothers' stress. This gap in the literature supports the need for further research on how fathers' involvement with their children with autism can lower mothers' stress level and well-being.

There are some suggestions that fathers cope differently with their child's behavior problems and diagnosis than mothers. Fathers of children with autism experience more higher levels of distress compared to fathers with typical developing children (Darling et al., 2012; Baker-Ericzen et al., 2005). A study conducted by Dardas & Ahmad (2015), examined 101 fathers of children (85 boys, 16 girls) who have been diagnosed with autism to assess their coping strategies. The results revealed that although the fathers had numerous types of coping responses, it did not affect their quality of life. The lack of utilizing coping resources for fathers may be due to the several life stressors such as parenting, social, and financial stressors. This study lacked any information regarding how the father utilized these coping responses with their child with autism to reduce parenting stress.

In relation to poor coping strategies, Hay (2016) explores seven male individuals using a phenomenology approach to examine the extent to which paternal coping skills, parenting style of choice, and cultural background affect the amount of involvement a father has in the life of his child diagnosed with autism. Some of the participants are passive when engaging with their child with ASD and had low to moderate levels of coping skills. The study revealed self-distraction, such as reading and substance use was used to manage the father's stress levels. Although the results from Hay (2016) on the reaction when receiving the diagnosis for their child was similar to mothers of children with ASD who expressed anger, sadness, disbelief and relief.

Social Support

Parents of children with ASD face numerous parenting challenges, including financial burden for services for their child, restrictions in social activities (Lecavalier et al., 2006), finding appropriate autism services (Ludlow et al., 2012) and stigma associated with ASD (Altiere & von Kluge, 2009; Lutz et al., 2012). As a result, parents coping with these challenges report greater levels of stress, depression, anxiety, isolation and loneliness (Sharpley et al., 1997; Zablotzky et al., 2013). There have been reports in the literature about the importance of social support for parents of children with a disability (Hastings et al., 2002; Lindblad et al., 2007; Sanders & Morgan, 1997) and how it can buffer the impact of stressful events associated with raising a child with ASD (Paynter et al., 2013; Sharpley et al., 1997) as well as improve the well-being of the parent (Ekas et al., 2010). Higher levels of social support have been shown to reduce fewer spousal problems (Dunn et al., 2001).

Informal social support is derived from personal networks such as immediate and extended families, friends, and other parents of children with disabilities. Grandparents have also been shown to provide emotional support to parents with children with autism (Hillman, 2007). The presence of informal support has been shown to diminish levels of stress and provide emotional support for families and parents. (Marsack & Samuel, 2017). Furthermore, parents and families satisfied with informal support predicted overall family resilience (Fong et al., 2021). In one study, informal support seem to be more effective than formal support to help reduce stress and address their child's behavior problems for mothers of children with autism (Boyd, 2002). Formal supports are provided through organizations or agencies that provide assistance to both the child and the parent and can either be free or require a fee for their assistance (Shepherd et al., 2020).

Siklos and Kerns (2006) found that parents of ASD desire better professionals who are knowledgeable about autism and desire for more intense intervention to improve their child's behavior. The study also found the need for better health services delivery for parents of children with autism who are more stressed compared to parents with children with Down syndrome (Siklos & Kerns, 2006). When focusing on mothers of children with ASD, (Bromley et al., 2004) high levels of psychological distress are linked to high levels of challenging behavior problems from the child and the lack of informal support from family members. The low level of support was most indicated for single mothers, parents with inadequate housing, or mothers who have a male child with ASD (Bromley et al., 2004).

A study done on 10 mother-father dyads parents of children with ASD has been examined (Pepperell et al., 2018) with one father out of the study due to technology failure. The results revealed that mothers seek out personal and professional support compared to fathers. Although, both regarded external support as being an important factor in early intervention for children with ASD and how it has been helpful to manage the child's behavior. In addition, mothers have also been shown to seek parental support groups for advice, emotional support and making connections. (Pepperell et al., 2018). A source of social support that both parties utilized were social media forums where parents can relate with other parents who are going through similar obstacles. Many barriers to seeking support were the demands of being a full-time parent, the lack of understanding from friends and family about autism, and the time and care of parents raising a child which has led to inadequate interaction with service providers (Pepperell et al., 2018). The role of their spouse has also been a vital source on sharing the emotional burden of raising a child with ASD since partners can relate to what they are going through. (Pepperell et al., 2018). Regarding extended families for these parents, some parents had access to internal social support while others lacked the involvement of their family

(Pepperell et al., 2018). The findings presented here are consistent with other research (Shepherd et al., 2020), that spouses are a commonly reported source of informal support, while relatives were less utilized as a source of support. Parents also reported that social media was useful to connect with other parents of children with similar cases. Several studies have also mentioned social media as a valuable platform as a means of receiving social support, getting advice and sharing stressful aspects of experiences as a parent (Ammari et al., 2014; Haslam et al., 2017).

While social support has typically been related to positive outcomes, some research suggests social support does not predict sibling relationship quality. In a study conducted by Rivers & Stoneman (2003), parent-sibling triads from 50 families (49 mothers, 1 father) with ASD which consisted mainly of Euro-American families, were surveyed. They were asked to respond to questions related to sibling relationship using the Sibling Inventory of Behavior (SIB) and modified version of the Satisfaction with the Sibling Relationship Scale; marital stress using the Marital Strains subscale of Family Inventory of Life Events and Changes (FILE); and family coping with stress using the Family Crisis Oriented Personal Evaluation Scales (F-COPES). The findings indicated that when marital stress was low, and when either low or high informal social support was used, there was positive sibling behavior. Although when families with high marital stress sought out formal support, typically developing siblings had reported more negative sibling behavior (Rivers & Stoneman, 2003). Formal support, however, may not always enhance the family functioning or decrease family stress.

Findings suggests that high levels of external and professional support influenced parent stress that is linked with overall levels of child problem behaviour (Plant & Sanders, 2007). A study conducted by McIntyre et al. (2018), focuses on 78 families with children with ASD on the usefulness of social support. The formal support that was utilized by the mothers included family doctor, pediatrician, day care center, professional

agencies, and spiritual organizations. The results of the study concluded that family doctor or pediatrician (94.9%) and professional helpers (93.6%) were used; with professional helpers (85.9%) and school or day center (74.3%) as most helpful for mothers. Another study focusing on parental satisfaction with formal support and education for children with ASD consisted of 244 parents of children with ASD (Renty & Roeyers, 2006). The data was collected using a questionnaire as well as data that was collected from 15 parents with children with ASD using a semi-structured interviews. There was dissatisfaction from parents about the delay of their child's diagnosis and the lack of information for their child such as appropriate services and education for them to attend (Renty & Roeyers, 2006). Parents satisfaction on support services depends on their experience with professionals who try to improve the family's atmosphere and to help parents respond to their child's needs (Robert et al., 2015).

Theoretical Framework

In this section, I will use the theoretical framework of ecological systems theory as it applies to this research. This researcher found these theories to be most effective when dealing with families who are presented with an ASD diagnosis.

Ecological Systems Theory

This ecological systems theory is important because the purpose of this research is to focus on the parental stress of the parent or caregiver and the coping strategies used while raising a child with ASD, and this theory would identify many factors such as a puzzle piece: Family and friend factors, work factors, government and economic factors, and cultural or social factors. The child with ASD is a member of a larger contextual system (family, school, community) (Symon, 2001). Bronfenbrenner's (1979) systems approach focuses on the developing individual and how that individual interacts in a setting that can impact their development. The theory has five environmental levels:

microsystem, mesosystem, exosystem, macrosystem, and the chronosystem. Each environmental layer impacts other layers. When looking at the microsystem, which is the smallest ecological level, Bronfenbrenner (1979) states that one must consider the environmental contexts in which the individual is present such as the home, school, playground, daycare, and neighborhood. It may be difficult to adapt to these environments. For example, a child with ASD may demonstrate problem behavior such as stereotyped behavior and angry outbursts (Khanna, 2011), as well as frustration, distress, self-injury, running away and other challenging behaviors (McGuire et al., 2016; Chowdhury et al., 2010). This may require parents to have little or no spare time for themselves, since the disabled child requires specific care (Ooi et al., 2016).

The mesosystem level defined by Bronfenbrenner (1979) is the relationship between two microsystems that are linked by some person who is actively participating in two or more settings. These can be larger institutions such as school, work, neighborhood, or government agencies. This may involve the school and home for example. The interaction with the child with autism and the parents may bring levels of stress for the parents, which in turn can lead the parent to have less overall job satisfaction/contentment, and report less satisfaction with their supervisor (Watt & Wagner, 2013). It can also lead to work-family conflict which can reduce the number of hours they work to meet the demands of having a child with ASD (Matthews et al., 2011). Also, what happens in the school, such as the lack of understanding of educating children diagnosed with autism, or the lack of support at the school can affect the family experience such as the parents coping because of the inadequate social support (Matthews et al., 2011).

The exosystem is the third layer, which is defined by decisions that affect microsystems. It does not directly involve the developing person, but it does influence their personal systems (Bronfenbrenner, 1979). One example of an exosystem would be

the leisure activity such as a family gathering that a mother of a child with ASD can attend. This type of informal support can play a crucial role in impacting family resilience for families raising a child with ASD (Fong et al., 2021). The support group that the parents have, such as extended family, friends, professionals, and agencies can serve as resilience factors to decrease the stressful events for families (Symon, 2001). Another example would be the father of the child with ASD who has a full-time job that keeps him away from home. This can impact the child since the mother who is usually the primary caregiver may report higher levels of stress and coping related to caregiving (Tehee et al., 2009).

The macrosystem, according to Bronfenbrenner (1979), influences all the other lower systems for the developing person and includes the culture norms, beliefs, form of behavior and social expectations. For instance, depending on your socioeconomic status, having a child with ASD can be a financial burden, given the health care expense and the economic impact of having low income (Cidav et al., 2012). Zablotsky et al. (2013) has also highlighted that lower-income has an impact on maternal stress and mental health in mothers of children with ASD. When thinking about the macrosystem with a child with ASD, stigma not only impacts the individual with ASD; it can affect the family members. According to the DSM-IV-TR (American Psychiatric Association [APA], 2000), children with ASD have impairments in social interaction and communication and restricted, repetitive patterns of behavior, interests, or activities. Lutz et al. (2012) spoke of a parent who wanted to hide her child who has autism from those who do not understand her son's behavior. These behaviors may expose parents to courtesy stigma from the public for their lack of control over their children which can lead to isolation and social rejection (Ellen et al., 2018; Gray 1993, 2002; Ludlow et al., 2012; Penn et al., 2000). This can lead to self-blame which is a common response for parents of children with development disability after their children's illness has been diagnosed (Fernández & Arcia, 2004).

The stigma surrounding autism is a potentially stressful event, and its consequences to the families of individuals with autism depend on the person's coping mechanism (Miller & Major, 2000; Gray, 2002). Their well-being depends greatly on their formal support such as school services which can reduce distress in these families (Tehee et al., 2009).

Although, educators and service providers receive very little training in evidence-based practices for children with ASD (Leblanc et al., 2009). The policies and laws implemented by the government can improve the development of a child with autism, which can reduce barriers for families of these children (Montes & Cianca, 2014).

The last of Bronfenbrenner's systemic approach is the chronosystem, which consists of all changes and constancy in the individual's environment over time (Bronfenbrenner, 1979). In other words, it refers to the stage of life that the child is in regarding the situations they are going through. A death of a loved one such as a parent of the child with ASD, can be impactful for the well-being of the child. There is a need to investigate the support and services available to families who will continue to support their child with ASD when they get older, since a majority of families may have significant levels of long-standing psychological distress (Hare, 2004). Although, some parents have stated that it became easier to deal with the challenging behaviors of their child as they got older (Ludlow et al., 2012; Smith et al., 2010).

Summary

Ecological systems theory was applicable to this study because it focuses on the interaction of the environment and individual. The presence of an ASD diagnosis in the family unit can be challenging, which is why this researcher identifies the theory that will allow families to overcome challenges when raising a child with ASD in hopes to promote coping styles, and utilize services depending on the family's situation. There is numerous literature on stress and coping styles in families of children with ASD.

Therefore, understanding the experiences of individuals affected by ASD is important to alleviate stress in these families and facilitate the development of more interventions to provide relief.

CHAPTER 3: METHODOLOGY

Introduction

The purpose of this study was to focus on the parental challenges and coping for parents or caregivers raising a child with autism spectrum disorder (ASD). This chapter presents and discusses the research design, participant recruitment, data collection, data analysis, protection of human subjects, strengths and limitations of the study, potential risks, and research questions.

Research Design

The following phenomenological qualitative study was intended to learn about participants' experiences raising their child with ASD. Phenomenology is an approach to qualitative research that focuses on the commonality of a lived experience. Two central questions guided this study: What type of stressors are linked to parents who are raising a child diagnosed with autism spectrum disorder?, What coping mechanism(s), if any, are parents utilizing when raising a child with ASD? These questions focus on the daily challenges faced by parents of children diagnosed with ASD and looking at the different ways that has helped them to cope. A thematic analysis of the data identified core themes: The understanding of the child's development, lack of support, dealing with challenging behaviors, impact upon the family, high stress levels, and coping. The findings help inform social workers and other professionals to improve or implement support programs and services depending on the parents situation. The experiences of stigma observed in the community toward families and persons with disability must also be focused when working with these families.

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Participant Recruitment

The study utilized a purposive sampling to identify parents of a child with ASD. The eligibility criteria for the study included parents or caregivers (mothers, fathers, grandparents) who live in Fresno County, California, and who were raising a child diagnosed with ASD. The participants were recruited on an online parent support group in Facebook, providing parents of children who have ASD a place to give and receive support. In an effort to minimize a significance age variance, I limited the target populations to parents whose child was under the age of 18 and resided in the family's household. Participants were ten parents of children with ASD who agreed to participate in the current study and able to communicate in English. There was no discrimination based on race, gender, educational or professional background. First, a participant

recruitment flyer (See Appendix C) was advertised on an online parent support group (Facebook) to seek out parents who are interested in the research study. Second, parents contacted the researcher directly who were interested in the study and the consent form and interview questionnaire (see Appendix B) were distributed via email who met the eligibility criteria. Lastly, parents who sent back the consent form and agreed to being interviewed, set a phone interview, zoom, or face to face appointment for the interview with the researcher. Participants were not compensated for their participation. To ensure transparency, upon completion, participants had the option to review the study's findings.

Data Collection

Data were collected phenomenologically using semi-structured, qualitative interviews within the family home or in a convenient place to promote familiarity, maintain participant confidentiality, and gain a unique understanding of family dynamics. Upon arriving to the interview, this researcher provided each participant with a consent form that was signed before conducting the interview. This researcher asked ten questions and was first approved by the researcher's advisor and the review committee before interviews were planned. The use of scribing and audio-recording was used to collect data and was transcribed into written form and then analyzed using thematic analysis. The participants were well acquainted with the interview guide and were familiar with the interview process. The questions also had open-ended questions, and probing were utilized throughout the interview. The interviews lasted an average of about 30 minutes to one hour to conduct.

Research Question(s)

The research questions guiding this study are:

- What type of stressors are linked to parents who are raising a child diagnosed with autism spectrum disorder?

- What coping mechanism(s) if any are parents utilizing when raising a child with ASD?

Interview Questions

To answer these research questions, the following interview questions were asked to participants:

- Tell me about your child.
- What was your reaction to your child's diagnosis? Can you tell me a bit on how your child got to be diagnosed?
- How would you describe a "typical" day at home?
- What do you consider your greatest stressors that you've contributed while raising your child? (list all that apply).
- What does your support system look like?
- How is your experience been seeking resources or services for your child?
- What coping mechanism(s) have you utilized to relieve your stress?
- Were there any setbacks or decisions that needed to be rethought of because of your child being diagnosed with ASD?
- Please explain your overall feelings and attitude about your child with ASD.
- What are some strengths you possess that has helped you raise your child?

Data Analysis

This qualitative study examined the lived experiences of parents raising a child with ASD. An inductive, descriptive thematic analysis was used on the interview transcripts to identify similarities and differences between families who are impacted by ASD. The transcripts were read and re-read highlighting and categorizing important statements that provide an understanding of parents' experiences and compile themes.

The data compiled were analyzed via a phenomenological approach. Domains within each core theme were developed. Coding was done in this study by having the researcher analyze the transcriptions to find common themes presented in these families due to their personal experiences with ASD. The researcher was the only one involved in the analysis and interpretation of data. The involvement of participants in data analysis ensured data was accurate and the process of ongoing informed consent. This researcher transcribed each audio-recorded interview in order to obtain all information for this study.

Protection of Human Subjects

The Institutional Subjects Review Board (IRB) in the Department of Social Work at California State University, Fresno, accepted the researcher's approval for this research study before actual data collection began. A consent form (see Appendix A) and interview questionnaire was given to all voluntary participants and was explained to every participant. The participants were all 18 years of age or older and considered to be minimal risk. Each participant was given the right to withdraw from participation at any time without penalty. Recordings and all other documents were currently stored on a USB drive and recording device, with the researcher only having access. This researcher was the only one listening to the tapes. Each transcript of the interview was void of names. Phone interviews, zoom, and in-person interviews were done at the participant's most convenient time and location to be sensitive to participants and conduct the interview in an accessible setting. There were debriefing after the interview to check in with the participants about any emotional stimulation that may have transpired during the interview. The participants were provided a resource list at the time of the interview in the event they became emotionally distressed. There were no immediate benefits to the participants. All research data were shredded and destroyed upon completion of the study.

Strengths of the Study

There is limited information regarding the experiences of family members who have been impacted by the diagnosis of autism spectrum disorder. The participation in this study provided information that can contribute to the understanding of parental challenges and perspectives of raising a child with ASD. This study will inform social workers and other practitioners to enhance or develop services for these vulnerable population.

Limitations of the Study

This researcher had worked with an agency that provides services to children with ASD and may have personal bias. The participants were recruited from two online support groups (Facebook) who give and receive support from other parents who have access to some level of external support, which may impact their experience of having a child with autism and opposed to those who do not have access to support. Another limitation was the limited number of questions which resulted in a limited amount of information. Moreover, this was a small qualitative study with only ten participants involved, so it does not represent generalizations to a larger population. If time permitted, the researcher would have included a larger sample size. Another limitation of the study was the location of the study since all participants resided in Fresno County, California. It also focused on participants who only spoke English.

Potential Risks

Although there are minimal risks in this study, most of the information is personally sensitive and includes questions about parenting experiences. Discussing these matters might be distressing for some parents or caregivers. However, participants may refuse to participate or withdraw at any time. The participants may choose to not respond to any questions that may make them uncomfortable. The participants are only identified

by age, gender, ethnicity, and role in this study. All research data will be shredded and destroyed upon completion of the study.

Summary

Ten participants were recruited through purposive sampling. The interviews were audio-recorded and took approximately thirty minutes to one hour. Face to face interviews, zoom, and phone interviews were recorded, and notes were taken using the interview questionnaire. The researcher analyzed and interpreted the compiled data into themes. This study used a semi-structured qualitative approach to discern the challenges and coping strategies of parents while caring a child diagnosed with ASD to help inform social workers and other professionals to improve or implement support programs and services depending on the parents situation. In chapter 4, the results of the interviews will be presented.

CHAPTER 4: DATA ANALYSIS

Introduction

The results of the study will be presented in this chapter. There were ten questions used for the interview with ten participants. The primary purpose of this qualitative study was to explore the experiences of parents or caregivers in regards to stress and the coping strategies used by parents raising their child with Autism Spectrum Disorder (ASD). The questions addressed in this study focused on the parents reaction to their child's diagnosis, their typical day at home with their child and the stressors that may come with it. It also explores the coping skills and support network that they may or may not have to assist with the challenges or stress that comes with raising a child with a disability. It provides the parents of children with ASD the opportunity to state their feelings and perspectives based on lived experiences. There were two central questions that guided this study: What type of stressors are linked to parents who are raising a child diagnosed with ASD?; What coping mechanism(s) if any are parents utilizing when raising a child with ASD? There is limited research that demonstrates the use of qualitative methodologies in learning from this population about these issues from a rural county. Therefore, a qualitative design was used to look into the personal experiences of parents of children with ASD.

Parents in support groups that live in the Fresno County area were asked to participate in the current research study. The participants were recruited from an online parents support group on Facebook providing parents of children with ASD a place to give and receive support and advice. A total of nine mothers and one father participated in the study. Data were collected in this study using qualitative methods. It focuses on the perspectives of the participants and the meaning they give to their experiences. The primary focus of a qualitative study is emergent, as the focus is to learn about the

problem from the participants. Data from the individual interviews were gathered from ten interview questions. Interviews were audio recorded and transcribed. Notes taken during the interview were analyzed for themes and content. This qualitative phenomenological study used a semi-structured interview which was done in person and by phone depending on what was most comfortable for the participants. A consent form was given to all participants before being interviewed. Interviews averaged about thirty minutes to one hour in length. Several themes emerged from the data. The themes that emerged will be discussed below and organized in the order of importance. The questionnaire will be used to guide this chapter.

Analysis

Several themes emerged from the data including: behavior of the child, reaction to diagnosis, typical day at home, unmet needs, challenging experiences, ways of coping, formal and informal support, seeking resources and services for their child, setbacks or decisions made, overall feelings for their child, and strengths the parents possess when raising a child with ASD. Each theme will be discussed in turn. The data was collected through face to face interviews or by phone over a two month period.

Behavior of Child

The study showed that the child's ASD had a huge impact on parents on a day to day basis. Many of the participants stated that their child exhibited behaviors such as tantrums, self-injury, screaming, smacking on the head, and meltdowns. This allowed some parents to use reinforcements. All parents stated positive behaviors and characteristics about their child such as being energetic, genuine, honest, patient, independent, and being able to have a full conversation with their parents. There were unique behaviors for some children such as lining up their car by color, watching the fan move, re-watching a movie, and high pain tolerance. Some ASD symptoms that were

seen by participants with their child were speech delay, communication difficulties, anxiety, confusion, lack of eye contact, tantrums, repetitive behaviors, lack of social skills, and many do not meet the milestones like other typical children do. Nonverbal communication was a major behavior that parents reported their child exhibited, especially two parents who stated their child did not start speaking until the age of five. Many parents also reported that because of the problematic behavior with their child or how sensitive they are to sound, many were not able to go to restaurants, movie theaters, or even sports games and one parent even has noise-cancellation headphones when their neighbors are too loud or to take during family events if needed. It must be noted that one child of the participant also has an additional disorder (ADHD). Many parents sought out services on how to manage their child's behavior and how to interact and communicate with them without setting them off. One participant stated that their child was reserved because they were an only child, only grandchild in the mother's side of the family, and was surrounded mainly with adults.

Reaction to Child's Diagnosis

One theme that emerged from the study was that parents in the ASD community had similar reactions when finally receiving their child's diagnosis by their pediatrician or doctor. The age of diagnosis for the children in this study ranged from 2 to 7 years old. Some parents saw signs of ASD by 16 months while one parent did not see the signs that her child had autism but she did see behaviors such as nonverbal communication, no eye contact, tantrums and meltdowns. Many participants reported that because of their background, such as two participants working with special needs children in the past and one participant being autistic themselves, it was easier to accept the diagnosis and seek treatment. Two participants did reveal that they had feelings of grief because of their visions of their ideal child and did not expect to have a child with ASD. Some of the

participants were not educated about autism or did not know anyone with autism until their child was diagnosed with ASD. Many parents felt relieved and accepting towards the diagnosis for their child. One parent knew what to expect because they saw the signs of ASD. Some parents took a couple years to accept the diagnosis and understand it by taking parenting classes to discipline their child, read books about autism, and looking for services for their child. There were feelings of relief, thankfulness, grief, acceptance, numbness, and shock by the diagnosis and even one parent broke down at the realization of having to deal with her child's diagnosis.

Typical Day

All parents in the study reported they had to adjust their life for their autistic child. A majority of parents reported that there will be times of off-schedule days in which the daily routine would be paused, in order to redirect the child. Those days that are stressful or just a bad day overall would be times when the child would have a meltdown, be noncompliant, or have feelings of frustration. Other individual symptoms of autism parents found most stressful are sleep patterns, bowel/bladder problems, and aggression. These behaviors required parents to constantly be vigilant which added another layer of difficulty because of additional time that took away from other activities, work, school, marital satisfaction, or self-care. One parent reported "it would take one hour to get her inside the car seat" and "there would be situations where she would harm her siblings, so we would have to supervise them". One participant stated that she finally found a medication that worked for her child in order for her child to sleep, since there have been times the participant would be awake for more than 24 hours. When answering how a typical day would look, many parents reported in addition to getting their child up for the day, eating, school, playing with the tablet or walking the dog; many parents would add speech classes, ABA therapy, one on one aid, individual sessions, or

occupational therapy into the routine. On bad days, many parents reported their child would either scream, start a meltdown, harm their siblings, or engage in attention-seeking behaviors. A majority of parents had to quit their job, get a new job, or had to adjust their work schedule in order to raise their child with ASD especially since ABA therapy is needed into the daily routine. One parent reported, “I had to put my teaching credentials on hold until my child was settled for a couple years and financially, it has been stressful since ABA isn’t cheap and insurance only pays for so much for it”. For other parents, difficulties arose from the transitions their child were experiencing including puberty or to master everyday skills. Toileting was reported by two parents who said it took a month to years to accomplish, and the use of diapers were needed to have their child with autism become more independent in toileting. Positive reinforcements, prompting the child, and reward or token system was also used in the parent’s daily routines for good behavior and to decrease negative behavior. One participant reported they would hug their child to calm them down when they exhibited meltdowns. Another parent reported, “When we first got our diagnosis, and started ABA therapy, he would scream for eight hours a day, because we would have two, four hour sessions everyday with the therapist, and he would scream the whole time until he would pass out”. Reasons for social deprivation included the inability to bring children to social gatherings due to behavioral concerns and fear of stigmatization. Two parents reported and witnessed their child being bullied with one parent stating, “I had to call the school because one of the kids had scratched my child, and had scratches in his body, and I still have pictures to this day”.

Stress

Health, the child’s problem behaviors, the child’s autism spectrum symptoms, financial stressors, and finding a job at home to take care of the child were all contributing factors to stress for parents in the study. Almost all participants reported that

nonverbal communication brought feelings of stress. One parent stated that she has the obligation of taking care of other members of the family as well as their autistic child. The biggest stressors that some parents reported were the anticipation whether their child was eligible for individualized education program (IEP) or special education since their child has to be evaluated for ASD. Some parents reported not being able to work since having children or having to do behavioral therapy and be part of the services for their child. Parents' reported feeling stressed and worried about current and future outcomes for their child including how they will be treated, graduating, get marriage, whether they will be able to live independently or who will care for them if they died. One parent reported, her sister would take care of her child if anything were to happen to her and her husband. One parent reported that school for her child was stressful, stating "he doesn't fit in with the other kids, he doesn't sound like the other kids, sometimes the other kids pick on him, the school part is so hard". About half of the participants stated they had feelings of anxiety, with one participant stating she has anxiety almost daily. One parent reported having depression and anxiety as well as her husband and times of isolation. Another parent who was diagnosed with depression at second grade stated,

depression gets worse because of some situation that we are in, and my anxiety goes through the roof especially if we do something new or I know has potential triggers which would be a simple as going to zoo with the possibility of a bunch of people there.

One participant expressed feelings of hopelessness, depression, overthinking, and her lack of faith because of her problems since she is a single mother raising not only her child with autism but also her nieces with disabilities. Feelings such as being overwhelmed was a common issue, particularly for parents who did not have a significant other or support group to assist with their child with ASD. Other parents noted feeling overwhelmed by having to search and apply for multiple services, or the struggle of

having her child be eligible for any services due to the child's age, their IQ being too high, or because the child does not meet the special education criteria.

Social Support

Support systems played an important role in parents' ability to cope and manage stressors when raising a child with ASD. When focusing on informal social support, participants stated that they had a great support system such as grandparents, siblings, and parents which allowed them to take a break, get some sleep, and get some alone time with their significant other. The support the parents utilized included: seeking social support from internal and external families, friends, healthcare professionals, and the school of the child. One participant when focusing on family support stated, "they all pretty much have been trained with the ABA therapist on how to handle meltdowns and the therapist is available via text and facetime if we need her". Findings indicated that children with autism can have an effect on other family relationships. Some participants in the study felt that they had inadequate social support mainly from friends and some of their extended family members. About half of the participants stated their extended family did not understand the actions and behaviors of their child and struggled to accept it. The parents stated the extended family were very supportive just unfamiliar with autism and that the older generation, such as the grandparents had an old school mentality. The participants expressed how they had to educate their family members and friends about autism. While for other participants, stigma and discrimination of the ASD diagnosis of the child was presented which led parents to distance themselves and be socially excluded from events. This had a ripple effect for some parents leading them to withdraw from some family members and friends. One participant reported losing three friendships because of their mentality about autism. Two participants stated that their biggest emotional support would be their husbands. When talking about their significant

other, one participant stated, “We help each other out when one of us is feeling tired, we’re a team”. Another participant reported, “he holds me when I cry, when I have a bad day”. When there are times of frustration such as their child exhibiting tantrums, both participants stated they are able to handle it because of their significant other. Most of the participants who were mothers would take care of the child rather than the father especially since the participants were either divorced, separated, the father is away for work, or the father is not involved in the child’s life. One participant stated, “my ex-husband left, he hasn’t seen his child in five years, and hasn’t talked to him in three years”. Specifically, one parent reported that she is her own emotional support system since her husband who is in the military only comes twice a year, but also stated that she has services for her child such as a twelve hours a month aid to care for her child. One participant stated that he does not get as stressed as his wife does because he works most of the time, and also does not know how to handle the negative behaviors of his child.

When focusing on formal support, a support system was presented as a major factor for parents since they felt that the most useful advice would come from other parents who can relate to day to day experience raising a child with ASD. This support system allowed parents to be part of the ASD community and gain suggestions for general coping, handling their child’s problematic behaviors, and information on services and resources. Two parent participants had similar issues from service providers who did not want to assist them until they showed proof of diagnosis for their child in order to start providing services and they had to go to a different doctor until their child was examined and determined the diagnosis with autism. Another participant stated that their first psychiatrics didn’t hear her concerns and was dismissive that the child even had autism because her child did not exhibit autism symptoms. Although when she was referred to another service provider she was delighted on the team that consisted of the doctor, case manager, which sets her family up with groceries and other necessities. One

participant stated that she has felt helpless at times when looking for services stating, “doctors and teachers would deny my child because of his high IQ”. The parent had difficulty in accessing services and struggled with her speech therapists for her child and her service providers because of her personality and her dissatisfaction with former therapists.

Parents who had successful service providers were able to gain tips to help improve their spouses’ and their other children’s understanding about their child and sibling with ASD. Parents sought help to deal with the child’s behavior and used the services that would help parents find jobs, gain access to social security for their child, as well as services that would advocate for them and their child. One participant stated their pediatrician gave her twenty referrals when she got the diagnosis for her child and was easier when her child was young, although as he has gotten older, she stated it has been a struggle because of his age since he did not qualify for some programs. When focusing on services from the school, there were positive and negative experiences for parents such as teachers being supportive, willing to work with the parents, and having good communication with them. Some schools provided speech therapy and special education classes for their children. Another parent reported, “three teachers still check in on him and want pictures of him, and want to know how he’s doing”. The parent also stated that “his school allowed him to eat his lunch in an office because he cannot stand the sound or smell of the cafeteria, and they have been incredible”. Although there were some parents who had a difficult time with the school handling their child’s behavior and even some schools did not have any form of special education funding and no way of providing services. This allowed one participant to do home school to have a one on one aid for her child. There were also signs of bullying in the school, in which one parent had considered removing her child from public school and into a charter school in order for him to finish on his own pace. Other forms of formal support were religious congregations. One

participant said she has a strong support group from her church members who adore and are rooting for her and her child. Another parent sought out services on her own and used therapeutic riding for her child so that there is some form of recreation activity into their routine.

Coping

Participants were asked what type of coping strategies if any are used while raising their child with ASD. Many participants stated that their mental health needs were unmet such as depression, anxiety, isolation, and lack of self-care when raising their child with ASD. Although all parents stated they had some form of positive coping strategy when raising their child with ASD such as going to get a massage, pray and attend online church, therapy, exercising, deep breathing, meeting up with friends or family members, support groups, and overall some alone time for themselves. One parent reported that he would have a day for himself for some alone time. Another parent stated, “I would see a therapist on and off, and would have thirty minutes that I devote to myself each day, read a book, and just escape”. This is similar strategy for another parent who also stated that they would go to therapy once a week. All participants stated that social support is needed in order to be able to self-care and get some alone time for themselves.

Setbacks

Findings in the study indicated that having a child with autism often produces several life changes. Some setbacks that parents had to put on hold or decisions that had to be made were not being able to work or putting their education on hold. One participant said,

I had to quit my job when he started doing ABA therapy, so I went from making my own money, from feeling independent and a grown up to staying at home every day. I had to move in with my dad because I couldn't afford rent if I wasn't

working. I went from being a wife with my own home, to being divorced with my own apartment, to moving in with my dad again at age 21. It also stopped me from meeting people and I couldn't leave my child with anyone, and my child would have a hard time if I went anywhere, so I was single and alone for a very long time.

When focusing on education, one parent stated, "I had to put my teaching credentials on hold, until she is settled for the first couple of years, financially a little stressful since ABA isn't cheap, so having to financially support her". One participant reported that his wife had to find a new job while he stayed at home with the child to take care of and was not able to work. One participant did not have any major setbacks because of her child being diagnosed with ASD but stated that she no longer had time for night outs or vacations. One parent had ideas of moving out of state. This participant stated:

We were planning on moving to Vermont and when you move states, you have to get all the assessments done again, but we couldn't because of COVID, so she can't get services or school, so we couldn't move and also I don't know how I'm going to work at home, manage school and all the occupational and behavioral therapy, I can't.

Overall Feelings of Child

All participants had positive appraisals for their child with ASD. Many parents reported that they will never give up on their child and are excited to see where the future holds for their child. One participant stated:

I have overwhelming love for her, I would do anything to see her succeed in life, and make friends but also the stress of the what if's and what if something

happens to me and who is going to watch over her, and also hypervigilant, always on guard.

Other participants said they are proud of their child, have lots of potential, surprise others, and can handle whatever is thrown their way. One participant stated that she makes sure he is true to himself. Another parent responded that it is a trial and error, that she is living in her child's world and she is learning along the way. Another parent reported,

I adore him, he is my best friend. If you want an honest opinion about anything he does not lie. He is the most incredible human being I have ever met in my life, even when things are rough, when he calms down, that hug, he gives the best hugs. If he is spending time with you, it is almost like an honor.

Strengths

Some strengths that parents had in themselves were to be assertive and to advocate for their child when dealing with service providers or family and friends. The parents reported being a voice for their child, and were very open about their child's diagnosis to strangers and family members. They stated they wanted others to be more aware and open about autism and mostly all parents wanted to educate others about ASD. One parent stated that he has a routine, has minimal meltdowns when raising his child, and is very determined. Another parent reported how she never gives up, is very patient, and makes sure to take care of herself. Two participants reported that a strength for them would be: being knowledgeable about certain areas about autism and being able to go head to head with school district and health care providers if they are not meeting the needs of their child. One participant stated,

Being a mother is all I know, so I think that's my strength. That between my family, the ABA therapist, and everyone that we've met through our journey has

taught me how to be a mother. It is all I know, and I know that I will never stop fighting for him.

Overall, all participants reported that while it is exhausting raising a child with autism, being determined, patient, and never giving up on their child is important. One participant stated that because her and her husband are autistic themselves, they are able to understand their child and use that as a strength.

Summary

The purpose of this research was to learn the lived experiences of parents raising a child with ASD and the challenges and coping that may come with it. The data was collected through face to face interviews, and phone meetings. The interview questions were implemented in order to empower future and current families who are raising a child with autism as well as provide vital information that can be applied to their specific situation. Chapter 5 will include a discussion comparing the finding to most recent research and how it is applied to theory. And the recommendations will be discussed.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

Introduction

The purpose of this study was to explore the relationship between stress and use of coping strategies among parents of children with autism. This chapter will discuss the themes that emerged from the data which include reaction to diagnosis of their child, behaviors of their child, stress, formal and informal support, coping, setbacks, overall feelings of their child, and strengths the parents possess when raising a child with ASD. It will also discuss the interpretations, limitations to the study, its relevance to social work practice and recommendations for further research. The research questions will be answered and the parents' lived experiences will be applied to theory.

Research Findings

The goal of the qualitative study was to gain insight from parents raising a child with ASD and the stress and coping strategies they use. A total of 10 participants were used in this study and all participants gave their response based on their experiences raising their child with ASD. The following research questions were examined: what type of stressors are linked to parents who are raising a child diagnosed with autism spectrum disorder?, and what coping mechanism(s) if any are parents utilizing when raising a child with ASD? After reviewing the literature, the findings produced both similar and contradictory results.

ASD is typically diagnosed in childhood and has a wide range of symptoms which consist of communication, socialization, behavioral and interest impairments, as well as minimal social skills (Weiss & Lunsky, 2011). First, the results concluded that these symptoms of the child presented a challenge for parents while raising their child and the demands such as time, attention, and energy. Some felt anxious and had to make personal sacrifices to focus on services like ABA therapy for their child which

corresponds with a previous study (DeGrace, 2004) that the daily routines for their child with ASD conflict with the family unit. This is consistent with previous research (Horner et al., 2002) in which children with autism have challenging behaviors of aggression, tantrums, self-injury, disruptions and noncompliance that demands the parents attention to develop a routine to meet the demands of the child with autism. Findings of the study showed a common thread among the parents such as two parents having feelings of grief because of their desire for their child to be typically developing. This aligned with the research (Randall & Parker, 1999; Mansell & Morris, 2004; Heiman, 2002; Altieri & von Kludge, 2009), that families who receive ASD diagnosis bring in feelings of loss of their ideal child. Although there were some parents in this study who were grieving, all parents had some form of feelings of relief, thankfulness, acceptance, and shock by the diagnosis but were able to accept it and seek out professionals and services for their child. Eventually, all participants became educated about autism after getting their diagnosis of their child while some parents knew about autism based on their own personal knowledge, media, education, and their own experience being diagnosed with autism. The results of the study are consistent with previous research (Altieri & von Kluge, 2009) in that parents were experiencing feelings of relief and sought out services for their child right after the diagnosis.

Many parents questioned the independence of their child with autism and the fear of the future on whether they will marry, graduate, which corresponds with a previous study (Navot, et. al., 2016) which mothers had fears for the future and the unknown. Stress represents a negative influence on intra- and extrafamilial relationships, family recreation, finances and the physical, emotional, and mental health of parents, and change in lifestyle. (Blacher, 1984). Speech delay was the most stressful for many parents in the study as well as their child feeling frustrated because they could not communicate the reasons for their frustration. This is consistent with previous studies (Bebko et al., 1987)

in which parents reported cognitive and communication impairment to be the most stressful and nonverbal communication for professionals from all other symptoms in severity.

Also, a few parents had gaps in their social support, especially support from grandparents and friends. One parent even reported the father of the child accepts his child's condition but is not involved in caring for the child when the child exhibits problematic behavior problems. The findings of this study also showed that parents of children with autism experienced abandonment by social networks of friends who were not comfortable dealing with a child with special needs. These results in the study are consistent with previous studies, (Altiere & von Kluge, 2009) that family members and friends had disconnected from them upon their child being diagnosed with ASD and were also not educated about autism. According to Hillman (2007), it is necessary to include extended family members especially grandparents who are educated in ASD that can serve as a valuable source of support. Mostly all participants in this study indicated some form of informal support such as relatives, siblings, and spouses that allowed them to escape from the demands of parenting. The results are consistent with a previous study (Navot et al., 2016) in which the spouse is an important emotional support for mothers of children with autism. This can decrease parenting stress levels and mental health problems in parents of children with ASD (Ekas et al. 2010). Although it should be noted that some participants were divorced, separated, or single parents. Two participants were the primary caregiver of her child, with the biological father absent in their life. This can be consistent with a previous study (Ludlow et al., 2012) in which mothers are typically more stressful because they are often the child's primary caregiver. Also mostly all participants except one parent had a male child with ASD. Participants were all gathered from a virtual support group on Facebook, where parents are able to provide advice, ask questions, and provide emotional support while making connections. The results are

consistent with previous studies (Ludlow, 2012; Pepperell et al., 2018), in which parents felt the support of other parents of children with autism has helped them cope, since they are a source of support who are experiencing similar issues.

The coping strategies that some parents utilized were emotional support, religion, family and social support, meditation, exercising, and overall self-care. The results from the study were not consistent with previous studies (Lee, 2009) in which avoidance and denial were coping strategies used to deal with the diagnosis of ASD of the child. Coping strategies have been noted as one mechanism by which individuals tend to respond to intimidators of stress such as stressors related with parenting a child with autism (Benson 2012). In addition, the parents reported negative personal emotions such as stress, anxiety, depression when raising their child with autism and financial burden as well as leaving the workforce to become the primary caregiver for the child with ASD. These findings correlate to previous studies (Harris, 1984; Koegel et al., 1992) that found that parents of children with ASD experience greater levels of stress, anxiety, depression than any other parent without this disorder and many leaving their jobs to take care of their child (Beer et al., 2013). Parents in the study reported difficulty in searching for resources and getting inadequate assistance from schools or professionals because of their child's challenging behaviors. This is similar to a study from Visser and Cole (2003), that the child's behavior problems can bring a lack of positive relationship from outside assistance. Two parents reported their doctors disregarding the parents' concerns about their child and possibility of having autism. This left these parents feeling discouraged, frustrated, and having to be referred to another doctor until they got their diagnosis. Previous studies found that parents are aware of their autistic child's limitations and provide accurate assessment of their child's behavior (Kysar, 1968). Mostly all parents have both positive and negative outcomes when dealing with professionals or schools. These findings correlated with previous studies (Robert et al., 2015) in which parents'

satisfaction on support services depends on their experience with professionals who try to improve the family's atmosphere and to help parents respond to their child's needs. When focusing on stigma, two participants stated they observed some type of bullying because of their child being diagnosed with ASD. The behavior problems of the child with ASD also did not allow some parents to go to public places since their autistic child are overly sensitive to their environment and may be bothered by sounds and large gatherings. In fact, other researchers (Estes et al., 2013) found that mothers of children with ASD may have higher parenting stress scores and higher levels of problem behavior compared to mothers of children with developmental delay without ASD (DD), and typical development (TYP).

Implication for Social Work Practice

It is important that social workers and other service providers be sensitive to the impact of stress on parents raising a child with autism. There should be ongoing assessments of the level of stress experienced by parents of autistic children which might help social workers provide effective services to this client population. Also, considering the stress experienced depending on the gender of the parent and the gender of the child, may help social workers address the needs of these parents and their child. Results of this study indicate that there was some inadequate or no services provided by service providers to these parents. If this finding is confirmed through future research, it is imperative that service providers be more supportive than obstructive. Social workers should work with pediatricians and other providers with the parents upon receiving the diagnosis of their child in order to provide emotional support as well as to assist them through the special education system and refer them to resources in their community for the parent and the child diagnosed. Social workers should also strive to refer parents who have just received an ASD diagnosis to support groups to get advice and support from

parents who have experience raising a child with autism. Future research using large sample sizes is imperative in order to fully understand the impact of raising an autistic child on the well-being of parents.

Theoretical Framework

The ecological perspective was used as the theoretical framework that best fits this study. The theory deals with circumstances within an individual's environment that influences the development of the individual (Bronfenbrenner, 2000). The child with ASD is a member of a larger contextual system (family, school, community) (Symon, 2001). Ecological systems theory consists of four structures called the microsystem, mesosystem, exosystem, and the macrosystem (Bronfenbrenner, 1977). From an ecological perspective, the focus is on the problems and needs associated with tasks involved in the life transitions that the parents must adapt in order to raise their child with ASD. The developmental stages of their child, status role of the parent such as caregiver or breadwinner in the family, and crisis situations such as the behavior problems that the child with ASD may exhibit must be looked into. The impact of ASD on the child and the parents make up the microsystem, while the availability and quality of services makes up the exo-level. The stigma experienced by parents of children with ASD make up the macrosystem. When attempting to understand the parents' experiences of ASD services and interventions, or lack thereof, the results conclude that there seems to be some inadequate services for parents especially from the school system either because of the lack of special education services in the school or teachers who are not educated or trained to work with special needs children. Working with the systems in the environment of the parent raising the child with ASD is imperative, to make them more responsible to the parent and their child's needs while working with the parents and the other systems to help improve their situation.

The child's ASD not only impacted the child themselves, but also the family members in a variety of ways which these findings in the study is consistent with ecosystems theory, that systems influence one another. This study found that a child with ASD impacted the parent's emotional and psychological well-being with one participant crying and being comforted by her spouse. This correlates with past studies (Howlin, 1988; Ellis, 1989) on the impact ASD has on families. The findings of this study also found that the child's ASD impacted on the family's social and interpersonal functioning in which most parents' time is being the caregiver of their child. It should be noted that this study also shows some parents quitting or adjusting their job schedule due to their child's ASD. This aligns with Bronfenbrenner's (1977; 1979) ecological theory, in which the child with ASD will impact the exosystem (the parent's workplace). Although while the child with ASD does impact the exosystem, it can lead to a positive outlet for parents. This study reports support groups have been used mostly by all participants to get advice and tips on how to raise their child with ASD, which aligns with a previous study in which support groups can serve as a resilience factor to decrease the stressful events for families (Symon, 2001).

When looking at the macrosystem in Bronfenbrenner's theory for this study, stigma not only impacted the child with ASD, but also the family members since most parents reported having a family member distance themselves because of their child and another parent stating they do not go to public events because of their child's behavior. This finding aligns with previous studies (Ellen et al., 2018; Gray 1993, 2002) in which behaviors of the child may expose parents to courtesy stigma from the public which can lead to isolation and social rejection. Participants in this study reported challenges and unmet needs in which the government must take into account when implementing policies and laws to reduce barriers for families of these children (Montes & Cianca,

2014). The eco-systems theory is useful in understanding the flow from one system to another specifically a child with ASD has on larger contextual systems.

Limitations of Study

There are several limitations to the study that should be noted. First, the parents who participated in this study were all part of an online ASD support group. While this seemed like an effective way to reach many ASD parents, having a sample of ASD parents who were part of an ASD support group may have affected some of the outcomes. For example, most parents in the ASD support group are seeking social support and are not escaping or avoiding. In order to get a better representation of parents who have a child diagnosed with ASD in Fresno County, the researcher should have collected data from parents who are involved in a support group and those who are not in a support group. Although the small sample size was appropriate for a qualitative study, the sample size makes the findings difficult to generalize to the overall population of parents with autistic children in Fresno County. It should be noted that the participants in the study had young children with ASD with ages under eight. This limits the accuracy of the findings for other age groups that have autism. Furthermore, there were more female participants than male participants in the study and male children with ASD were being raised by the participants while only one participant was raising their daughter with ASD. The underrepresentation male participants in this study raises concerns for possible biases within the findings which may not be representative for the whole community. If time permitted, the researcher would have liked to recruit more male participants, since the study had only one father participating. This would have allowed the researcher to determine if there were any differences in stress and coping mechanism used between mothers and fathers of children with autism. Also, due to Coronavirus disease 2019 (COVID), there were more phone interviews with parent participants and only one face-

to-face interview which may have impacted the results of the study. The study was limited by the response bias inherent to the nature of the study procedures. All participants voluntarily joined the study and may not have shared the same lived experience of the other members of the ASD community. They may also be guarded and not forthcoming with information about their experiences raising their child to be seen in a better light. The participant may minimize, exaggerate or have forgotten some information. A participant may also not understand a question that may make the information incomplete or difficult to understand by the researcher. Since there is no compensation for participants, this might have affected the participants motivation to participate in the study.

Strengths of Study

Despite these limitations, this study provides insight into the lived experiences of parents of children with ASD. The knowledge that the researcher had about Autism Spectrum Disorder (ASD) was limited, although the researcher has worked with children with autism and their parents as a behavioral instructor for a few months in their own homes. By directly interviewing parents of the ASD community, the researcher felt they were able to hear the lived experiences and get an understanding of the challenges and coping strategies parents utilize. The in-depth interviews produced rich details of perceived benefits and processes that impeded helpfulness that a quantitative study would not have provided. The researcher asked questions and practiced reflective listening to elaborate on the parents' stories. Parents in the study were diverse, with different ages of the child and the time they were diagnosed with ASD. Having an understanding of the challenges and lack of well-being in parents of children with ASD is relevant to the practice of mental health professionals and social workers as it can serve as a guide in delivering services to the unmet needs of families. It is especially important for the

efficient delivery of services to parents receiving diagnosis for their child and lack of education on autism. Understanding the family experience when raising a child with ASD, can contribute to creating changes in policies and improvement in serving delivery for them.

Recommendations for Future Research

The information that was revealed by the parents in the research is valuable on every level. The research information should be shared with the participants in order to validate the participants to know that they have helped the ASD community but also educate others who are not knowledgeable about autism. The participants would likely feel good about themselves for participating in the research which may lead them to advocate or mentor other parents raising a child with ASD, and it could provide some much-needed advice and tips for parents as they continue their journey on raising their child with autism.

This research should also be shared with the urban county from where these parents emancipated and should be shared in the virtual support group page in which the researcher obtained the participants for other parents to have access to. It is important for agencies to be aware of the needs of the parents raising their child with autism so that they can be better prepared to cope with problematic behaviors, autistic symptoms, and the stigma involved with the disability. This information should be shared to agencies working with the parents of the child with ASD and be aware of the challenges and needs of the parents and will reveal a gap in services. This could lead to better training for staff and better outcomes for the parents.

The sharing of this research should not stop at social workers but also to parents, the community, behavioral instructors, schools, occupational therapists, and other professionals who come in contact with any individual with developmental or

neurological disorders that should be knowledgeable of the specific disorders their clients have, such as ASD. This study also contributes to the body of research in the urban county on the ASD community.

Students, social workers and others who have contact with the ASD community should continue to educate themselves about the challenges and unmet needs that parents face as they raise their child with autism. Further, each agency working with these parents should have an exit interview to make sure they are referred to the appropriate services and access to resources for their child with ASD. It is important that each parent tell their lived experience to the agency to learn the unmet needs and challenges of the parents and strive to improve services for them.

It would also be useful for educated and experienced parents to participate in educating parents who are currently getting a diagnosis for their child. The research showed that parents are big advocates about bringing awareness to their family members and some parents who were not knowledgeable about autism when getting their diagnosis for their child. A parent whose child currently got their diagnosis for ASD will more likely listen and take seriously the advice of a parent who has struggled before getting services and the stigma behind ASD which could make a significant difference in the attitude of the parents who are barely preparing to raise their child in an urban community and who may have limited formal or informal support and resources and need to understand that they will have struggles as they raise their child with ASD but that they can overcome these challenges and have an easier transition and positive coping strategies if they listen and prepare.

Summary and Conclusion

This study contributes to the small body of literature on the lived experiences of parents raising a child with Autism Spectrum Disorder. This research adds to the

emerging literature on developing ways to improve the parents' services to better prepare them on the challenges and coping that may come when raising their child with autism. It is clear that parents of children with autism are under a significant amount of stress. Some parents are better able to cope with this stress than are other parents depending on their support system, coping strategies, and the child's specific symptoms of autism. Social workers and other professionals should address the impact of stress and unmet needs in their work with families of children with autism. There must be more public awareness of ASD, advocating for changes in policies and the improvement in services is crucial to effective change for children and families affected by the disorder.

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APPENDICES

APPENDIX A: INFORMED CONSENT FORM

*Parenting Stress and Coping among Parents or Caregivers Raising a Child with an
Autism Spectrum Disorders (ASD)*

I have been informed that this study involves research which will be conducted by Elizabeth Alvarez, a graduate student of Social Work at the California State University, Fresno. I understand that this thesis is designed to study the experience of parenting stress, and styles of coping among parents or caregivers raising a child with Autism Spectrum Disorder. I have been asked to participate in this study because I am an adult, 18 years or older, and I have a child who has been diagnosed with Autism Spectrum Disorder who is under the age of 18. I understand that my participation in this study will involve the completion of an interview designed to understand my experience of parental stress and style of coping. The purpose of the interview is to fill the informational gaps that exist in the professional literature about this topic.

I am aware that my participation will involve answering interview questions (face to face, zoom, or phone interview) designed to understand parental stress and coping skills among parents or caregivers raising a child with autism spectrum disorder. I understand that I will be voice-recorded or conducted via phone to record my responses. I have been informed that my participation in this study is voluntary and I can refuse to participate or withdraw at any time. I am aware that my involvement in this study will take approximately between thirty minutes to one hour of my time. I understand that my identity as a participant will be kept in confidence and that no information other than age, gender, ethnicity, and role in this study will be used and will not be released without my separate written approval. I am aware that all information that identifies me will be protected to the limits allowed by law.

I have been informed that only Elizabeth Alvarez, B.A. and Randy Nedegaard, Ph.D. will have access to any data that identifies me personally. The Institutional Review Board may also review my research and view your information. I have been informed that all personal identifiers from the data collected from me will be destroyed by Elizabeth Alvarez, B.A. after completion of the study. Once the audio recordings have been transcribed they will be deleted. I have been informed that some questions may make me feel uncomfortable. If this occurs, Elizabeth Alvarez, B.A., will provide a community resource list if necessary. I am aware that although I may not directly receive benefits from this study, my participation in this research may benefit parents of children with autism spectrum disorder, like myself and will make an impact with the university.

I understand that I may contact Elizabeth Alvarez at ealvarez700@mail.fresnostate.edu or the faculty overseeing the research, Randy Nedegaard, Ph.D. at nedegaard@csufresno.edu or (559) 278-6129 if I have any questions about this study or my participation. I understand that at the end of the study I may request a summary of results or additional information about the study from the above student.

A signature indicates your understanding of this consent form. I am 18 years or older and I voluntarily agree to participate in this research study. You will be given a copy of this

form to keep. If I have received this Consent Form and the Interview Questions via email, by returning my answers via reply, I am agreeing to the above-stated conditions.

Date:

Participant's Signature:

Date:

Researcher's Signature:

APPENDIX B: INTERVIEW QUESTIONS

1. Tell me about your child (personality, behavior, limitations, and assets).
2. What was your reaction to your child's diagnosis? Can you tell me a bit on how your child got to be diagnosed?
3. How would you describe a "typical" day at home?
4. What do you consider your greatest stressors that you've contributed while raising your child?
5. What does your support system look like?
6. How is your experience been seeking resources or services for your child?
7. What coping mechanism(s) have you utilized to relieve your stress?
8. Were there any setbacks or decisions that needed to be rethought of because of your child being diagnosed with ASD?
9. Please explain your overall feelings and attitude about your child with ASD.
10. What are some strengths you have that helps raise your child?

APPENDIX C: PARTICIPANT RECRUITMENT FLYER

Are you a parent or caregiver of a child with autism spectrum disorder (ASD)?

**Would you be interested in participating in a study and help further research on
parents or caregivers raising a child with ASD?**

Parent or Caregiver must be 18 years or older

Must live in Fresno County

**Your child must be between the ages of 0-18 and must be formally diagnosed with
Autism**

Only one child diagnosed with ASD will be needed in the study per family



**Please email ealvarez700@mail.fresnostate.edu and indicate your interest in
participating in the study. Thank you for your interest. Your participation is greatly
appreciated.**

APPENDIX D: COMMUNITY RESOURCE LIST

Directory of some community resources:

Link: <https://www.co.fresno.ca.us/home/showdocument?id=17156>

Central Valley Suicide Prevention Hotline

- (888) 506-5991
- 24 hours a day, 365 days a year
- centralvalleysuicidepreventionhotline.org

Dept. of Behavioral Health Access Line

- (800) 654-3937
- 24/7 information connecting to Mental Health Services

Fresno National Alliance on Mental Illness (NAMI)

- (559) 224-2469
- 7545 N. Del Mar Avenue, Suite 105, Fresno
- Website: [Click Here](#)

Medical / GR Eligibility

- (877) 600-1377 (Automated)
- (855) 832-8082 (Live Person)
- Website: [Click Here](#)

Substance Use Disorder Assessment Center

- (559) 600-3800
- 2212 N. Winery, STE. #122, Fresno
- Website: [Click Here](#)

Fresno County Resources and Information

- Dial 2-1-1
- Website: [Click Here](#)

APPENDIX E: HUMAN SUBJECTS CERTIFICATE



Completion Date 20-Sep-2019
Expiration Date 19-Sep-2022
Record ID 32938326

This is to certify that:

Elizabeth Alvarez

Has completed the following CITI Program course:

Social & Behavioral Research - Basic/Refresher (Curriculum Group)
Social & Behavioral Research (Course Learner Group)
1 - Basic Course (Stage)

Under requirements set by:

California State University, Fresno

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?wee467a6d-5a92-409c-919c-e157af3a3399-32938326