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An Exploration of the Effects of Parenting a Child Diagnosed with Autism Spectrum Disorder

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Eastern Kentucky University

An Exploration of the Effects of Parenting a Child Diagnosed with Autism
Spectrum Disorder

Honors Thesis
Submitted
In Partial Fulfillment
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An Exploration of the Effects of Parenting a Child Diagnosed with Autism
Spectrum Disorder

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Abstract

There is an increasing prevalence of ASD diagnoses, which calls for more research on the caregivers. This study's goal was to explore primary and secondary sources to identify themes of potential research within this topic. This study analyzed the existing literature and archival data to create seven themes: parental stress, stress-inducing ASD symptomology, ASD vs. other disorders, mothers vs. fathers, coping mechanisms of caregivers, substance use, and incarceration. A potential future research project idea is presented.

Keywords and phrases: autism spectrum disorder, challenges, caregiver, stress, substance abuse, incarceration, themes of research

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Introduction

Autism Spectrum Disorder (ASD) is classified as a developmental disorder. Someone living with ASD can have a range of conditions, and it's important to understand that no two people with ASD look exactly alike. They fall along a spectrum, either being high functioning, low functioning, or anywhere in between. Some of the conditions include social-interaction difficulties, communication challenges, a tendency to engage in repetitive behaviors, and a lack of eye contact. The number of children who are being diagnosed with Autism Spectrum Disorder has increased rapidly over the last twenty years (Solomon & Chung, 2012). In 2009, statistics suggested that one in every 91 people were diagnosed with ASD (Kogan et al., 2009). One in 68 people were diagnosed with ASD in 2016, showing that there is an increase of diagnoses of ASD (CDC, 2016).

Children who have been diagnosed with ASD require special attention from their parents or guardians, as any child with special needs would. Being a caregiver of a child with ASD could produce potential challenges in everyday life. Parents may need to deal with both a burden of finances and time because their child needs therapy, for example. It is arguable that there can be a high amount of stress put on the parent or guardian because of their child's diagnosis of ASD. With the prevalence of ASD increasing and the symptomology in mind, there is call for further investigation of the effects on the parents.

This study should be viewed as a pilot study, or an exploration of a topic. The aim of this research is to explore primary and secondary sources to identify

themes of potential research pertaining to caregivers of ASD. Both the literature and an archival data source were analyzed, looking for any gaps or “next steps”. More specific than just studying ASD in general, this study looked at the effects on caregivers of children with ASD because of the lack of research in this area. Each theme that was identified should be continued in future research.

Literature Review

The Challenges of Raising a Child with ASD

In the scholarly journal article titled, *Searching For Acceptance: Challenges Encountered While Raising a Child With Autism*, the authors, Altieri and von Kluge (2009) explore how raising a child with Autism can bring about challenges and successes to the parents who are responsible for raising them. The researchers interviewed 52 parents (26 married couples) of children with Autism. They found that there were five challenges that emerged from the families’ experiences that were expressed in the interview. These five challenges were termed Development, Questioning, Devastation, Solutions, and Growth. Parents explained their confusion surrounding the behavior that was being displayed by their children and their feelings of loss and devastation upon their child being diagnosed with Autism. Even though there were challenges along the way, almost every parent described many positive experiences, which references the Solutions and Growth terms that the article mentioned.

Altieri and von Kluge’s (2009) data was generated from the semi-structured interviews. By using a semi-structured interview, they provided a

detailed qualitative analysis. Also, the dialogue followed the speaker's course, which allowed for more dialogue from the interviewee. A semi-structured interview is advantageous because more information was gathered than if they would have used a structured interview, which would have had very specific questions with limited answers. One disadvantage in using the semi-structured interview, was that the way in which information was gathered was not standardized, and could result in a weak statistical analysis. In addition, there could have been difficulty recalling experiences, since these parents were asked to recall events about their child's birth and early childhood, which could have happened years prior to this study.

The Altieri and von Kluge (2009) article sheds light on one's understanding of parents' perceived challenges and introduces terminology needed to categorize such challenges. The challenges noted may explain why parents sometimes decide to use unhealthy coping mechanisms, such as engaging in substance use. Stress is something that people need to cope with in some way, however, some people may cope with this in an unhealthy way, and this is the focus of this paper and this current research project. This focus of this research aligns with other studies which have shown that parents of children with Autism have many challenges, more so than the parent raising the typical child.

Parental Stress

It is already known and well-documented in the literature that a child with ASD brings stress to the entire family. Derguy, M'Bailara, Michel, Roux, & Bouvard

(2016) interviewed 115 parents of children with autism. They administered to them the Parenting Stress Index Short Form, which measured stress levels, and the French Autism Questionnaire which measured broad autism phenotype traits. Additionally, they used the Wechsler Preschool and Primary Scale of Intelligence to measure IQ of the children involved in the study. The statistical power for the experiment was adequate and the measures were strong. A weakness of the study is that there should have been a more direct measure of behavioral disorders and severity of symptoms. Also, the term “predictors” was meant to be a correlation, rather than causation so the results should be interpreted cautiously.

Pastor-Cerezuela, Fernández-Andrés, Tárraga-Mínguez, & Navarro-Peña (2016) also measured the IQ of children with ASD and parental stress. In this study, the researchers had three specific questions they wanted to address. First, they wanted to compare parental stress levels between parents who are raising a child with ASD and those parents who are raising a typically-developing child. They also ask the question, “What is the relationship between parental stress levels, ASD symptom severity, and verbal and performance IQ scores?” This research also examined the relationship between parental stress and parental resilience. Consistent with the findings from other research, this study found that the parents of children with ASD had more significant stress levels than the group with typically-developing children. The severity of symptoms of ASD worked as a predictor of parental stress, because the child was hyperactive or easily distracted. The child’s verbal IQ score also worked as a predictor of parental stress, but only in the group of parents with a child with ASD, was the

child's performance IQ score a predictor of parental stress. Parental resilience was a predictor of parental stress.

Giovagnoli et al. (2015) looked at whether or not parents of children with ASD, experience more stress than parents who have typically developing children, but what they did not know was what risk factors accounted for that increased stress level. This study focused on preschool aged children with ASD compared to typically-developing preschool aged children, and found ways to evaluate parental stress levels and behavioral and emotional problems. They also investigated the role of certain factors on a parent's stress levels, including severity of the symptoms typical for ASD, adaptive skill sets, cognitive abilities, and the child's behavioral and emotional problems. The findings from this study, confirmed that parents of children with ASD have higher reported stress levels than parents of typically developing children. The study found that having a child with behavioral and emotional problems was a strong predictor for the presence of parental stress. Interestingly, there was no association found between the severity of the ASD symptoms and the rate of parental stress. Dysfunctional behaviors in the group of children with ASD strongly influenced parental stress, and the researchers emphasized that these behaviors could affect the well-being of the entire family. Findings support the need for introducing early detection and management strategies into these families so that parental stress can be prevented or decreased as soon as possible.

"The Need for an Ecological Approach to Parental Stress in Autism Spectrum Disorders: the Combined Role of Individual and Environmental

Factors” is a scholarly journal article written by Derguy et al. (2016), continued the theme of focusing on individual and environmental factors, aimed at identifying parental stress predictors in parents who are raising a child with autism. In this study, the researchers used a multiple regression analysis to examine information collected on 115 parents of children with autism who were ages 3-10. The objective of the study was to identify the best predictors of parental stress. They found that poor quality interactions within extended family, high levels of expressed emotion, and absence of children’s schooling were associated with higher stress.

Kelly, Garnett, Attwood, & Peterson (2008) examined the impact of family conflict, family cohesion, and peer support/bullying on children who had ASD. The researchers acknowledged that while these factors had already been studied in the literature time and time again for other childhood disorders, it was still unclear if these same factors might apply to children with ASD, because those with ASD seemed to have their own very specific problems. Parents of children with ASD, Asperger Disorder, Pervasive Disorder Not Otherwise Specified, or children without ASD or no diagnosis at all were asked to complete an online questionnaire. The results of the study showed that anxiety, depression, and ASD symptomatology were all significantly related. They also found that ASD symptomatology was better predicted by family conflict than family/peer influences.

Hall and Graff (2012) studied maladaptive behaviors, family supports, parental stress, and parental coping, all specific to children with a diagnosis of

ASD. This study examined these factors by looking at the parent's views using the ABCX Model of family behavior. Their results show that the more internalizing maladaptive behaviors their child showed, the higher the parents' stress levels were. This study has implications, providing support for the notion that the parents of children with ASD report that their children's maladaptive behaviors are a large factor contributing to their stress.

Saunders et al. (2015) focused on financial and employment burden of parents /guardians who were raising a child with ASD because those children have many services that they need. Sometimes, children with ASD can have a comorbid diagnosis of intellectual disability (ID), and this study aimed to see what the additional impact on those families compared to those with children who had a diagnosis of ASD or ID alone. Saunders et al. used the 2009-2010 National Survey of Children with Special Health Care Needs. They classified children as having ASD alone, ID alone, or having both ASD and ID. The study found that of all the children who had a diagnosis of ASD, there was also a comorbid diagnosis of ID in 24% of them. Fifty-two percent of parents/guardians of children with both diagnoses reported that they experienced some financial difficulty and 51% reported that, to take care of the many needs of their child, they had to discontinue working. Parents who had children with both diagnoses were more likely to report financial difficulty, cutting work hours, or having to stop working altogether. These findings were not evident among parents who were raising a child with one or the other of these diagnoses. This study provides evidence that

having a child with ASD and ID can negatively impact families by creating financial burdens.

McStay, Trembath, and Dissanayake's (2014) article titled, "Stress and Family Quality of Life in Parents of Children with Autism Spectrum Disorder: Parent Gender and the Double ABCX Model" concentrates on the impact of family-related variables on mothers and fathers within the same family by investigating the potential predictors of maternal/paternal stress and the family's quality of life. This study used a sample of 196 Australian parents of children with Autism Spectrum Disorder (ASD) who were between the ages of three and sixteen. They argued that a child's externalizing behaviors has a negative impact on their parents. Externalizing behaviors are very common in children with ASD. Primary findings revealed further support for the negative impact of externalizing behaviors demonstrated by children with ASD on their parents. Additionally, the results showed the importance of a family sense of cohesion.

A study by Lohahus et al. (2017) did not necessarily just focus on children with ASD, but the findings do give us a better understanding of the impact of a child's externalizing behavior and parental stress levels, specifically in foster mothers and foster fathers. The foster children, all between the ages of 2 and 7, in this study have experienced maltreatment or neglect, and therefore are likely to display negative mental health symptoms, which is made evident through externalizing behaviors and their internal challenges. Because of these factors, it is hypothesized that the foster parents' stress levels will be increased as compared to parents of their biological children. Using the Child Behavior

Checklist, an empirically supported assessment tool, mental health problems were assessed. The stress of the parents was reported using a parenting stress questionnaire that specifically looked at stressful experiences and perceived support. It is important to note that, while this study's goal was to examine both mothers and fathers, mostly mothers completed the Child Behavior Checklist. However, both mothers and fathers completed the parental stress assessment. The results of this study align well with their hypothesis, meaning that the foster children's increased externalizing scores correlated with increased perceived stress of the foster mothers, but interestingly, not with the foster fathers. Externalizing behaviors were good predictors of parental stress in both the mothers and fathers, whether or not that child was biological or a foster child. As noted in the earlier studies, children with Autism Spectrum Disorder are known to exhibit externalizing behaviors, so this study further supports that there is added parental stress when these behaviors are evident.

Shawler and Sullivan (2017) also addressed externalizing disruptive behaviors in children with ASD. They examined the relationship between parent stress, parental discipline strategies, child disruptive behaviors, level of ASD symptoms and the parent child relationship. This study looked at parents of children between the ages of three and 11 years old. Parents consistently reported their stress levels to be high, as well as noting a high amount of child disruptive behaviors. Parent stress levels and disruptive behaviors of children were linked together by harsh parental discipline strategies. Harsh parenting styles correlated with more stressed out parents and more disruptive behaviors

were exhibited by their children, although it is safe to say that this correlation could also be interpreted from two opposing perspectives: one, the harsh parenting could have been a reaction to the stress and disruptive behaviors, or alternatively, the stress and disruptive behaviors could have been a result of the harsh parenting.

Based on the studies previously discussed, there seems to be growing evidence that raising a child with ASD can be stressful on parents and their marital relations. Ramisch, Timm, Hock, & Topor (2013) looked into solutions to the marital stresses associated with parenting children with ASD. It makes sense that raising a child with the types of symptoms children with ASD have, that the stresses of parenting can leak into the marriage. By looking into three couples' experiences of a 10-week in-home couples therapy, which used Emotionally Focused Therapy, the researchers found that couple's going through marital struggles because of their parenting situation would benefit from this specific intervention. Their marital relationships came out stronger on the other end. Since parents with children with ASD are so susceptible to stresses, this is a great resource for married couples raising these children. If they can help prevent the stress before it becomes a major problem between the couple, they may have better odds of improving their marriage.

Perhaps one of the most telling outcomes on just how much of a toll these stressors can have is reflected in studies looking at the actual divorce rates among parents of children with this diagnosis. Hartley et al. (2010) looked into the timing of divorce in parents who had a child with ASD. Their study consisted

of 391 parents of children with ASD, and they were comparing this to parents who had children without disabilities. Their results showed that parents of children with ASD had a higher rate of divorce than the parents of children without disabilities. In those children with ASD, their parents' rates of divorce remained high throughout childhood, all the way into young adulthood. In comparison to the parents with children with ASD, parents of children without disabilities rates had decreased following childhood. The researchers found two predictors of divorce for those who had children with ASD: younger maternal age when the child was born and having the child be one of the younger siblings. This research shows that having a child with ASD puts a strain, not only on parenting, but also on a marriage.

Coping With Stressors

The previously noted studies attempted to look at the challenges of coping with raising a child with ASD. Several studies have been directed at looking at coping with the related stressors. A review of 37 research studies underscored two main coping strategies that parents of children with ASD adopt in coping with caregiving stress (Lai & Oei, 2014). The two most useful coping strategies problem-focused coping and social support. Problem-focused coping, includes seeking instrumental support, planning, problem-solving, confrontation, compromising, changing expectations, and sense-making. Seeking social support would include from immediate and extended family, friends, co-workers, and healthcare professionals.

Mancil, Boyd, & Bedesem's (2009) study also supported the well documented finding that parents who have children that are diagnosed with ASD report that they have more stress than parents who are raising typically developing children. They also mention that these parents experience more stress than parents who are raising children with other developmental disabilities. Mancil et al. (2009) endorsed the need examine coping strategies for these parents, and compiled a review of the literature to outline all of the ways parents of children with ASD do successfully cope. This review is a resource that can be given to parents who are at risk for higher levels of stress because their children have ASD.

In a related study conducted by Hsiao (2016), 429 parents of children with ASD served as participants. The findings revealed that to cope with having a family member, including a child, with some sort of disability, the parent had to have a healthy psychological quality of life. If a parent was mentally unhealthy, this lessened their chances of finding new ways to adapt to the changes that inevitably face them because of the disability. Specifically, this study showed that it is important to know what factors play a role in psychological health and quality of life, if we wish to gain a better understanding of how these might be affected in families of children with ASD. This study aimed to gain a better perspective on the mental health-related quality of life within families having a child with Autism. The researchers attended to factors, such as parental stress, children's performance, medical support, and neighbor support, which could all be linked to mental health wellness. The results showed that each of the proposed factors

were very important to the mental health-related quality of life among the parents surveyed.

Another study that examined coping was conducted by Higgins, Bailey, & Pearce (2005). This study, which took place in Victoria, Australia, surveyed caregivers of children with ASD. This study not only included biological parents, like many other studies, but also included those who were not parents, but who were taking care of these children (i.e., grandparents). They wanted to explore the relationship between three factors: ASD characteristics, family functioning, and family coping strategies. Results from the survey, that covered the three factors, found that these caregivers had a healthy level of self-esteem. Additionally, the caregivers reported lower marital satisfaction, family cohesion, and family adaptability than caregivers of children without ASD. The presence of good and solid coping strategies did not have a significant effect on these other results.

There is clearly a need to conduct more studies that look at ways that parents and caregivers of children with ASD attempt to cope with the stresses that they experience. The current study was an attempt to further this line of research.

A Comparative Look at ASD and Other Disorders

Seltzer, Abbeduto, Krauss, Greenberg, and Swe (2004) conducted a study titled, "Comparison Groups in Autism Family Research: Down Syndrome, Fragile X Syndrome, and Schizophrenia". They outlined the methodological challenges

of conducting research on families with children with Autism Spectrum Disorder (ASD). They also outlined the challenges of comparing these families to those whose children have a different disability or no disability at all. Typically, comparative research is done between ASD and Down Syndrome. Seltzer et al. (2004) utilized many sources from other comparative research to find the challenges associated with studying each of these disorders. They found new opportunities for comparative autism family research: Fragile X Syndrome and Schizophrenia. They also provided information on how to conquer some of the challenges presented. For example, it is recommended that researchers control the variance associated with potentially confounding between-group differences.

In another study, "Psychological Well-Being of Mothers of Youth with Fragile X Syndrome: Syndrome Specificity and Within-Syndrome Variability", Lewis et al. (2006) examined the mothers of sons with different disabilities. They targeted the stress put on these mothers who were raising a child with Fragile X syndrome, Fragile X syndrome with a comorbid diagnosis of Autism, and Down Syndrome. Specifically, they were looking at the different degrees and patterns of stress in these mothers and comparing the groups. Self-report measures were administered to mothers that assessed mental health status, perceptions of their son's and family's functioning, and approach to coping with their son's disability. They found that the combination of Fragile X and Autism was particularly challenging, more so than Fragile X alone and Down Syndrome, showing that ASD has the potential to cause elevated stress levels in mothers, especially when compared to Down Syndrome and Fragile X Syndrome. In this study,

Lewis et al.'s (2006) used standardized tests, such as the Positive Affect Index and the Multidimensional Coping Inventory (COPE). These are empirically supported tests that have been shown to meet the criteria for adequate standardization and validity, strengthening the conclusions made in the article. However, this study used a small sample size, which limits the statistical power of the results.

Van Steijn, Oerlemans, van Aken, Buitelaar, & Rommelse (2015) studied the quality of family climate of families who had a member with ASD and/or ADHD, whether that be a parent or a child. Of the 103 families recruited, all had at least one child with an ASD and/or ADHD diagnosis, at least one biological sibling (that did or did not have a diagnosis), and two biological parents who both participated. All family members were assessed for ASD and ADHD symptoms and family climate was measured using the Dutch Family Environment Scale. Families with one child with a diagnosis had higher family relationship scores than the normal score, but families with two or three children with a diagnosis had similar scores to the norm. Families with any number of children who had a diagnosis, had similar scores to the norms of the family structure index. Parents, both mothers and fathers, who had ASD symptoms and fathers who had ADHD symptoms negatively affected family relationships. Mothers with ADHD symptoms had a negative impact on family structure.

Gender Differences Between Mothers and Fathers

Mothers and fathers may differ in their responses to the stresses of raising a child with ASD. There is a gap in the area of study focused on examining gender differences between mothers and fathers, with much less attention being given to fathers. Hartley et al. (2012) study acknowledged this deficit in the literature and noted that there are more studies done on mothers of children with developmental disabilities than on fathers. Hence, the psychological well-being of fathers of children with developmental disabilities is not a well-understood topic. Psychological well-being is a very broad topic, so these authors generated an operational definition that is based on measures of depressive symptoms, pessimism, and coping. This study was for fathers who had adolescents or young adults with developmental disabilities, specifically ASD, Down Syndrome, and Fragile X Syndrome. The fathers who had children diagnosed with ASD reported higher rates of depressive symptoms than the other groups. The fathers of children with Down Syndrome reported lower levels of pessimism than the other groups. There were no significant differences found in coping styles between the two groups. It was purported that group differences in depressive symptoms and pessimism were attributable to differences in the ages of the fathers, what behavioral problems the children presented with, having other children with a developmental disability, and if the mother was also displaying depressive symptoms.

In a study titled, "Effects of a Father Based In-Home Intervention On Perceived Stress and Family Dynamics in Parents of Children with Autism", Bendixen et al. (2011) looked at parental differences of perceived stress before

and after an in-home training program. They assessed their stress with several empirically researched measures. They found that both mothers and fathers reported high pre-intervention levels of stress. After the intervention was completed, fathers' stress declined, but it was not a significant reduction. However, mothers' scores were significantly reduced. Parenting styles were also significantly different before and after the intervention.

Johnson, Frenn, Feethan, & Simpson's (2011) study titled, *Autism Spectrum Disorder: Parenting Stress, Family Functioning and Health-Related Quality of Life* (2011) explored the relationship of parenting stress, support from family functioning and the physical and mental health of both parents. Some of the study's primary findings indicated that female discrepant scores between "what is" and "should be" family functioning was larger in female parents than male parents. Additionally, higher female caregiving stress was correlated to lower female physical health.

Johnson et al.'s (2011) study used a web-based survey that focused on parenting stress, family functioning, and physical and mental health. Parents raising children with Autism Spectrum Disorder (ASD) completed the online surveys. There was a large sample size, which was a strength of the study. The study also posed potential limitations. The researchers in this study did not confirm the diagnosis of ASD with the participants. Also, there was a lack of verification that parents completed their surveys individually. This study highlighted a need to explore the differences in mother's and father's individual expectations about family functioning. The findings generated from this

comparative look at research on mothers and fathers of children with ASD, continues to support the presence of parental stress. This is very consistent with the findings from the earlier studies discussed previously, noting an increased level of parental stress in parents who are raising a child with ASD compared to the national averages.

In the study, *Stress Levels and Adaptability in Parents of Toddlers With and Without Autism Spectrum Disorders*, Baker-Ericzen, Brookman-Frazee, & Stahmer (2005) also explored the stress levels in parents who are raising a child with Autism Spectrum Disorder (ASD) versus parents raising typically developing children. They examined how participation in an all-inclusive toddler program may be related to these stress levels. After the inclusion program, mothers reported reductions in parent-related stress. Fathers did not report any change in their stress; it remained about the same. Also, they found that a child's level of social skills can be used as a predictor of child-related maternal stress for children with ASD. However, this should not also be used for fathers, due to the outcome of the research.

This study used the Parenting Stress Index (PSI) as a measure to assess the impact of the parenting role on the individual's stress level, the Bayley Scales of Infant Development, 2nd Edition (BSID-II), as a measure of developmental functioning, and the Gilliam Autism Rating Scale (GARS), as a measure of the severity of autistic symptoms based upon a national sample of individuals diagnosed with ASD. The GARS and PSI was given to parents at the beginning of the experiment and one month prior to the child exiting the program. The

BSID-II was given before the experiment and used as a screening process for the study. The inclusion program was the Children's Toddler School (CTS) in Southern California.

Baker-Ericzen et al. (2005) used many empirically-sound research instruments, such as the PSI, BSID-II, and GARS, which is an important strength of the study. Also, its similarities to other studies show consistent findings on the presence of parental stress in families with a child diagnosed with ASD. However despite this consistency, it should be noted that there were several limitations in this study. There was no control group, so there is no way to tell if the reductions in mothers' stress was due to the inclusion or just early intervention itself. They should have used a control group of children with ASD who were enrolled in a self-contained or in-home early intervention program. They also did not control for the length of time that the children were enrolled in the program. In addition, mothers appeared to be the primary caregivers (most of the time) in both groups of children. It is unknown how stress may be related to the share of responsibility of child-rearing for each parent.

The findings from this study continue to highlight the stress levels in parents who are raising a child with ASD, while providing support for why such stress should be reduced. Inclusion is the integration of children with disabilities with those who do not have disabilities, which could reduce the stress of the parents because the children are receiving important services they need, such as different types of therapy. Additionally, the battery of assessment instruments used in this study may be ones that can be used in this researcher's future

research, since they have been shown to be valid measures of Autism and stress levels. Consistent with the findings of other studies reviewed, there is continued support for the notion that parents who are raising children with ASD are more stressed than parents who are raising typically developing children and a need to further investigate the relationship between gender of the parent and coping and psychological well-being.

Timmons, Willis, Pruitt, & Ekas (2016) looked specifically into gender differences in Hispanic mothers and fathers who are raising a child with ASD. These hypothesized differences included dispositional optimism, coping, and depressive symptoms. Results showed that mothers reported a higher number of depressive symptoms than fathers. They also used positive support and coping strategies more often than fathers did. Both genders had very similar levels of reported optimism and frequency of avoidant coping. Since mothers reported more depressive symptoms than fathers, they may be at a high risk for self-medication.

Substance Abuse

A look at the prevalence of substance use among parents of children with ASD is a very under researched topic. In a study conducted by Wade, Cox, & Hull's (2014) were among the first to establish a relationship between child externalizing behaviors, parental broad autism phenotype (BAP) traits and substance use among parents of children with Autism Spectrum Disorder (ASD). The findings from this study indicated that parents of children with ASD reported greater rates of alcohol use and lower rates of tobacco and illegal substances

than the national averages. The presence of children's externalizing behaviors was used as a predictor for higher rates of substance use. Rigidity, a BAP trait, predicted both increased and decreased parental substance use. Rigidity is having difficulty adapting to a changing environment or situation, which is common for people who have ASD.

Wade et al. (2014) utilized archival data from Simons Simplex Collection (SSC) Version 14, which is part of the Simons Foundation Autism Research Initiative (SFARI), to analyze this relationship by using data from the SCC Substance Use History Form. The SCC Substance Use History Form only tells if substance use is present, by using a "yes or no" format, and does not specify the frequency or quantity of the substance use. In critiquing this study, it should be noted that the archival data used, was not representative of all the United States' population with regards to socioeconomic status, marital status, race, and ethnicity. Hence, the findings are somewhat limited in terms of who they are applicable to. Despite this shortcoming, Wade et al. (2014) were among the first to look into this relationship between parental stress in families with a child diagnosed with ASD and prevalence of substance abuse. This study helped lay the ground work for my thesis.

Pillow, Barrera, & Chassin (1998) also examined parental stress and substance in families with a child diagnosed with ASD. This study used a cluster analysis to place stressful life events into categories that looked at the relationship between parental alcoholism, parental psychopathology, and adolescent substance use. The researchers were able to explore effects on the

children whose parents had a substance use problem. Using 326 families to gather their data, four clusters were created including family-related conflict, general child relationship problems, parent problems, and major illness/bereavement. These four clusters were found to be important for understanding the link between a parent with substance use problems and their child having substance use problems.

The Current Study

The current study attempted to further investigate the prevalence of substance use among parents raising a child with ASD by examining archival data. This data was originally produced by Dr. Myra Beth Bundy, a clinical psychologist who specializes in the treatment and research of the ASD population. Dr. Bundy's client files were examined with the intent of looking further into the stress experienced by parents who were raising a child with ASD and the prevalence of subsequent substance abuse issues. Most of Dr. Bundy's clients were children, so their parents were a major part of the data gathering process. Parents went through an intake interview, providing information that helped to determine if their children met the criteria for ASD.

On the intake form, parents completed a checklist that described individual family members of the child. The checklist asked about the mental health of the parents, grandparents, siblings, and other family members of the child. On the checklist, "alcohol and drug problems" was an item that could be checked if any of these individuals had experienced these difficulties. Among those assessed, it should be noted that not every client received a final diagnosis of ASD.

Primary Sources

As noted throughout this paper, there are numerous studies supporting the claim that raising a child with ASD is an especially stress-inducing task and this was the continued focus of the current study. Following an Institutional Review Board (IRB) approval, as noted above archival data was collected. The office from which this data originated was The Commission for Children With Special Health Care Needs located in Lexington, Kentucky. This was the place where Dr. Bundy interviewed the parents of children who sought assessment for ASD. Some of the children had been referred by pediatricians, teachers, or the parents themselves who thought that their child might meet the criteria for ASD. As noted above, upon arrival at the Commission, parents completed an intake form that had a complete patient history. The patient history included a list of diagnosis(es), the time at the clinic, medical and psychological background, among other important documents.

Sixty-two randomly selected client files were selected for this current study. Of the 62 files, only 56 were able to be used because the remaining six files did not include the diagnoses of those children. All of the files used in the study involved children who were under the age of 18. Although the initial aim of the study was to investigate the challenges posed when parenting a child with ASD, upon examining the files, it became apparent that not all caregivers for these children were their biological parents. For that reason, this study had to take into account and clearly identify who had custody of the child, and expand the focus from just parents to whoever was identified as the caregiver.

From this primary source, the focus also narrowed to examining only one page of the intake form. This page directed the caregiver to check off any descriptors that were applicable to the child and their experiences. Please refer to Appendix A. There were many characteristics and the caregivers were asked to check off who these characteristics applied to. Not all of the characteristics were relevant to the current study's focus. The two that this study focused on evaluating were "problems with drugs and/or alcohol" and "time spent in jail". The caregivers were asked to note if either of these applied to the following family members: "biological mother", "biological father", "brother", "sister", "grandmother", "grandfather", "aunt", "uncle", and a column for "other". If the characteristics applied to any of these child's family members, they were asked to indicate this by placing a check mark in the appropriate boxes.

The archival data also included a page that listed the children's diagnosis(es). For each participant, it was determined if the child had a diagnosis of ASD, who had custody of the child, and if who possessed custody of the child were known to have problems with drugs and/or alcohol or have spent time in jail. The group of children who did have a diagnosis of ASD were then compared to the group that did not have a diagnosis of ASD on presence and absence of the above noted characteristics.

Every child in this study had a psychological diagnosis of some sort, whether that be ASD, or another mental disorder. Based on the findings noted in the literature review section of this paper, it is purported that in all likelihood, the presence of any mental disorder caused some extra stress on the parents or

caregivers when compared to those with children who did not have a mental disorder. However, since ASD is an especially stress-inducing mental disorder, this researcher proposed this disorder was more likely to cause more stress among parents and other caregivers.

Analysis of Data

Data was broken up into four different categories. The first category looked at those who had custody of the child and reported that they, themselves, had “trouble with alcohol and/or drugs”. Zero out of 24 (0.00%) adults who had custody of a child with ASD reported that they had troubles with drugs and/or alcohol. One out of 32 (3.12%) adults from the comparison group reported that they had these same issues. Next, time spent in jail was examined. Five out of 24 (20.83%) adults who had custody of a child diagnosed with ASD reported that this was true, while one out of 32 (3.12%) of the adults who had custody of a child in the comparison group reported that this was true.

Four Pearson chi-square tests for nominal data using SPSS Crosstabs were calculated. Here, the researcher examined the relationship between the presence of an autism diagnosis and rate of caregiver incarceration. This was significant ($\chi^2_1=4.496$, $p<.05$). Those diagnosed with autism were 6.5 times as likely to have caregivers who abused alcohol or drugs.

While this study focused on those who had custody of these children, the study also looked to see if any of the other family members were reported to have trouble with drugs and/or alcohol or had spent time in jail. Twelve out of 24

(50%) of children diagnosed with ASD had another family member, besides their custodial guardians, who was reported to have trouble with drugs and alcohol. The comparison group reported that nine out of 32 (28.12%) children who had another family member, besides their custodial guardians, who were reported to have trouble with drugs and alcohol. Eleven out of 24 (45.83%) children with a diagnosis of ASD had a family member, besides their custodial guardians, who were reported to have spent time in jail. Eleven out of 32 (34.37%) of the children from the comparison group had a family member, besides their custodial guardians, who were reported to have spent time in jail.

Conclusion

The results of this study did not align with those reported in the literature, and this could be because of several limitations to this study. First, there was a small number of participants, which could have affected the validity and generalizability of the data. Also, this was a self-report measure, which may have deterred caregivers from disclosing sensitive information about themselves or other family members. Additionally, the information request on the checklist was somewhat vague- indeed, a checklist definitely cannot tell the whole story. It was also unknown, if issues reported were current or from the past. And finally, since there was limited information on the caregiver's demographics, details needed to provide a clearer explanation of why the findings differed from those found in the literature review was not available.

Discussion

The Commission for Children With Special Health Care Needs is a project for families who do not have stable financial means. Most of the families who seek services there are financially needy, which is very important to take into account. Financial neediness can cause stress of its own, which could be a reason that people chose to self-medicate, and may account for why some of the parents and caregivers were shown to use alcohol and/or drugs in the current study. As far as time spent in jail, since it cannot be determined the reason for some parents and caregivers spending time in jail, it is unclear if it could have had something to do with coping with financial stress imposed by their socioeconomic statuses.

Themes

There were many common themes generated from this research study, and from both the literature and in the primary resources. These are highlighted below. It is purported that all of these themes need to be further researched.

Parental Stress

The first theme is parental stress. Hsiao (2016) reported that parental stress, children's performance, medical support, and neighbor support were all linked to mental health wellness. Higgins et al. (2005) linked this stress to lower marital satisfaction, family cohesion, and family adaptability. Key findings from various other studies also provide evidence of an increased level of stress found in parents and caregivers of children with ASD (Johnson et al., 2011; Giovagnoli et al., 2015; Pastor-Cerezuela et al., 2016) More specifically, two studies found that

ASD symptomology correlated with parental anxiety and depression (Kelly et al., 2008; Hartley et al., 2012). One study found that parents often experienced feelings of loss and devastation upon having their children's diagnosis confirmed (Altiere and von Kluge, 2009). Additionally, caregivers were shown to experience a financial burden (Saunders et al., 2015) and poor quality interactions within extended family (Derguy et al., 2016) when a child was diagnosed with ASD.

Stress-Inducing ASD Symptomology

There are certain traits of children with ASD that are linked to the presence of stress on the parents. The first is externalizing behaviors (Wade et al., 2014; McStay et al., 2014). These are behaviors such as physical aggression, and disobeying rules. They are basically behaviors that are aimed at lashing out at the external environment around them. Baker-Ericzen found that the lower the level of social skills, the more stress the parents experienced. Behavioral and emotional problems also accounted for stress, as well as internalizing maladaptive behaviors (Giovagnoli et al., 2015; Hall & Graff, 2012). Internalizing behaviors are those that are internally directed, such as social withdrawal. Also, children who are hyperactive, easily distracted, and have low verbal IQ scores (language based reasoning) can cause stress among parents (Pastor-Cerezuela et al., 2016).

ASD vs. Other Disorders

In a study from 2006, Lewis and his colleagues looked into comparing fragile X, Down Syndrome, and ASD's unique challenges. They found that a

combination of Fragile X and ASD presented much more challenges than by raising a child with Fragile X alone or Down Syndrome. It shows that when you throw ASD and its specific symptoms in the mix, things become much more challenging.

Mothers vs. Fathers

After interventions, mothers reported decreased stress levels, while fathers reported little or no change (Bendixen et al., 2011; Baker-Ericzen et al., 2005). Mothers report more depression and use positive support and coping strategies more often than fathers do (Timmons et al., 2016). Higher female caregiving stress correlated to lower female physical health (Johnson et al., 2011). There was an extreme lack of research specifically on paternal stress.

Coping Mechanisms of Caregivers

Two most useful coping strategies parents used were problem-focused coping and social support (Lai & Oei, 2014). There is such a lack of research on coping strategies, and this is something really important. If there is little research being done for caregivers to cope with the stress of parenting a child with ASD, how will professionals help these clients?

Substance Use

When beginning this research, it was reasonable to believe that since there was so much stress put on parents of children with ASD, they would be finding coping mechanisms, and some could be unhealthy. This researcher had assumed that parents of children with ASD would use substances more often

than parents of typically developing children as a way to cope with the stresses associated with ASD. One study found that parents had higher rates of alcohol and lower rates of tobacco and illegal substances when parenting a child with ASD (Wade et al, 2014). The researchers did not give a specific reason for this correlation, so this is something that needs to be explored further. Primary sources used in this study, did not support the findings of this study, but this could be due to the many limitations of the study. Regardless, this is an area that needs more research.

Incarceration

After collecting data through from several primary sources, one last theme was determined- incarceration. This is something that did not come up in the literature. Even with a small number of participants, the primary sources indicated significant results, showing that children with ASD are more likely to have a parent who has spent time in jail. However, this finding is very vague and not easily explained, therefore it is in further need of research.

Discussion

The current study is to be classified as a pilot study and a way for this topic to begin to spark research interest in the field. The goal of this thesis project was to generate common themes in what is known about the effects of having a child diagnosed with ASD. Hopefully, by identifying these themes, a door has been opened to motivate others to do more research in this field. To recap, the

themes were parental stress, stress-inducing ASD symptomology, ASD vs. other disorders, mothers vs. fathers, coping mechanisms, substance use, and incarceration. Additionally, the goal was to determine where there were deficits in the research and determine what should be studied in the future.

Future Implications

More research needs to be done on each theme. This researcher hopes to put continued effort into studying the relationship between an ASD diagnosis in children and substance use and incarceration. Since there was a very small number of participants, one of the most important changes that will be made is to increase the number of participants. The goal would be to aim for 150 participants at a minimum to increase the robustness of the findings.

In future research, more detailed information will be gathered by asking parents and other caregivers, to complete less vague questionnaires. One instrument to be used will be the Caregiver Strain Questionnaire (CSQ) along with an original questionnaire that will be created. Similar to earlier studies, these questionnaires will be administered to parents of children with ASD, parents of children with some other mental disorder(s), and parents of typically-developing children. The CSQ is an empirically researched questionnaire that is reliable to use. The questions ask about the family during the past six months. An example of a question would be "Disruption of family routines due to your child's emotional or behavioral problems?" and they could indicate if this happened "not at all", "a little", "somewhat", "quite a bit", or "very much". The original questionnaire will include demographic information, family dynamics, both Likert scale and open-

ended formatted questions, specific questions about substance use (how often, quantity, type), and questions about jail (charges, time period).

It is expected that these results will show that parents of children with ASD tend to use substances more often than other parents. Given the scarcity of research examining incarceration rates among the targeted population of interest, the findings on this area of interest are somewhat unknown. It is anticipated that the results may be similar to those found in this current study. To ensure that more specific data is generated, future studies will ask more precise questions pertaining to why parents of children with ASD might spend more time in jail than other parents of typically developing children.

In closing, ASD is an increasingly common diagnosis that undoubtedly creates increased levels of stress to the parents. A healthy family environment is at risk for families with ASD, so steps should be taken to help parents understand their susceptibility to stress because of their child's diagnosis. This research will provide families and therapists with information about their potentially increased risk of practicing unhealthy coping mechanisms. As an aspiring social worker, this researcher will be able to apply this knowledge to better understand interventions that need to take place when dealing with this specific population. Having parents in a household who are abusing substances will be damaging to the rest of the family. Understanding this risk factor will help parents be aware of their potential for substance abuse and look for healthier ways to cope with their stress. Therapists, and other professionals working with this population, can help

clients understand that they are at risk for abusing substances and teach them healthy coping strategies.

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