ASSESSING THE IMPACT OF CHILD AND CAREGIVER SPECIFIC FACTORS ON CAREGIVER MENTAL HEALTH WHILE RAISING A CHILD WITH AUTISM SPECTRUM DISORDER

by

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Abstract

Parenting involves navigating many challenges that impact the social, emotional, mental, and physical well-being of both the parent and the child. Caregiver strain is often higher when childcare demands are higher. Caregivers raising a child diagnosed with ASD often face heightened strain, therefore leading to an increased risk of mental health challenges. Due to the increase in prevalence of ASD, it is essential to examine the impact this diagnosis has on caregiver mental health. This capstone examined the current research on the impact child-specific factors (symptom severity, comorbidities) and caregiver-specific factors (gender, socioeconomic status, culture, and access to external supports) had on caregiver mental health outcomes while raising a child with ASD. This capstone concluded that the current research has yielded mixed findings, leading to the proposal of a new research study aimed at developing a caregiver mental health assessment for practitioners working with this population.

Keywords: Autism Spectrum Disorder, caregiver mental health, mental health outcomes, caregiver-specific factors, child-specific factors

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Chapter 1: Introduction

Overview of Topic

A common saying that being a parent is the most difficult yet rewarding job resonates with many people (Nomaguchi & Milkie, 2020). Parenting involves navigating many challenges that impact the social, emotional, mental, and physical well-being of both the parent and the child (Nomaguchi & Milkie, 2020). Due to the trials and tribulations of raising a child, parental mental health and quality of life may vary depending on the demands and conflicts inherent in the parenting role (Nomaguchi & Milkie, 2020). Nomaguchi and Milkie (2020) suggest that parent well-being has implications for children's developmental trajectories; therefore, it is essential to investigate the factors that influence parental mental health outcomes. Parental mental health is defined as "subjective well-being (e.g., life satisfaction, life meaning, loneliness), emotional health (e.g., anger, guilt), mental health (e.g., depression, anxiety), and physical health" in relation to the roles involved in "raising, supporting, and socializing children throughout their lives" (Nomaguchi & Milkie, 2020, p. 199).

Social, economic, cultural, and institutional changes within the last decade have shaped parental mental health outcomes. Gender norms and roles, socioeconomic status, parenting style, demands, life stressors, and access to resources all contribute to parent well-being outcomes (Nomaguchi & Milkie, 2020). According to the American Psychological Association (APA, 2024), over the past decade, parents have consistently reported increases in parenting stress. Recent data suggest that parents of children under the age of 18 are more likely to report higher stress compared to the general population, with one-third of parents rating their stress as significant compared to only 20% of the general population (APA, 2024). Furthermore, 41% of parents report that their stress impacts their daily functioning most days, and 48% say it is completely overwhelming, compared to 20% of other adults (APA, 2024). According to Nomaguchi and Milkie (2020), parenting strain is higher when childcare demands are greater. Advances in research over the past decade have focused on the challenges faced by parents raising children with special healthcare needs or emotional and behavioral problems (Nomaguchi & Milkie, 2020). Parents raising children with special needs have unique stressors, such as increased financial and time burdens and navigating social stigma around special needs children (Nomaguchi & Milkie, 2020). In the next section, this capstone will discuss the unique challenges that parents face while raising a child with Autism Spectrum Disorder (ASD).

The World Health Organization [WHO] (2023) estimates that 1 in 100 individuals are diagnosed with Autism Spectrum Disorder. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) defines ASD as a neurodevelopmental disorder characterized by persistent deficits in social communication and interactions and restricted, repetitive patterns of behaviour (American Psychological Association [APA], 2022). Manifestation of ASD often presents differently between individuals; however, most individuals with ASD exhibit limited language ability, difficulties with social interactions such as the inability to detect social cues, rigidity, which includes requiring others to speak or behave in specific ways, and restricted repetitive behaviours such as fixated interests or insistence of sameness through patterns (Hirota & King, 2023). ASD can also include the presence of other conditions such as intellectual disability, sensory challenges, sleep difficulties, anxiety, and depression (Hirota & King, 2023). The exact global prevalence of ASD is difficult to estimate, as most research is conducted in high- to middle-income countries, such as the United States, United Kingdom, and Canada (Zeidan et al., 2022). However, most of the literature evaluating the prevalence of ASD suggests an upward trend, with more diagnosed individuals in recent years (Zeidan et al., 2022).

The Autism and Developmental Disabilities Monitoring (ADDM) Network has been monitoring the prevalence of ASD over the past decade (Maenner et al., 2020). Specifically, the ADDM has been providing estimates on the prevalence of ASD in 8-year-old children across multiple sites in the United States over multiple years (Maenner et al., 2023). In 2020, the ADDM reported that the prevalence of ASD in this population was 1 in 36 (Maenner et al., 2023). This is higher than the overall prevalence estimates of 1 in 150, 1 in 68, and 1 in 54 reported for 2000, 2010, and 2016, respectively, suggesting an upward trend over time in the number of children being diagnosed with ASD (Maenner et al., 2020). Although the ADDM is an American network, other countries have seen an increase in the prevalence of ASD as well. In 2019, the Government of Canada (2022) reported that 1 in 50 children aged 1 to 17 are diagnosed with ASD. This rate is higher compared to rates reported in 2018, which reported that 1 in 66 children are diagnosed with ASD in Canada (Government of Canada, 2018). It is currently unknown if the increased prevalence of autism is due to the condition truly becoming more common as time progresses or if it is the result of broader diagnostic criteria or an increased awareness of this condition (APA, 2022). The prevalence of ASD has also varied by geographical region, with higher prevalence estimates reported in countries such as the United States and Australia compared to Asian countries (Salari et al., 2022). Lastly, there is a higher prevalence of ASD diagnosis among males compared to females, with a ratio of 4:1 (APA, 2022).

Due to the increased prevalence of ASD, the impact of the diagnosis is reaching more individuals. Having a child with ASD impacts various aspects of family life, such as housekeeping, finances, the emotional and mental health of parents, marital satisfaction, sibling relationships, relationships with extended family and friends, and a decrease in recreation and leisure activities (Begum & Mamin, 2019). In a systematic review, Begum and Mamin (2019) suggest that ASD strongly influences family dynamics, with up to 70% of mothers and 40% of fathers reporting severe levels of stress. Further, some studies have found that siblings of children with ASD are at higher risk of developing cognitive, social, and learning difficulties, and siblings have reported high levels of loneliness and problems with peers (Begum & Mamin, 2019). An ASD diagnosis is also associated with a financial burden, with a recent study showing that mothers of children with ASD earn an average of 35% less compared to mothers without a child with ASD (Begum & Mamin, 2019). Begum and Mamin (2019) suggest that ASD impacts not only the individual but the entire family system, including the parental, marital, sibling, and extended family systems. Given the reported increased prevalence of autism and the impact ASD has on the family, it is important to consider the well-being of the parents of children with autism.

Transitioning into parenthood and raising a child can have profound impacts on an individual's mental health. Often, caregivers of children with complex needs or disabilities experience exacerbated impact (Scherer et al., 2019). For example, a meta-analysis published in 2019 found that parents of children with autism had higher levels of depressive symptoms (Scherer et al., 2019). Further, they reported that, on average, 31% of parents raising a child with an intellectual disability have increased levels of anxiety and depression compared to parents whose children have typical development (Scherer et al., 2019), which is important to note as intellectual disability commonly co-occurs with a diagnosis of autism, as discussed above (Khachadourian et al., 2023). The association between elevated levels of anxiety and depression in parents of children with neurodevelopmental disabilities has been well corroborated by other literature (Alibekova et al., 2022; Marquis et al., 2020; Nadeem et al., 2024; Papadopoulos, 2021; Stewart et al., 2017). Parents of children with autism have also been found to experience elevated levels of parental stress (Alibekova et al., 2022; Nadeem et al., 2024). Additionally, parents of children with autism have been found to experience caregiver burnout (Vogan et al., 2014) and report emotional deterioration within their relationship with their spouse due to their inability to prioritize personal relationships while caring for their autistic child (Papadopoulos, 2021). Although the majority of the research confirms that parents raising a child with ASD are more likely to experience mental health challenges, the explanation as to why that occurs remains variable.

Vogan et al. (2014) looked at how different factors impact differences in parent mental health while raising a child on the autism spectrum. Vogan et al. (2014) divided these factors into three different categories: child factors, parent factors, and service system factors. Child factors include but are not limited to, the severity of ASD symptoms, medical problems, and intellectual functioning (Vogan et al., 2014). Parent factors include, but are not limited to, education level and marital status (Vogan et al., 2014). Service system factors include, but are not limited to, access to healthcare services and unmet healthcare needs (Vogan et al., 2014).

Vogan et al. (2014) used baseline data from a larger longitudinal project that looked at health service utilization among adults and adolescents with ASD to determine how child, parent, and service system factors impact parent mental health. Vogan et al. (2014) collected data from a baseline survey completed by parents while their child was seeking healthcare services. The participants in this study were parents whose children were between the ages of 12 and 30, all diagnosed with ASD, with half being diagnosed with ASD and an intellectual disability (Vogan et al., 2014). Specific child factors that were accounted for included age, gender, ASD severity, mental health problems, medical problems, daily activities, residence, and the presence of an intellectual disability (ID) (Vogan et al., 2014). A 9-item caregiver burden scale evaluated the caregiver's physical, psychological, and social impact of caring for their child with ASD (Vogan et al., 2014).

Vogan et al. (2014) found that overall levels of caregiver burnout were high, which supports previous literature. Vogan et al. (2014) also found that the presence of an ID, ASD symptom severity, and medical problems of the child all influenced caregiver burnout. Further, children with more severe externalizing behaviors were associated with higher levels of caregiver burnout compared to those raising children without externalizing behaviors (Vogan et al., 2014). Most notably, outside of caregiver age, no other caregiver factor was found to increase caregiver burden (Vogan et al., 2014).

Krakovich et al. (2016) also evaluated the impact different child and parent factors have on parent mental health while raising a child with ASD. Similarly to Vogan et al. (2014), Krakovich et al. (2016) looked at the severity of ASD symptoms, parent level of education, parent race, and access to external services and supports. The participants in this study included 80 parents whose children were between the ages of 3 and 9, all diagnosed with ASD (Krakovich et al., 2016). Similarly to Vogan et al. (2014), this study also relied on self-report questionnaires to capture parent factors such as demographics and their self-reported levels of stress (Krakovich et al., 2016).

Krakovich et al. (2016) found that the severity of ASD symptoms was the strongest predictor of overall parenting stress, which supports the findings of Vogan et al. (2014). Contrary to Vogan et al. (2014), Krakovich et al. (2016) found that parents who had higher levels of education and higher annual income reported reduced parenting stress. Krakovich et al. (2016) also reported that non-White parents reported significantly higher parenting stress. Krakovich et al. (2016) suggest that parent race impacts access to services. Lastly, Krakovich et al. (2016) found that access to child-specific supports led to a decrease in parenting stress; however, this effect only occurred after the parents had adjusted to their baseline level of stress. Furthermore, Krakovich et al. (2016) also found that the more intense services the family received, the higher the stress within the child and parent.

A recent study by Sanchez Amate and de la Rosa (2024) evaluated the overall quality of life of caregivers raising a child with ASD. Specifically, Sanchez Amate and de la Rosa (2024) looked at different factors that led to variability in the quality of life of caregivers, as well as how raising a child with ASD impacts family dynamics. Sanchez Amate and de la Rosa (2024) conducted a narrative review of articles that met the inclusion criteria, which included peer-reviewed journals in English or Spanish, research conducted for educational purposes, and specifically related to family members and individuals with ASD.

Similarly to Krakovich et al. (2016), this study found that social support and other solution-focused coping interventions are associated with a better quality of life (Sanchez Amate & de la Rosa, 2024). Sanchez Amate and de la Rosa (2024) also found that the severity of the child's symptoms has a significant impact on caregivers' quality of life, which corroborates findings by Vogan et al. (2014) and Krakovich et al. (2016). Sanchez Amate and de la Rosa (2024) emphasize the variability in levels of depression and anxiety among caregivers of individuals with ASD. Some of the studies included in their narrative review found moderate levels of anxiety and depression in caregivers; however, other studies found clinically significant levels of anxiety and depression in caregivers (Sanchez Amate & de la Rosa, 2024).

Research consistently shows that parents of children with ASD experience higher levels of depression, anxiety, and burnout compared to parents of neurotypical children. Studies by Vogan et al. (2014) and Krakovich et al. (2016) found that factors such as the severity of ASD symptoms, medical issues, and intellectual disabilities contribute to caregiver burnout, while access to services and parental education can reduce stress. Sanchez Amate and de la Rosa (2024) found that social support and coping strategies improve caregivers' quality of life, though depression and anxiety levels vary. To better understand parental mental health while raising a child with ASD, it is essential to look at both child-specific and caregiver-specific factors that influence mental health outcomes. The purpose of this paper is to examine how different child-specific factors and caregiver-specific factors impact parent mental health outcomes while raising a child with ASD.

Purpose Statement

The purpose of this research paper is to highlight how raising a child with ASD impacts the overall mental health of caregivers. Despite the increasing number of studies on ASD, there is still a lack of consistent findings on the specific factors that influence caregiver mental health and little understanding of how different child and caregiver-specific factors contribute to mental health outcomes. This research paper aims to investigate how variables such as the severity of ASD symptoms, comorbid diagnoses, caregiver gender, socioeconomic status, culture, and access to external supports affect caregiver mental health. Currently, these factors are inadequately supported, leaving a significant gap in understanding their combined effects.
The individuals impacted by this issue are the caregivers of children with ASD, who may experience high levels of stress, anxiety, and depression as a result of the unique challenges they

face. Failure to prioritize caregiver mental health issues may lead to burnout and long-term consequences for both the caregiver and child if not addressed.

The research question guiding this capstone is: How do child-specific factors (severity of ASD symptoms, comorbid diagnoses) and caregiver-specific factors (gender, socioeconomic status, culture, access to external supports) contribute to variability in caregiver mental health outcomes? This research will provide important insights for practitioners working with this population, helping to inform the development of a new study that can be utilized to create a caregiver assessment tool. This tool will enable practitioners to meet caregivers where they are while implementing services for children with ASD. Lastly, this paper will also discuss the importance of a multi-dimensional approach in supporting caregivers and how the findings from this paper can guide future research.

Theoretical Framework

This paper will utilize family systems theory to review and analyze the research. Family systems theory draws on constructs from general systems theory, which suggests that explanations should move beyond a linear cause-and-effect framework and instead focus on terms of wholeness, self-organization, relationships, and interactions between parts (Kim-Appel & Appel, 2021). General systems theory suggests that biological, psychological, and social factors all contribute to an individual's overall functioning. Family systems theory suggests that individuals, families, and societies are all influenced by biological, psychological, and social patterns (Kim-Appel & Appel, 2021). The current research is evaluating how biological components such as developmental disorders and the severity of ASD symptoms, psychological components such as comorbidities with ASD, and social components such as gender, socioeconomic status, culture, and access to supports impact parent well-being.

According to family systems theory, family relationships have a highly influential nature on individual functioning (Keller, 2020). Family systems theory views families as an emotional unit, suggesting that each individual is an integral part of that unit (Keller, 2020). According to family systems theory, an individual's stress, anxiety, differentiation of self, and emotional cutoff impacts family functioning (Keller, 2020). Differentiation of self refers to each family member becoming an emotionally separate person and being able to think, feel, and act for oneself (Kim-Appel & Appel, 2021). Highly differentiated individuals can initiate change under family stress, whereas less differentiated individuals suffer chronic anxiety and often feel stuck. Further, poorly differentiated individuals can become dysfunctional under stress and start to exhibit symptoms of anxiety and depression (Kim-Appel & Appel, 2021). While viewing this from a family systems perspective, one could suggest that caregivers are taking on the stress of their child and, therefore, are demonstrating poorer mental health outcomes. In the next chapter, it will be essential to evaluate how child-specific and caregiver-specific factors combine to either alleviate or aggravate caregiver well-being.

Family systems theory also suggests that in lower-differentiated families, there is a higher degree of emotional fusion, meaning that an emotion exhibited by one individual is felt by all individuals within the family (Kim-Appel & Appel, 2021). When this occurs, the family often exhibits instability and attempts to address the issues through fighting, distancing, under functioning of one partner, or acting out by a child (Kim-Appel & Appel, 2021). While evaluating the current research using a family systems lens, one may suggest that families impacted by an ASD diagnosis exhibit a greater degree of emotional fusion; therefore, it is essential to evaluate how different factors will either increase or decrease stability within the family.

Family systems theory also suggests that societal emotional processes, including forces of sexism, racism, and poverty, impact the overall emotional functioning of a family (Kim-Appel & Appel, 2021). The current research will evaluate the impact gender, socioeconomic status, culture, and access to services have on caregiver mental health while raising a child with ASD. While evaluating the research through a family systems lens, one could suggest that gender norms within caregiving, lower socioeconomic status, poverty, and access to services all interact with one another and impact overall caregiver functioning while raising a child with ASD.

Methodology

The collection of the literature mentioned in this paper consists of scholarly, peer-reviewed journals accessed through the City University Library and Google Scholar databases. The articles referenced are all from the last 10 years, ranging from 2014 to 2024. All the articles discussed involve ASD and its relation to caregiver mental health. Searches for caregiver mental health included terms such as caregiver well-being, caregiver burnout, caregiver stress, and caregiver quality of life, as these all fall under the definition of caregiver mental health. Articles involving caregivers of adult children (ages 18+), neurotypical children, or children with other developmental disabilities (except when discussing comorbidities with ASD) were excluded. With the formulated research question, keywords were used in search engines to identify relevant material. To initially screen the literature, the abstract and discussion sections were reviewed. Next, an in-depth review identified key themes, methodology, geographical location, authors, and limitations, all categorized in an excel spreadsheet. The literature was organized based on two child-specific factors: (1) severity of ASD symptoms and (2) comorbidities with ASD, as well as four caregiver-specific factors: (1) gender, (2) socioeconomic status, (3) culture, and (4) access to external supports.

Throughout this process, the author attended writing workshops led by City University faculty and collaborated with faculty members and fellow students. After the final edits, a second reader viewed the paper and provided feedback. Subsequently, the paper was sent to a certified APA editor to ensure it met APA-7 guidelines.

Contribution to the Field

This research paper demonstrates the significant impact that raising a child with ASD has on caregiver mental health. Specifically, it highlights a complex combination of interconnected factors rather than a simple cause-and-effect relationship impacting caregiver mental health. Further, this paper emphasizes that many caregiver-specific factors are more significant in predicting poor mental health outcomes compared to child-specific factors, underscoring the need for caregiver-focused interventions when working with this population.

Many caregivers report dissatisfaction with current services for children and families affected by an ASD diagnosis (Fong et al., 2023). Due to the increased stress and burnout associated with raising a child with ASD, caregivers report difficulties accessing services (Fong et al., 2023). Fong et al. (2023) found that symptoms of prolonged stress, such as poor sleep, lack of energy, and chronic pain, served as barriers to caregivers accessing support for their children. Furthermore, dissatisfaction with services was associated with higher levels of anxiety and depression among caregivers raising a child with ASD (Fong et al., 2023). Services for families often involve high out-of-pocket costs, debt, and negative impacts on employment, with many caregivers reporting that they needed to quit their jobs to manage the demands of service delivery (Fong et al., 2023).

Another study by Gholipour et al. (2023) found that caregivers reported dissatisfaction with both the accessibility and delivery of services for families affected by an ASD diagnosis.

Gholipour et al. (2023) noted that caregivers are aware of the emotional, financial, and social strain an ASD diagnosis places on their family; however, many service deliveries fail to provide adequate family support to address these concerns. Although many service programs include parent training and education, these interventions do not adequately address the mental health concerns of caregivers (Gholipour et al., 2023). This research highlights the profound impact caring for a child with ASD has on caregiver mental health. Moreover, caregiver-specific factors play a significant role in mental health outcomes. Given these findings, combined with reports of dissatisfaction with services, a new study will be proposed to create an assessment tool that prioritizes caregiver mental health while delivering services to this population.

This research applies to professionals working with families impacted by an ASD diagnosis, such as psychotherapists, psychologists, counseling therapists, occupational therapists, speech-language pathologists, behaviour consultants, and therapeutic community workers. At a minimum, professionals working with this demographic can gain a deeper understanding of the mental strain raising a child with ASD imposes on parents. However, they can also take an active role by adopting a more accommodating approach, offering workshops, and connecting families with community resources to support their mental health. This research is also relevant to larger organizations providing services to families affected by ASD. For example, in Edmonton, Alberta, Canada, organizations such as Children's Autism Services of Edmonton (CASE) receive government funding to provide professional support to families. Larger organizations can incorporate parent mental health support, such as counseling or support groups, that are accessible and affordable.

Reflexivity and Positionality Statement

My positionality and unique personal experiences influence my work on this topic. Various aspects of my social identity inform my positionality. As a White, cisgender, educated female, I hold positions of privilege within my community. Growing up, I was encouraged and supported by my family to pursue higher education, which allowed me to explore and satisfy my natural curiosity about mental health and wellness through an undergraduate degree in psychology and a master's in counseling psychology. My personal experiences with mental illness, particularly anxiety, which shape the way I interact with and interpret literature on mental health, are also impacted by my decision to pursue these degrees.

Additionally, my interest in the impact of raising an autistic child on parental mental health stems heavily from my current work experience as a Behavior Consultant with an organization called SHINE Beyond Limits over the past three years. In this role, I have had the privilege of providing support to children with neurodevelopmental disabilities, many of whom have autism. While working as a Behavior Consultant, I also developed supportive relationships with many of the children's caregivers, which allowed me to gain insight into the hardships and challenges of raising a child with complex needs. Through this position, it became increasingly apparent to me that many caregivers have unmet emotional support needs. Furthermore, as I advanced in this position, I noticed that many caregivers experienced mental health challenges, including struggles with anxiety and depression, due to the demands of raising their children. While many caregivers felt equipped to access support for their children, some expressed feeling ill-equipped to access counseling support for themselves due to a lack of time and exhaustion. Many caregivers also informed me that healthcare professionals often overlooked their mental health, as conversations primarily focused on support and resources for their children. My hope for this research is to highlight the complexity of the mental health challenges experienced by caregivers of a child with ASD. Specifically, my ultimate goal is to inform and improve mental health support and the service delivery of these supports for caregivers.

Roulston and Shelton (2015) suggest that researcher bias poses a threat to the credibility of research. Furthermore, researcher bias can be hidden from the researcher, making it difficult to detect (Roulston & Shelton, 2015). Although researcher bias will be present, reflective practices that focus on examining one's subjectivity and its influence on the research process can decrease its impact (Roulston & Shelton, 2015). Recognizing my positionality and how my identity influences my perspective on the research question is the first step in mitigating research bias. Due to my personal experiences working with caregivers raising children with ASD, I possess the preconceived notion that there are elevated mental health challenges within this population. Therefore, it is essential for me to consider research on both sides of the issue and avoid deliberately excluding research that does not support my research question. It is also essential to establish inclusion and exclusion criteria to avoid incorporating irrelevant research that could skew the results of the intended research question.

Another way to mitigate research bias is by evaluating the literature with a critical lens (Roulston & Shelton, 2015). Roulston and Shelton (2015) suggest assessing the transparency of authors, the appropriateness of the research design, methods, and strategies, and determining if any methods were overlooked. In chapter 3, I will explore the limitations of the research discussed in my capstone. Acknowledging that no research design is perfect and discussing limitations demonstrates that I am critically evaluating the literature.

Definition of Terms

Autism Spectrum Disorder:

A neurodevelopmental condition characterized by persistent deficits in social communication and interaction and by restricted, repetitive patterns of behavior, interests, or activities (APA, 2022).

Caregiver:

An individual in relation to the roles involved in raising, supporting, and socializing children throughout their lives (Nomaguchi & Milkie, 2020).

Caregiver Mental Health:

Subjective well-being (e.g., life satisfaction, life meaning, loneliness), emotional health (e.g., anger, guilt), mental health (e.g., depression, anxiety), and physical health in relation to the roles involved in raising, supporting, and socializing children throughout their lives (Nomaguchi & Milkie, 2020).

Child-Specific Factors:

Factors pertaining to the child such as but not limited to severity of symptoms, medical problems, mental health issues, presence of a comorbidities (Vogan et al., 2014).

Caregiver-Specific Factors:

Factors pertaining to the caregiver such as but not limited to gender, age, education, socioeconomic status and culture (Vogan et al., 2014).

Outline of Capstone Project Chapters

As discussed in Chapter 1, the overall impact of raising a child with ASD on caregiver mental health is evident. However, the differences in parent mental health outcomes due to child-specific and caregiver-specific factors remain variable. The limited research on this topic presents a challenge for counselors and other professionals who may be unaware of the significant impact raising a child with autism has on caregiver mental health. Given the variety of existing data and the diverse, complex ways in which caring for a child with autism can influence mental health, Chapter 1 suggests the need for more research to acknowledge these factors and spread awareness of this issue. To propose a new study, this paper will review the current literature to identify key factors that should be considered when working with this population.

Chapter 2 will explore research examining how child-specific factors—severity of ASD symptoms and comorbidities—and caregiver-specific factors—gender, socioeconomic status, culture, and access to external supports—impact caregiver mental health while raising a child with ASD. Specifically, this chapter will highlight differences and similarities in caregiver mental health outcomes when considering individual factors. This paper anticipates that further research will uncover additional factors related to parenting a child with autism and its influence on mental health. In chapter 3, the research analyzed in chapter 2 will guide the proposal of a research study with the intention to create a caregiver mental health assessment tool that practitioners can use while working with this population emphasizing the prioritization of caregiver mental health while supporting children with ASD. All the chapters will be guided by the research question: How do child-specific factors (severity of ASD symptoms, comorbid diagnoses) and caregiver-specific factors (gender, socioeconomic status, culture, access to external supports) contribute to variability in caregiver mental health outcomes?

Chapter 2: Literature Review

The purpose of this research paper is to examine how raising a child with ASD impacts the overall mental health of caregivers. Chapter 1 outlined that caregivers report more stress than other adults and raising a child with ASD further exacerbates mental health challenges amongst caregivers. Chapter 1 also highlighted that although the exact global prevalence of ASD is difficult to estimate, recent trends indicate that the number of individuals diagnosed with ASD is on a steady incline; therefore, the impact on caregivers continues to amplify. Lastly, chapter 1 highlighted that caregiver mental health outcomes are variable and often depend on child-specific and caregiver-specific factors.

Common child-specific and caregiver-specific factors continuously mentioned in previous literature are the severity of the core symptoms of ASD, comorbidities in ASD, caregiver gender, socioeconomic status, culture, and access to support services. Child-specific and caregiver-specific factors significantly impact caregiver mental health outcomes; however, an in-depth review examining the impact of these factors is necessary. This chapter will highlight the differences these factors have on outcomes of caregiver mental health while raising a child on the autism spectrum in order to answer the research question: How do child-specific factors (severity of ASD symptoms, comorbid diagnoses) and caregiver-specific factors (gender, socioeconomic status, culture, access to external supports) contribute to variability in caregiver mental health outcomes?

Clinical Characteristics of Autism Spectrum Disorder

Prior to evaluating the impact the severity of the ASD symptoms has on caregiver mental health, it is essential to understand the clinical features of this disorder. According to the DMS-5-TR, ASD is characterized by sustained deficits in social communication and interactions in conjunction with restricted or repetitive behaviors (APA, 2022). The communication and social impairments observed in ASD are diverse and often include language delays and deficits, such as poor language comprehension, a complete lack of speech, a lack of emotional reciprocity during social engagements, minimal initiation of social interactions, and deficits in nonverbal communication (APA, 2022). Restricted or repetitive behaviors commonly observed in individuals with ASD include but are not limited to fixated interests, firm adherence to routines and inflexible behavior, stereotyped and/or repetitive motor behaviors, and abnormal responses to sensory input (APA, 2022). In order to meet diagnostic criteria for ASD, affected individuals must exhibit features of ASD in early childhood, and the features must significantly affect their daily functioning (APA, 2022). Most commonly, individuals with ASD first show signs of this condition between 12 and 24 months of age (APA, 2022).

The severity of social communication deficits and repetitive behaviors can vary considerably among individuals with ASD, with some diagnosed individuals requiring significantly greater degrees of daily support (APA, 2022). Based on the current DSM-5-TR criteria, an ASD diagnosis includes three levels of severity, with level 1 being "requiring support," level 2 being "requiring substantial support," and level 3 being "requiring very substantial support" (APA, 2022). Severity is assessed based on the two core features of ASD, social and communication difficulties and restrictive or repetitive behaviours (Waizbard-Bartov et al., 2023). For a level 1 diagnosis, an individual would need to demonstrate difficulty initiating social interactions, decreased interest in social interactions, inflexibility of behaviour that causes significant interference in functioning, and difficulty transitioning between activities (APA, 2022). However, for a level 1 diagnosis, most deficits are only noticeable when supports are not in place (APA, 2022). For a level 2 diagnosis, an individual would need to demonstrate difficulty in verbal and nonverbal communication skills, limited initiation and difficulties in social interactions, inflexibility of behaviour, difficulty transitioning between activities and restricted/repetitive behaviours that interfere with daily functioning (APA, 2022). Further, for a level 2 diagnosis, impairments are still visible even with support in place (APA, 2022). For a level 3 diagnosis, an individual would need to demonstrate severe deficits in verbal and nonverbal communication skills, limited initiation of social interactions, minimal response to others, inflexibility of behaviour and extreme difficulty coping with change in all aspects of functioning (APA, 2022). The challenges of a level 3 diagnosis are evident, regardless of support in place, and individuals often require assistance in all aspects of daily functioning (APA, 2022). Those with ASD also experience a greater incidence of comorbid medical conditions in comparison to individuals without a diagnosis of ASD, which can further exacerbate the severity of the condition (APA, 2022; Hossain et al., 2020; Khachadourian et al., 2023). When an ASD diagnosis is severe, it typically presents as having a co-occurring intellectual disability, little to no language, and requiring extensive long-term care from others (Waizbard-Bartov et al., 2023)

Research has demonstrated that nearly 75% of people with ASD are diagnosed with at least one co-occurring medical condition, with the three most commonly diagnosed comorbidities being attention deficit hyperactivity disorder (ADHD), learning disabilities, and intellectual disability (Khachadourian et al., 2023). Psychiatric disorders, such as anxiety and depressive disorders, conduct disorders, and other psychotic disorders, are also commonly observed in individuals with ASD (APA, 2022; Hossain et al., 2020). Individuals with ASD can also demonstrate difficulty in emotional regulation and exhibit behavioural difficulties (Hastings et al., 2022). For instance, individuals with ASD may show an elevated level of behaviour problems including disruptive/antisocial behaviour, communication disturbance, and difficulties relating with others (Hastings et al., 2022). Outside of the core features of ASD, many caregivers report that their child exhibits significant difficulty with cooperation, self-control, assertion, impulsivity, and attention difficulties (Hastings et al., 2022). Given the different levels of ASD severity as well as the prevalence of comorbidities within ASD, it is essential to evaluate how both of these factors impact caregiver mental health outcomes.

Child Specific Factors

Severity of ASD Symptoms

Gardiner and Iarocci (2015) examined how a child's severity of ASD symptoms impacts Family Quality of Life (FQOL). Gardiner and Iarocci (2015) define FQQL as "conditions where the family's needs are met, family members enjoy their life together as a family and have the chance to do things which are important to them" (p. 199). Through the use of formal assessments and self-report questionnaires, eighty-four caregivers of a child with ASD participated in determining the impact of symptom severity on the family's FQQL (Gardiner & Iarocci., 2015). The ASD symptoms evaluated in this study included communication, daily living skills, socialization, and motor skills. Gardiner and Iarocci (2015) also examined adaptive behaviours, which include social competence, conduct problems, insecure/anxious self-injury/stereotypy, self-isolation/ritualistic, and overly sensitive symptomatology. Caregivers completed phone surveys as part of the research to collect data (Gardiner & Iarocci, 2015).

Gardiner and Iarocci (2015) found that communication skills did not significantly impact FQQL. Gardiner and Iarocci (2015) found that adaptive functioning, specifically the child's daily living skills, greatly impacted FQQL. However, this is the only adaptive functioning behaviour that had a significant impact on the FQQL (Gardiner & Iarocci, 2015). Further, children with greater daily living challenges had a more profound impact on the FQQL (Gardiner & Iarocci., 2015). Gardiner and Iarocci (2015) hypothesized that socialization and other areas of adaptive functioning, such as the presence of self-injurious behaviour, would have more of a profound impact on FQQL; however, this was not the case. Gardiner and Iarocci (2015) suggest that daily living functioning has significant implications for adaptive functioning, contributing to its substantial impact on the FQQL. Although this research was done in 2015, it captures the current symptomology of ASD as defined in the DSM-5-TR. Furthermore, it offers insight into how the core features of ASD, such as communication skills, affect family quality of life.

Bradshaw et al. (2021) suggest that the severity of the clinical features of ASD has a significant impact on caregiver mental health, with the more severe symptoms leading to greater caregiver fatigue, burnout, and stress. Bradshaw et al. (2021) assessed how the severity of the clinical features of ASD impact caregiver strain, which is the perceived negative experiences associated with raising a child with a disability. Elements of caregiver strain assessed involved impact on work, finances, daily routine, feelings of sadness, fatigue and worry. Bradshaw et al. (2021) evaluated how the severity of social and communication difficulties within the child impacted caregiver strain. Bradshaw et al. (2021) found that caregivers whose children demonstrated moderate to severe symptoms of social and communication difficulties reported higher levels of strain. Furthermore, severe communication difficulties within the child consistently predicted higher levels of caregiver strain, which corroborates findings from previous studies (Bradshaw et al., 2021; Gardiner & Iarroci, 2015). However, Bradshaw et al. (2021) found that the clinical features of ASD (communication and social difficulties) were fewer predictors of caregiver strain compared to child behaviour and emotional difficulties. Specifically, children who displayed high levels of disruptive behaviour, such as irritability and hyperactivity, were associated with high levels of caregiver strain (Bradshaw et al., 2021).

Golya and McIntyre (2018) evaluated the impact of ASD symptom severity and caregiver depression. Golya and McIntyre (2018) assessed how the severity of the child's communication, social skills, and daily living skills either increased or decreased levels of caregiver depression. This study found that higher levels of severity in communication, social skills, and daily living skills were only moderately associated with higher levels of caregiver depression. Increased impairment in the social skills of the child was a greater predictor of caregiver depression; however, Goyla and McIntyre (2018) suggest that the severity of ASD was not significantly associated with caregiver depression.

Baykal et al. (2018) also evaluated how child ASD symptom severity impacts primary caregiver burnout. A variety of tools, such as the Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), and the Zarit Caregiver Burden Scale (ZCBS) which measured five different dimensions of caregiver tasks that include psychological tensions and impaired private life, irritability, impaired social relationships, and economic burden assessed caregiver burnout. (Baykal et al., 2018). It is important to note that this study contained a more in-depth definition of caregiver mental health compared to studies by Goyla and McIntyre (2018) and Bradshaw et al. (2021). The ASD symptoms evaluated in this study included sensory behaviour, social relationships, body and object use, language and communication skills, and social and adaptive functioning skills in 70 children aged 3-15 (Baykal et al., 2018).

Baykal et al. (2018) found that severe language and communication symptoms were the most significant predictor of higher levels of caregiver burden, which corroborates findings by Bradshaw et al. (2021). Baykal et al. (2018) also found that severe destructive behaviours were associated with higher levels of caregiver burnout but did not comment on how these behaviours presented themselves. Outside of language, communication, and destructive behaviours, no other

ASD symptoms were mentioned as having a profound impact on caregiver burnout (Baykal et al., 2018). This finding is inconsistent with other literature, which found that severe disruptive behaviour and deficits in social skills were associated with poorer caregiver mental health outcomes (Bradshaw et al., 2021; Goyla & McIntyre, 2018).

Salomone et al. (2018) sought to examine the impact ASD severity has on caregiver mental health. Salomone et al. (2018) proposed that children with elevated emotional and behavioural difficulties would have the most profound impact on caregiver mental health. One hundred four caregivers of children with ASD completed a General Health Questionnaire and a Mental Well-being Scale, which assessed the feelings and functioning of caregivers (Salomone et al., 2018). The ASD symptoms assessed in this study included social affect, restricted and repetitive behaviours, verbal ability, cognitive functioning, adaptive behaviour, and emotional and behavioural difficulties (Salomone et al., 2018).

This study found that the child's level of language or communication impacted caregiver mental health, with more severe challenges associated with poorer mental health outcomes. These findings replicate those from other studies (Baykal et al., 2018; Bradshaw et al., 2021; Salomone et al., 2018). Furthermore, the severity of restricted or repetitive behaviours, as well as social affect, was only a moderate predictor of caregiver mental health, which corroborates findings from previous studies (Goyla & McIntyre, 2018; Salomone et al., 2018). However, Salomone et al. (2018) found that caregiver mental health challenges were higher when the child's daily living skills were greatly impacted, as well as had elevated emotional and behavioural difficulties. Furthermore, Salamone et al. (2018) found that emotional and behavioural difficulties had the most profound impact on caregiver mental health and overall well-being, which is similar to the findings by Bradshaw et al. (2021). Interestingly, Salomone et al. (2018) found that caregiver mental health or well-being was not necessarily directly affected by the severity of ASD symptoms. Rather, that parent mental health and well-being are impacted by child-specific comorbidities and characteristics as well as parent-specific characteristics (Salomone et al., 2018).

Waizbard-Bartov et al. (2023) suggest that the environment plays a significant role in the way ASD impacts one's life, meaning that parent mental health while raising a child with ASD plays a critical role. Further, social biases, negative attitudes, and stigmatization towards ASD can drastically impact ASD severity (Wiazbard-Bartov et al., 2023). Waizbard-Bartov et al. (2023) suggest that the environment can influence the severity of ASD symptoms and may also lead to challenges within it. Further, when an ASD diagnosis is severe, it is highly likely that the individual is diagnosed with another condition, such as ADHD, learning disability, or intellectual disability (Waizbard-Bartov et al. (2023). Therefore, it is essential to evaluate how other child-specific factors, such as comorbidities with ASD, impact caregiver mental health outcomes.

Comorbidities

Another child-specific factor that impacts caregiver mental health is ASD and comorbidities with other mental health disorders. Bougeard et al. (2021) estimate that children and adolescents diagnosed with ASD have a 54.8% chance of being diagnosed with a comorbid psychiatric disorder, with 94% of these being ADHD, anxiety, depressive disorders, and sleep disorders. Further, individuals with ASD are more likely to have other comorbidities such as epilepsy, gastrointestinal disorders, sight and hearing impairments, and other sensory processing concerns (Bougeard et al., 2021). Another co-occurring symptom of ASD is emotional and behaviour difficulties, with some children being diagnosed with oppositional defiance disorder (ODD) or conduct disorders (Bougeard et al., 2021). When evaluating ASD symptom severity, a common theme was that child behaviour and emotional difficulties were a greater predictor of poor caregiver mental health outcomes compared to the clinical features of ASD, which include communication and social deficits. Bougeard et al. (2021) suggest that comorbidities in ASD have the potential to negatively impact the quality of life of individuals impacted by the diagnoses as well as further the strain on relationships. Further, comorbidities have the potential to heighten ASD symptoms as well as lead to an increased need for healthcare services and support (Bougeard et al., 2021).

Yorke et al. (2018) suggest that children with ASD commonly exhibit both internalizing behaviours, such as anxiety and depressed mood, and externalizing behaviour, such as hyperactivity, oppositional behaviour, and conduct problems. In line with Bougeard et al. (2021), Yorke et al. (2018) suggest that comorbidities within ASD have a significant impact on parent mental health outcomes. Yorke et al. (2018) sought to examine the impact autistic children with emotional and behavioural problems have on parents' mental health outcomes. Yorke et al. (2018) found that increased emotional and behavioural difficulties within the child resulted in a moderate impact on parent mental health outcomes. However, this effect was bidirectional, meaning that parent mental health also impacted child's behaviour and emotional difficulties.

Dovgan and Mazurek (2019) also evaluated how co-occurring emotional and behaviour problems within autistic children impact mental health challenges within the family. Similar to Yorke et al. (2018), Dovgan and Mazurek (2019) hypothesized that the presence of comorbid emotional and behaviour problems in children with ASD would be associated with greater mental health challenges in the family. Dovgan and Mazurek (2019) suggest that co-occurring conditions increase a caregiver's financial and time-related burdens as children with comorbidities often require greater need for healthcare services, psychiatric medications, and increased hospitalization rates, which is in line with suggestions by Bougeard et al. (2021). Dovgan and Mazurek (2019) assessed how the presence of ADHD, depression, anxiety, and behavioural or conduct difficulties within the autistic child impacted family mental health outcomes.

Dovgan and Mazurek (2019) found little evidence that comorbid conditions of children with ASD impact family mental health. Specifically, comorbid conditions did not have an impact on families receiving support, work-life challenges, or access to counselling (Dovgan & Mazurek, 2019). This finding is similar to that of Yorke et al. (2018), who found only a moderate impact of comorbidities and ASD on caregiver mental health. It is essential to note that Dovgan and Mazurek (2019) evaluated family mental health, whereas Yorke et al. (2018) focused specifically on the mental health of caregivers. However, regardless of the conceptualization of caregiver mental health, both Dovgan and Mazurek (2019) and Yorke et al. (2018) did not find a significant relationship between comorbidities within ASD and caregiver mental health outcomes. Rather, Dovgan and Mazurek (2019) found that parent-specific factors such as gender, education levels, and income had a greater impact on parent mental health while raising a child with ASD with comorbidities.

Lanyi et al. (2022) evaluated the impact child comorbid psychopathology had on parental well-being. Specifically, how parent's quality of life, sleep, stress, anxiety, depression, and perceived social support differed depending on the severity of the comorbid psychopathology of their child (Lanyi et al., 2022). Lanyi et al. (2022) found that severe comorbidity of their child impacted the parent's quality of life and elevated both anxiety and depression levels. In parents whose children had both tantrums and depressive behaviors, their overall quality of life was lower compared to groups with minimal tantrums and depressive behaviors (Lanyi et al., 2022).

However, Lanyi et al. (2022) found that overall parental stress was higher when there were lower levels of comorbid psychopathology in the child. These findings partially support previous studies that suggest child comorbidities and ASD only have a mild to moderate effect on parent mental health outcomes (Dovgan & Mazurek, 2019; Yorke et al., 2018). Lanyi et al. (2022) suggest that the mixed findings could be because parents whose children have more severe symptomatology tend to reach out for support compared to those without, meaning that the lower comorbidity is associated with less severe child symptoms. Lanyi et al. (2022) suggest that other parent factors, such as marital status, social support, and gender, also have the potential to mitigate parental stress.

Other comorbid conditions with ASD frequently mentioned within the literature are sleep disturbances (Bougeard et al., 2021; Yorke et al., 2018). Liu et al. (2020) suggest that sleep disturbances are more common in children with ASD compared to children without. Liu et al. (2020) suggest that sleep disturbances in children may alter the sleep quality of their parents, contributing to a poorer quality of life. In their study, Liu et al. (2020) aimed to investigate the impact of sleep disturbances in children with ASD on their parents' quality of life. Factors that assessed parents' quality of life included physical, emotional, and social functioning. Liu et al. (2020) found that sleep disturbances were associated with poorer physical health for parents. Further, Liu et al. (2020) found that sleep disturbances had a greater impact on maternal mental health compared to paternal mental health.

Martin et al. (2020) suggest that sleep disturbances within a child with ASD may have different impacts on maternal and paternal mental health. Martin et al. (2020) suggest that sleep disturbances may be viewed differently between parents; therefore, they evaluated the effect sleep disturbances had on maternal mental health while raising a child with ASD. Martin et al.

(2020) found that sleep disturbances had a small impact on maternal well-being, which is similar to the findings by Liu et al. (2020). Martin et al. (2020) found that child sleep initiation and duration were the greatest predictors of poor maternal well-being; however, the effect was moderate. Martin et al. (2020) found that hyperactivity and impulsivity were a greater predictor of poor sleep in children with ASD, suggesting that these co-occurring conditions may have a more profound effect on caregiver mental health compared to sleep.

One of the more commonly co-occurring conditions with ASD is ADHD (Khachadourian et al., 2023). Recent literature suggests that there is up to a 50-70% chance of individuals with ASD also being diagnosed with ADHD (Hours et al., 2024; Khachadourian et al., 2023). Impulsivity and hyperactivity are key features of ADHD but also common behaviours of autistic individuals (Hours et al., 2024). Previous literature suggests that the presence of hyperactive and impulsive behaviour within children with ASD may lead to poor caregiver mental health outcomes (Bougeard et al., 2021; Martin et al., 2020). This capstone found no relevant literature on comorbid ASD and ADHD in children and the impact on caregiver mental health. Therefore, more research is needed to determine the extent of co-occurring ASD and ADHD in children on caregiver mental health.

Summary of Findings

In summary, it is evident that child-specific child-specific factors, including the severity of ASD and co-occurring conditions within ASD, have an impact on caregiver mental health; however, the extent to which caregiver mental health is affected is variable. While evaluating symptom severity, the majority of the literature did not suggest a significant relationship between child ASD symptom severity and caregiver mental health outcomes (Bradshaw et al., 2021; Goyla & McIntyre, 2018; Salomone et al., 2018). Further, while looking at specific symptom severity of communication and social challenges, some studies indicated communication challenges were a greater predictor of poor caregiver mental health outcomes, whereas other studies suggested that social challenges were a greater predictor of poor caregiver mental health outcomes (Baykal et al., 2018; Bradshaw et al., 2021; Goyla & McIntyre, 2018). However, a common theme amongst the studies analyzed in symptom severity is that other child-specific factors, such as emotional and behavioural challenges, were a greater predictor for poor caregiver mental health outcomes.

Another child-specific factor that had a variable impact on caregiver mental health outcomes is ASD and comorbidities. Some of the previous research suggests that raising a child with ASD and other co-occurring conditions only minimally impacts caregiver mental health outcomes (Dovgan & Mazurek, 2019; Lanyi et al., 2022; Yorke et al., 2018;) Other research suggested that co-occurring conditions within ASD have a moderate impact on caregiver mental health; however, this could be attributed to caregiver gender (Liu et al., 2020; Martin et al., 2020). However, one common theme throughout the literature is that there are several different factors impacting caregiver mental health while caring for a child with ASD. Specifically, most of the literature emphasized that caregiver-specific factors such as gender, race, socioeconomic status, and access to external support have a significant impact on mental health outcomes (Lanyi et al., 2022; Liu et al., 2020; Martin et al., 2020; Salomone et al., 2018; W.aizbard-Bartov et al., 2023). Therefore, it is essential to look at the impact caregiver-specific factors have on mental health outcomes while raising a child with ASD.

Caregiver Specific Factors

Gender

Yaffe (2023) suggests that mothers and fathers play different roles in parenting, with mothers typically being more present and responsive to the child's needs. In contrast, the fathers typically take on the protective and provider role. A meta-analysis conducted across cultures in Israel found that mothers were perceived as more responsible, supportive, and autonomy-granting, whereas fathers were perceived as more restrictive and punishment-based (Yaffe, 2023). Furthermore, previous literature suggests that mothers continue to play a more central and crucial role in raising children compared to fathers (Yaffe, 2023). Argumedes et al. (2018) suggest that gender differences within parenting play a role in caregiver mental health while raising a child with ASD. Specifically, caregiver gender impacts how the symptomology of the child is viewed, dealt with, and internalized, with mothers typically being more impacted by their child's emotional, social, and behavioural challenges compared to fathers (Argumedes et al., 2018). The impact of caregiver gender on mental health outcomes while raising a child with ASD is not a new concept, with previous literature suggesting that mothers typically experience higher levels of stress compared to fathers (McStay & Trembath, 2014). Previous literature has also supported gender differences in the perception of child symptomology, with externalizing behaviour having a greater impact on maternal stress. In contrast, a sense of cohesion has a greater impact on fathers within the family unit (McStay & Trembath, 2014). Given the prevalence of gender differences within parenting as well as previous literature supporting the idea that caregiver gender impacts caregiver mental health outcomes while raising a child with ASD, it is essential to look more in-depth at the relationship between caregiver gender and caregiver mental health outcomes (Argumedes et al., 2018; McStay & Trembath, 2014; Yaffe, 2023).

Grebe et al. (2021) sought to examine the impact parent gender had on adjustment, support, coping, and stress while raising a child with ASD. Further, to examine the impact of how mothers and fathers conceptualize their child's ASD diagnoses on parents' mental health outcomes (Grebe et al., 2021). This study included 361 American parents, with 80% being mothers and 20% being fathers. Parents completed an illness perception questionnaire as well as self-report questionnaires to assess stress and family adjustment (Grebe et al., 2021). Grebe et al. (2021) found that mothers reported higher stress levels compared to fathers; however, fathers' self-reported stress levels were still significant, which supports previous findings by McStay and Trembath (2014). Further, Grebe et al. (2021) found that mothers' and fathers' stress was impacted by different child factors, with mothers facing more stress regarding the child's self-regulation skills, whereas fathers faced more stress with their child's externalizing behavior. Although this finding supports the previous literature in that caregiver gender impacts the perception of child symptomology, it contradicts findings that the child's externalizing behaviour has a greater impact on mothers compared to fathers (Argumedes et al., 2018; McStay & Trembath, 2014). Grebe et al. (2021) also suggested that the mother's education level, as well as their income, impacted their stress levels, whereas for fathers, it did not. These findings suggest that gender does have an impact on overall parent mental health; however, there are other factors to consider.

Ang and Loh (2019) also suggest that parents raising a child with ASD have greater levels of stress compared to those raising a child without ASD. Further, parent gender plays a key role in parental stress, with mothers typically reporting higher stress compared to fathers (Ang & Loh, 2019). Ang and Loh (2019) had 203 Singaporean parents, 106 mothers, and 97 fathers complete self-report questionnaires that assessed their levels of depression, anxiety, and stress while raising a child with ASD. Ang and Loh (2019) predicted that mothers would report higher levels of stress, anxiety, and depression and that differences in coping styles between genders would have a profound effect on these outcomes. Ang and Loh (2019) found that mothers reported significantly higher levels of stress than fathers; however, levels of anxiety and depression did not emerge as being significant. This corroborates previous findings that mothers report more stress than fathers; however, it also highlights that paternal stress is still significant, similar to other studies (Grebe et al., 2021; McStay & Trembath, 2014). Ang and Loh (2019) did not find that coping differences between genders led to any significant impact on parental stress, anxiety, or depression, which is contrary to previous literature that suggests that caregiver gender leads to differences in perception and coping of their child's symptoms (Argumedes et al., 2018; Grebe et al., 2021).

Giannotti et al. (2023) sought to examine the impact parent gender had on parenting stress while raising a child with ASD. Contrary to the previous studies, Giannotti et al. (2023) hypothesized that parent gender would have no significant impact on overall parenting stress. This study included Italian parents raising children with ASD and without ASD with a total of 100 parents, 50 of them mothers, and 50 of them fathers (Giannotti et al., 2023). Parents completed a self-report questionnaire that assessed parental distress, parent-child relationship, and the difficulty of the child (Giannotti et al., 2023). Giannotti et al. (2023) found no significant differences in parenting stress between mothers and fathers, which contradicts findings from McStay and Trembath (2014) and Ang and Loh (2019). However, Giannotti et al. (2023) did find gender differences in factors that impact parental stress, which supports the findings by Argumedes et al. (2018) and Grebe et al. (2021). Difficulties in social communication, interpersonal relatedness, and the display of repetitive and restricted behaviours within the child led to higher levels of maternal stress (Giannotti et al., 2023). Further, ASD severity had a greater impact on maternal stress compared to paternal stress (Giannotti et al., 2023).

The majority of the previous literature supports that caregiver gender impacts mental health outcomes while raising a child with ASD. However, the literature also suggests that mothers are typically overrepresented in research studies, resulting in skewed results (Giannotti et al., 2023; Grebe et al., 2023; Rafferty et al., 2020). Rafferty et al. (2020) suggest that paternal stress is generally more impacted by the co-parenting relationship, placing less emphasis on child symptomology, which could explain previous literature finding that maternal stress is higher while raising a child with ASD. Rafferty et al. (2020) sought to determine the impact raising a child with ASD had on fathers' parenting experiences. This study found that fathers reported stress in relation to their child's mood or behaviour, as well as feelings of isolation and loneliness, which has been a common theme in maternal mental health. Interestingly, Rafferty et al. (2020) found that all the fathers in this study tended to follow traditional gender roles, with mothers taking charge of their child's treatment and fathers focusing on providing for the family. This finding suggests that gender roles have an impact on parenting and supports previous literature that mothers typically take on the bulk of child-rearing, leading to increased maternal stress while raising a child with ASD (Argumedes et al., 2018; Rafferty et al., 2020; Yaffe, 2023).

In summary, the literature highlights that caregiver gender does impact caregiver mental health outcomes while raising a child with ASD (Ang & Loh, 2019; Grebe et al., Giannotti et al., 2023; McStay & Trembath, 2014; Rafferty et al., 2020). However, how gender impacts caregiver mental health outcomes is variable, with some studies suggesting higher maternal stress and other studies suggesting no gender differences in stress; however, there are gender differences in how the caregiver perceives the child's symptoms. Yet, a common theme within the literature is that there are other caregiver-specific factors outside of gender that have impacts on caregiver mental health outcomes while raising a child with ASD, such as socioeconomic status and access to external supports; therefore, it is essential to evaluate these in the context of raising a child with ASD (Enea & Rusu, 2020; Grebe et al., 2021; Giannotti et al., 2023).

Socioeconomic Status

Socioeconomic status is a complex and multifaceted construct that characterizes an individual's access to various resources, including economic, financial, and social resources (Navarro-Carrillo et al., 2020). Socioeconomic status has numerous implications for psychological well-being, as lower status is typically associated with lower income, a lower education level, and more barriers to accessing various resources (Navarro-Carrillo et al., 2020). Navarro-Carrillo et al. (2020) found that education and occupation had a significant impact on psychological well-being, with lower education level and lower income being associated with less favourable well-being outcomes. Given these findings, it is essential to evaluate how socioeconomic status impacts caregiver mental health outcomes while raising a child on the autism spectrum.

Liao and Li (2020) suggest that caregivers raising a child with ASD have adverse employment impacts as well as sustained financial burdens. Raising a child with ASD comes with both direct and indirect economic costs (Liao & Li, 2020). Direct costs involve money spent on child-specific services, such as speech-language therapy, occupational therapy, behavioural interventions, and medical health services. Indirect costs, on the other hand, involve job stability and time restraints. In a cross-cultural meta-analysis, Liao and Li (2020) suggest that some American caregivers spend roughly $850 USD per symptom their child displays; however, this amount varies due to insurance coverage and funding available to the family. However, Liao and Li (2020) suggest that increased insurance coverage is associated with less financial burdens on the family. Many caregivers also report job disruptions as a portion of their time is allocated to bringing their child to appointments, attending workshops, or staying home with their child due to limited childcare options (Liao & Li, 2020). Employment disruptions are more likely to impact females, and in some studies, 66% of the participants report that having a child with ASD has led to occupational restrictions. Lastly, raising a child with ASD poses time restraints, with some parents reporting they spend, on average, 60 hours per week dedicated to supporting their child (Liao & Li, 2020). Liao and Li (2020) suggest that estimating the socioeconomic impact of raising a child with ASD is difficult due to the differences in funding, insurance policies, and cost of services; however, they suggest that there is evidence that lower socioeconomic status is associated with greater challenges while raising a child with ASD.

The idea that caregivers raising a child with ASD face heightened economic burdens is not a new concept, with previous literature suggesting that families of children with ASD often require extensive interventions from a variety of healthcare professionals, which are often not covered by insurance policies (Liao & Li, 2020; Zablotsky et al. (2014). The lack of insurance coverage leaves families having to pay out of pocket for services, often resulting in further economic burden, as better-quality services are not available (Liao & Li, 2020; Zablotsky et al., 2014). Pickard and Ingersoll (2016) found that parents with lower socioeconomic status (SES) are less likely to be aware of services available for their child, which contributes to the use of fewer services for their child, resulting in increased parenting stress. Pickard and Ingersoll (2016) also found that parents with both low and high SES recognized the need for services; however, parents with lower SES were less likely to report being satisfied with their child's services. Furthermore, lower SES families faced additional barriers, including work schedules and limited transportation, in accessing services (Pickard & Ingersoll, 2016). The previous literature suggests that higher financial stress within the family may lead to poorer mental health outcomes for both the child and the family (Liao & Li, 2020; Navarro-Carrillo et al., 2020; Zablotsky et al., 2014). Green et al. (2021) suggest that higher household income correlates positively with better mental health outcomes. Further, caregivers who work reduced hours show greater well-being outcomes while raising a child with ASD compared to parents who have limited time restraints (Green et al., 2021). Green et al. (2021) found that family socioeconomic status was a predictor of parents' mental health outcomes while raising a child with ASD; however, the impact was very minimal. However, Green et al. (2021) suggest that SES, combined with other factors such as caregiver gender, may have more of a profound impact.

Zhou et al. (2019) sought to understand the impact SES had on maternal caregivers of children with ASD. Similarly to Grebe et al. (2021), Zhou et al. (2019) suggest that mothers are typically the primary caregivers; therefore, they typically face a variety of problems, such as financial burden, discrimination, stigma, and ineffective therapy. In their study, Zhou et al. (2019) looked at how SES impacted maternal anxiety and depression while raising a child with ASD. A total of 180 mothers completed various self-report questionnaires to determine the impact of SES on maternal mental health (Zhou et al., 2019). Zhou et al. (2019) found that SES played a role in maternal mental health outcomes. Specifically, mothers' education level had the most significant impact on mental health outcomes, with increased anxiety and depression in those with a primary education level compared to a university education level. After adjusting for other factors such as gender of children, age, marital status, and family financial burden, only education level had a significant impact on maternal mental health (Zhou et al., 2019). Zhou et al. (2019) suggest that mothers with a higher education level may begin to notice symptoms sooner and receive support sooner, which may contribute to lower levels of anxiety and depression.

Mathew et al. (2019) suggest that many of the studies done on the impact of SES on parents' mental health while raising a child with ASD have been focused on mothers; therefore, they suggest that the findings that SES impacts mothers more than fathers may be due to the over-representation of this population within the literature. Mathew et al. (2019) sought to determine the impact of SES on parent mental health; however, they specifically explored the differences between mothers and fathers. Matthew et al. (2019) hypothesized that higher socioeconomic status would serve as a protective factor for parent mental health in both genders.

Mathew et al. (2019) found that in Australia, SES did not have a significant impact on levels of parenting well-being, competence, or efficacy alone; however, when combined with other factors, there was an impact, which supports suggestions by Green et al. (2021) who suggests that SES alone may not be a strong predictor of mental health outcomes. Mathew et al. (2019) found a moderate effect between lower SES and levels of stress and anxiety in fathers. Further, Mathew et al. (2019) found that mothers in the highest SES bracket reported greater parental efficacy and satisfaction, whereas fathers in the highest SES bracket found that, when their child had severe symptoms, there was a lower sense of parenting efficacy. Contrary to previous findings by Zhou et al. (2019), Mathew et al. (2019) suggest that SES alone does not have an impact on parent well-being; however, they propose that the differences in the research may be due to different conceptualizations of SES. However, the interactions between SES and caregiver gender found within this study replicate findings by Liao and Li (2020) and Zhou et al.

(2019), suggesting that caregiver mental health outcomes are a complex combination of factors rather than being reduced to a single factor.

Yan et al. (2023) also evaluated the impact of SES on parenting stress while raising a child with ASD; however, they also looked at how the impact of SES changes with race. Yan et al. (2023) hypothesized that SES would serve as a protective factor against parenting stress and increase parent involvement in 165 Chinese parents. Parents in this study completed a variety of self-report questionnaires, such as the Parenting Stress Index (PSI) and Family Involvement Questionnaire (FIQ), to assess socioeconomic status (SES), parenting stress, family involvement, and social responsiveness.

Yan et al. (2023) found that higher socioeconomic status positively predicted parental involvement among children, which is similar to findings in Western societies. Yan et al. (2023) found that lower parent SES led to higher levels of parenting stress, which in turn reduced parent involvement among children with ASD. Yan et al. (2023) suggest that low-SES Chinese parents also spend a lot of their time working; therefore, they do not have a lot of spare time to spend with their children, resulting in greater parenting stress. Yan et al. (2023) suggest that China has recently evolved into a different social stratification, with a significant emphasis on work; therefore, parents with low socioeconomic status (SES) spend less time with their children, which increases overall stress levels. These findings support previous literature that SES has an impact on caregiver mental health (Mathew et al., 2019; Pickard & Ingersoll, 2016; Zhou et al., 2019); however, they also highlight the importance of examining other influences on caregiver mental health, such as parent mental health and culture.

Liao and Li (2020) found that caregivers, especially mothers, experience financial stress and time constraints, leading to worsened mental health. Research by Green et al. (2021)

suggests that higher SES improves caregiver well-being, while Zhou et al. (2019) found that lower education levels in mothers correlate with higher anxiety and depression. Mathew et al. (2019) noted that SES alone does not strongly predict mental health, but its effects are influenced by gender and child symptoms. Yan et al. (2023) emphasized that cultural factors, like work demands in China, also impact caregiver stress. Overall, caregiver well-being is influenced by a combination of socioeconomic status (SES), education, gender, and cultural factors.

Culture

Cardon and Marshall (2021) suggest that cultural backgrounds greatly influence how caregivers perceive an ASD diagnosis. Differences in etiological views, religious beliefs, and other cultural factors impact the interpretation and treatment of ASD (Cardon & Marshall, 2021). Kim et al. (2020) suggest that there are ethnic and racial differences in parenting stress while raising a child with ASD, with some ethnic groups reporting higher stress. Specifically, African American families have reported increased parenting stress in relation to their child with ASD compared to White or Hispanic families in the United States (Kim et al., 2020). Fisher et al. (2023) suggest this could be due to the fact that caregivers of colour often experience unequal care and provider biases when accessing support for their child resulting in increased parenting stress. Specifically, caregiver ethnicity and race lead to system-level barriers such as financial concerns, provider factors such as racial bias, and individual and family factors such as extended family members' understanding of the diagnosis (Fisher et al., 2023). All of these factors combined may lead to poor caregiver mental health outcomes; therefore, it is essential to evaluate the impact of culture on caregiver mental health while raising a child with ASD.

Williams et al. (2019) suggest that there are racial differences in stress and coping as some races experience additional stressors such as structural racism, discrimination, fewer resources, and single-parent homes, leading to increased stress. Williams et al. (2019) sought to understand differences in stress and coping between African American and Euro-American caregivers while raising a child with ASD. Williams et al. (2019) had 52 Euro-American and 51 African American caregivers complete self-report questionnaires that assessed parental stress, autism-related parental stress, proactive coping, and coping behaviours in relation to their child with ASD. Williams et al. (2019) found that African American caregivers reported higher stress compared to Euro-American caregivers. Further, African American caregivers who reported low levels of acculturation were at the highest risk for increased stress. These findings support the findings by Kim et al. (2020), who found that African American families reported lower resilience and higher parenting stress in relation to their child with ASD due to differences in support and coping.

Cardon and Marshall (2021) sought to understand the differences in parental experiences while raising a child in the United States versus Sub-Saharan Africa. This study aimed to understand the broader influence of culture by comparing caregivers in two different countries. In their study, Cardon and Marshall (2021) conducted a phenomenological interview with seven caregivers from Senegal and seven from the United States. The themes noted in the interview were diagnostics and care, daily life, social relationships, and introspection (Cardon & Marshall, 2021). While seeking support for their child, the U.S. group had access to in-depth research and books, leading to a diagnostic journey through a multidisciplinary team, whereas the Senegalese group sought spiritual advice and interpretations before consulting any healthcare professionals (Cardon & Marshall, 2021). Once a diagnosis was received utilizing the DSM-5 criteria, the U.S. group reported that there was a time-consuming system to receive services in which parents felt personally responsible for the outcome of their child. Senegalese parents reported that they had limited access to services and often had to homeschool their children; however, they were able to accept the diagnosis through trust in a higher power (Cardon & Marshall, 2021). Another key difference between the groups was that U.S. parents reported feelings of loneliness and isolation, whereas these concerns were not mentioned in the Senegalese group (Cardon & Marshall, 2021). Senegalese parents reported themes of togetherness and numerous opportunities for social interactions, whereas U.S. parents reported a scattered community of friends, a lack of childcare, and further social isolation (Cardon & Marshall, 2021). These findings highlight that culture influences coping, services, and interpretation of an ASD diagnosis, resulting in differences in caregiver mental health outcomes, which corroborates findings from other literature (Fisher et al., 2023; Kim et al., 2020; Williams et al., 2019).

Similar to Cardon and Marshall (2021), Giannotti et al. (2021) also evaluated cultural differences between two groups while raising a child with ASD. Giannotti et al. (2021) had 92 parents from Italy and 89 parents from Japan complete self-report questionnaires to assess parenting stress and parenting social style. Giannotti et al. (2021) predicted that parenting stress would be higher in Japanese parents due to the emphasis on maintaining harmony and the collectivist background. Further, Japanese parents engage less in the social aspect of parenting and have fewer parent-child interactions (Giannotti et al., 2021). Giannotti et al. (2021) found that parenting stress was higher in Japanese parents, specifically the distress subscale, which evaluated the extent to which parents feel competent, supported, and depressed in their role as parents. Further, Japanese parents showed fewer positive interactions with their children, which could be due to the perception that ASD symptoms are impacting the family's harmonious structure (Giannotti et al., 2021). Further, the social-cultural collectivist view may have increased perceived parental stress in Japanese parents (Giannotti et al., 2021). Giannotti et al. (2021)

suggest that individualist cultures, such as Italy, are more focused on promoting uniqueness and development, with a focus on personal characteristics rather than group expectations. Giannotti et al. (2021) suggest that these beliefs play a role in parenting stress, as ASD behaviour in collectivist cultures may be viewed as a disturbance rather than unique. Overall, this study supports the notion that parenting stress and outcomes are impacted by socio-cultural factors, as seen in the study by Cardon and Marshall (2021).

Rather than comparing two cultures in two separate geographical locations, Millau et al. (2019) sought to examine the quality of life of immigrant parents raising a child with ASD in the host culture. Millau et al. (2019) evaluated the quality of life of 29 immigrant families in comparison to 29 Canadian-born families while caring for a child with ASD. Parents completed a quality-of-life assessment that evaluated overall satisfaction regarding various aspects of family life (Millau et al., 2019). Millau et al. (2019) found no statistically significant differences in quality of life between immigrant and Canadian-born parents. These findings suggest that cultural differences did not impact caregiver mental health, which contrasts findings by other literature (Cardon & Marshall, 2021; Giannotti et al., 2021; Kim et al., 2020; Williams et al., 2019). However, Millau et al. (2019) found that Canadian parents reported higher family satisfaction levels compared to immigrant parents. Further, Canadian parents reported having greater access to social support compared to immigrant parents, which increases the risk of isolation within this group (Millau et al., 2019). These findings support the notion that there are cultural differences in coping and access to services, a theme also explored in other literature (Cardon & Marshall, 2021; Fisher et al., 2023; Giannotti et al., 2021). The only dimension in which immigrant parents reported higher levels of satisfaction was the parenting subscale, which related to parents caring for the needs of their children (Millau et al., 2019). Millau et al. (2019)

suggest that this is due to the proportion of immigrant mothers who were homemakers and able to spend more time with their children. This study also suggests cultural differences in parental quality of life, which align with findings by Giannotti et al. (2021) and Cardon and Marshall (2021), with the most significant differences observed in perceived social support.

In summary, the literature provides compelling evidence that there are cultural impacts on caregiver mental health in relation to raising a child with ASD. Cultural backgrounds significantly shape perceptions of ASD diagnoses, as highlighted by Cardon and Marshall (2021). Racial and ethnic differences also play a role in parenting stress. Kim et al. (2020) and Williams et al. (2019) found that African American caregivers reported higher stress levels than White or Hispanic caregivers. This disparity stems from systemic barriers, including provider bias, financial challenges, and reduced access to social support. Cultural contexts further influence parenting styles and stress levels, as demonstrated by Giannotti et al. (2021). Their study found that Japanese caregivers, influenced by collectivist values and the need to maintain harmony, reported higher stress and fewer positive parent-child interactions compared to Italian caregivers, who valued individualism and uniqueness.

In contrast, Millau et al. (2019) examined the quality of life among immigrant and Canadian-born caregivers, finding no significant overall differences in quality of life. However, immigrant caregivers reported lower social support, increasing their risk of isolation, while Canadian-born parents expressed higher satisfaction with family life. These findings collectively highlight the critical role of culture, systemic barriers, and social support in shaping the experiences of caregivers of children with ASD, with a common theme being differences in support and coping.

Access to External Support

Rivard et al. (2022) suggest that access to services, information, and formal caregiver training can serve as a protective factor against parental stress while raising a child with ASD. Furthermore, when external support is lacking, it can exacerbate pre-existing vulnerabilities, such as challenges posed by the child, social isolation, heightened risk of adjustment difficulties, and lower quality of life (Rivard et al., 2022). Smith-Young et al. (2020) found that caregivers reported higher stress about the delay of services and support compared to the symptomology of their child, highlighting the value of support while raising a child with ASD. However, both Rivard et al. (2022) and Smith-Young et al. (2020) suggest that although access to support can serve as a protective factor against caregiver mental health challenges, many caregivers report dissatisfaction with their services and increased caregiver stress in relation to the services provided. Nonetheless, findings from Rivard et al. (2022) and Smith-Young et al. (2020) highlight differences in caregiver mental health outcomes while accessing support for their children with ASD.

Zaidman-Zait et al. (2017) suggest that parents with ASD are faced with a unique set of circumstances and have increased parenting stress. To cope with stress, Zaidman-Zait et al. (2017) suggest that personal and social resources play a key role. Among parents raising a child with ASD, coping strategies have either reduced or heightened parenting stress depending on the strategy implemented (Zaidman-Zait et al., 2017). This corroborates findings by other literature that suggest caregivers are dissatisfied with services, increasing caregiver stress (Rivard et al., 2022; Smith-Young et al., 2020). Zaidman-Zait et al. (2017) suggest that personal and social resources have the potential to mitigate parenting stress; however, this is not always the case. Zaidman-Zait et al. (2017) had 283 Canadian mothers complete self-report questionnaires that assessed parenting stress, family functioning, parental social support, and parental coping strategies. Zaidman-Zait et al. (2017) sought to determine the role of personal and social resources on parenting stress while raising a child with ASD. Zaidman-Zait et al. (2017) found that mothers who reported insufficient personal and social resources also reported higher levels of parenting stress. However, mothers who employed active coping strategies, such as seeking external support, reported lower levels of parenting stress (Zaidman-Zait et al., 2017). This study also found that mothers who had social and family support reported less parenting stress compared to mothers with limited support.

Hayes et al. (2022) also examined the impact of external support and parent well-being. However, Hayes et al. (2022) focused on the impact that social and community support has on building family resilience, which ultimately affects parent mental health. Hayes et al. (2022) hypothesized that community support would positively correlate with caregiver mental health and family resilience behaviours. This study had 1,254 American parents of a child with ASD complete self-report questionnaires that evaluated perceptions of community support, family resilience, and overall caregiver mental health. Hayes et al. (2022) found that community support, caregiver mental health, and family resilience behaviours were significantly positively correlated. Most notably, Hayes et al. (2022) found that community support was a significant protective factor for caregiver mental health and that despite variations in caregiver mental health levels, higher levels of community support were associated with higher levels of resilience within the family. These findings replicate findings by Zaidman-Zait et al. (2017), who found that social and family support lowered maternal stress in mothers raising a child with ASD. Further, in terms of external support, social and family support appears to have the most substantial impact on caregiver mental health outcomes (Smith-Young et al., 2020; Zaidman-Zait et al., 2017).

Shepherd et al. (2018) aimed to investigate the effects of symptom severity, number of interventions used, and overall caregiver stress. Thus far, there has been evidence that supports the notion that increased external support leads to more favourable parent mental health outcomes. However, Shepherd et al. (2018) suggest that children who have more severe ASD symptoms require more intensive support; therefore, the more support needed, the greater the caregiver stress. Shepherd et al. (2018) had 184 New Zealand parents of children with ASD complete self-report questionnaires that assessed the helpfulness of interventions and caregiver stress. Shepherd et al. (2018) found that the perceived helpfulness of interventions was moderate; however, interventions that focused on social-emotional learning had higher levels of perceived helpfulness. Overall, Shepherd et al. (2018) found that the interventions buffered the impact of caregiver stress; however, this effect was only moderate. Shepherd et al. (2018) found a parental tendency to prefer in-home services; however, if these services stretched the capacity of the parents, it led to increased caregiver stress. These findings support the previous literature that suggests access to services can serve as a protective factor for caregiver mental health challenges; however, if the family is dissatisfied with the services, it can lead to increased caregiver stress (Rivard et al., 2022; Smith-Young et al., 2020). Furthermore, among all the interventions, those associated with advocacy and intervention-related activities had the most significant impact on reducing caregiver stress (Shepherd et al., 2018).

Catalano et al. (2018) also examined the relationship between external support and caregiver mental health outcomes. Using a critical interpretive synthesis, Catalano et al. (2018) examined 23 studies in which an intervention was delivered to one or both parents of the child and the outcome of these interventions on caregiver mental health. Catalano et al. (2018) found three main themes within the literature. The first is the importance of social support by other parents, the second is the effectiveness of training parents in stress management and problem-solving techniques, and the third is the importance of providing caregivers with relevant and accurate information about ASD and available resources (Catalano et al., 2018).

Catalano et al. (2018) found that the most effective factor that mitigated the mental health outcomes of parents was their network of other parents of children with ASD. These networks often reduced feelings of isolation, lowered stress levels, and provided a space to share and exchange resources. Furthermore, these networks led to increased parental confidence in coping with daily challenges (Catalano et al., 2018). These findings support a common theme in other literature, suggesting that social support has the most significant impact on caregiver mental health outcomes in relation to external support (Hayes et al., 2022; Smith-Young et al., 2020; Zaidman-Zait et al., 2017). Catalano et al. (2018) also found that parents who attended workshops focused on teaching stress management techniques and problem-solving skills experienced a positive effect on their mental health. Further, when parents received factual and accurate information about ASD, they reported a decrease in stress, anxiety, and depressive symptoms (Catalano et al., 2018). From these studies mentioned, caregiver-specific support rather than child-specific support appears to have more favorable outcomes on parents' mental health.

In summary, the current literature suggests that access to external supports does have an impact on caregiver mental health outcomes while raising a child with ASD. Rivard et al. (2022) and Smith-Young et al. (2020) highlight that access to services and caregiver training reduces stress, serving as a protective factor against caregiver mental health challenges. However, dissatisfaction with services and delays in receiving support often exacerbate stress, with caregivers reporting more distress from service-related issues than from their child's symptoms.

The role of community and social support is particularly emphasized by Hayes et al. (2022), who found that such support fosters family resilience and positively correlates with improved caregiver mental health. These findings align with Zaidman-Zait et al. (2017), who highlight the significance of social and family support in reducing stress, especially for mothers raising children with ASD. Shepherd et al. (2018) report that while interventions, particularly those focusing on social-emotional learning, moderately reduce caregiver stress, dissatisfaction or excessive demands from in-home services can increase stress, which corroborates findings from Rivard et al. (2022) and Smith-Young et al. (2020). Catalano et al. (2018) emphasize that social support networks with other parents of children with ASD are especially effective in reducing stress, fostering confidence, and alleviating feelings of isolation, highlighting the importance of social support in relation to access to external support. Collectively, these findings suggest that parent-specific support, such as peer networks and training, may have a more profound impact on caregiver well-being compared to child-focused interventions.

Summary of Findings

The current literature highlights the multifaceted factors impacting caregiver mental health outcomes while raising a child with ASD. While child-specific factors such as the severity of ASD symptoms and co-occurring conditions impact caregiver mental health, the effects are variable, with the majority of the studies not finding a significant impact between overall symptomology and caregiver mental health challenges. However, out of child-specific factors, communication, and social difficulties combined with emotional and behavioural challenges appear to have the most significant impact on caregiver mental health.

The current literature also suggests that caregiver-specific factors such as gender, SES, culture, and access to external supports also influence caregiver mental health outcomes while raising a child with ASD. While some studies suggest higher maternal caregiver stress, other studies suggest that this may be due to the overrepresentation of females in recent studies. However, the majority of the literature highlights that caregiver gender impacts the perception of ASD as well as coping with challenges posed by their child. Raising a child with ASD has a socioeconomic impact on caregivers, with increased financial burdens, work interruptions, and time constraints. The current research does suggest that higher SES may mitigate some of the challenges posed by raising a child with ASD; however, the findings did not present a significant effect. Cultural factors such as race and ethnicity also play into caregiver mental health outcomes while raising a child with ASD, with the current research suggesting that culture impacts perception, access to support, coping, and overall adjustment to an ASD diagnosis. Lastly, access to external supports is another critical factor influencing caregiver mental health outcomes while raising a child with ASD. Social support, caregiver training, and access to accurate information are shown to mitigate challenges posed by ASD, whereas dissatisfaction with services can exacerbate caregiver stress.

Overall, the current literature highlights that caregiver mental health outcomes while raising a child with ASD are a combination of child-specific and caregiver-specific outcomes such as the severity of ASD symptoms, co-occurring conditions with ASD, caregiver gender, caregiver SES, culture, and access to external supports. The purpose of this capstone was to demonstrate that caregivers raising a child with ASD face a wide range of challenges, resulting in variable mental health outcomes. Although previous literature has suggested that caregivers raising a child with autism are at increased risk of poor mental health outcomes, the explanation as to why remains variable. In this chapter, the variability of caregiver mental health outcomes was further demonstrated by evaluating specific child and caregiver factors. Overall, this chapter suggests that caregiver mental health outcomes while raising a child with ASD are not a simple cause-and-effect relationship; rather, an interconnected, complicated relationship between many different factors.

While viewing this literature from a family systems perspective, it is evident that family relationships have a highly influential nature on individual functioning. Furthermore, building upon the general systems theory that biological, psychological, and social factors are interrelated leads to variability in individual functioning. Family systems theory highlights the importance of family stability and healthy adaptation to stress or change. This chapter highlighted that raising a child with ASD changes many dynamics within the family, leading to increased financial, social, emotional, and individual challenges within the family. Further, differences in biological, psychological, and social factors impact caregivers' ability to adapt to the change that comes with raising a child with ASD.

Although this chapter supports the idea that caregiver mental health outcomes are variable while raising a child with ASD, there were many limitations to this research that will be discussed in detail in the next chapter. Keeping in mind the basic assumptions of family systems theory, chapter 3 will propose a new research study to create a caregiver mental health assessment tool that practitioners can use while working with this population that emphasizes the importance of using a wholistic approach to address caregiver mental health while raising a child with ASD. Lastly, chapter 3 will revisit this capstone's positionality statement and discuss any shifts, tensions, and continued professional development unfolding from the capstone process.

Chapter 3: Discussion and Applied Practices

The previous chapter explored research on the mental health challenges caregivers face while raising children with ASD. Both child-specific factors and caregiver-specific factors explored the complexity and variability in mental health outcomes of caregivers whose child has ASD. This chapter will discuss the purpose of this research, highlight its limitations, and propose a framework that may be of use to practitioners when working with this population. Lastly, a personal reflection will also be included in this chapter, highlighting any shifts, tensions, and continued professional development that emerge from the capstone process.

The purpose of this capstone project is to highlight how raising a child with ASD impacts the overall mental health of caregivers to develop a framework that practitioners can use while working with this population. Specifically, to address the research question: How do child-specific factors (severity of ASD symptoms, comorbid diagnoses) and caregiver-specific factors (gender, socioeconomic status, culture, access to external supports) contribute to variability in caregiver mental health outcomes? To do so, this capstone highlighted that these mental health challenges can either be heightened or hindered depending on child-specific and caregiver-specific factors.

To demonstrate the complex interconnectedness of these factors on caregiver mental health, this capstone assessed different themes found within the literature in detail. These themes were identified in chapter 2 and include the severity of ASD symptoms, comorbidities with ASD, caregiver gender, caregiver socioeconomic status, culture of the family, and levels of external support accessed by the caregivers. The purpose of identifying these various themes was to highlight discrepancies within the findings and propose a new research study to develop a caregiver mental health assessment tool that can be utilized by practitioners working with this population.

The first theme examined in chapter 2 is child-specific factors, which include the severity of ASD symptoms and comorbidities. The severity of ASD symptoms utilized the DSM-5-TR diagnostic criteria, which contains three levels of severity, with level 1 being "requiring substantial support" and level 3 being "requiring very substantial support" (APA, 2022). The severity of ASD symptomology is based on the core features of the disorder, which are social and communication difficulties and restrictive or repetitive behaviours (Waizbard-Bartov et al., 2023). The impact severity of ASD symptoms had on caregiver mental health was inconsistent, with some studies reporting a significant impact on caregiver mental health and others reporting only a moderate impact on caregiver mental health.

Gardiner and Iarocci (2015) examined how a child's ASD symptom severity impacts family quality of life, finding that daily living skills had the most significant effect, while communication skills did not. Bradshaw et al. (2021) explored how ASD severity affects caregiver strain, revealing that disruptive behaviors, rather than social and communication difficulties, were stronger predictors of poor caregiver mental health outcomes. Golya and McIntyre (2018) found that while ASD severity was moderately linked to caregiver depression, social skill impairments were a stronger predictor. Baykal et al. (2018) identified severe language and communication deficits as key contributors to caregiver burnout. Salomone et al. (2018) confirmed that emotional and behavioral difficulties had the most significant impact on caregiver mental health, while ASD severity alone was not a direct determinant.

Another theme analyzed under child-specific factors was comorbidities, which is the presence of another psychiatric disorder or other health-related challenges coupled with ASD

(Khachadourian et al., 2023). The current data suggests that comorbidities within ASD are common, with 75% of people with ASD diagnosed with at least one co-occurring medical condition (Khachadourian et al., 2023). Similarly to the severity of ASD symptoms, the impact of child comorbid conditions on caregiver mental health was variable. Some studies demonstrated that raising a child with both ASD and co-occurring conditions has only a minimal impact on caregiver mental health (Dovgan & Mazurek, 2019; Lanyi et al., 2022; Yorke et al., 2018). Other studies suggest that these co-occurring conditions have a moderate effect, although this may be influenced by the caregiver's gender (Liu et al., 2020; Martin et al., 2020). While some research highlights a significant impact, others find little to no effect.

Although the impact severity of ASD symptoms and comorbidities had on caregiver mental health outcomes was mixed, one reoccurring theme within the literature focused on child-specific factors was that caregiver mental health outcomes are multifaceted and cannot be reduced to a single factor. Further, 5 of the studies emphasized the influence of caregiver factors on mental health outcomes such as race, gender, socioeconomic status, and access to external support (Lanyi et al., 2022; Liu et al., 2020; Martin et al., 2020; Salomone et al., 2018; Waizbard-Bartov et al., 2023). Due to caregiver-specific factors being a common theme within the literature, it was essential to analyze each of these in more depth.

The first caregiver-specific factor analyzed in chapter 2 was caregiver gender. The literature consistently highlights that caregiver gender influences mental health outcomes when raising a child with ASD. Three studies suggest that mothers experience higher levels of stress than fathers due to their primary caregiving role and their sensitivity to the child's emotional and behavioral challenges (McStay & Trembath, 2014; Argumedes et al., 2018; Ang & Loh, 2019). Fathers, on the other hand, are more affected by factors such as family cohesion and their role as providers (Yaffe, 2023; Rafferty et al., 2020). However, some research challenged the assumption that mothers experience significantly more stress, finding no significant gender differences in overall stress levels but highlighting differences in how parents perceive and react to their child's ASD symptoms (Giannotti et al., 2023).

Additionally, research suggests that traditional gender roles persist, with mothers assuming more of the caregiving responsibilities, which may explain higher reported stress levels (Rafferty et al., 2020). However, the underrepresentation of fathers in research may skew findings, emphasizing the need for further studies exploring paternal experiences and stressors in ASD caregiving (Giannotti et al., 2023; Grebe et al., 2023). Another key theme across studies is that while gender plays a role in caregiver mental health, other factors, such as socioeconomic status, access to support, and co-parenting relationships also contribute to caregiver mental health outcomes. (Grebe et al., 2021; Enea & Rusu, 2020).

Socioeconomic status was another caregiver-specific factor analyzed in chapter 2. The research collectively underscores the significant but multifaceted role of socioeconomic status (SES) in caregiver mental health while raising a child with ASD. Higher financial stress, reduced access to essential services, and greater parenting strain, particularly for mothers, are associated with lower SES (Liao & Li, 2020; Pickard & Ingersoll, 2016; Zhou et al., 2019). Higher SES, on the other hand, is associated with improved mental health outcomes, greater access to resources, and increased parental involvement (Green et al., 2021; Yan et al., 2023). However, some studies argue that SES alone is not the strongest predictor of well-being, emphasizing that its effects depend on factors such as education, gender, child symptom severity, and cultural influences (Mathew et al., 2019; Yan et al., 2023).

A key difference among studies is whether SES independently predicts mental health outcomes. While Zhou et al. (2019) highlight that lower maternal education is a strong predictor of anxiety and depression, Mathew et al. (2019) argue that SES alone is not a determining factor but interacts with gender and other stressors. Cultural context also plays a role, as Yan et al. (2023) suggest that in China, work demands among lower SES parents further limit their involvement, exacerbating stress levels. Overall, while SES influences caregiver well-being, its impact is shaped by intersecting factors such as education, gender roles, and cultural expectations.

Chapter 2 also reviewed caregiver culture and its impact on caregiver mental health outcomes. The research discussed in chapter 2 highlights how cultural backgrounds shape caregiver experiences, stress levels, and coping strategies when raising a child with ASD. Cardon and Marshall (2021) emphasize that cultural perceptions of ASD impact diagnosis and treatment, with U.S. caregivers relying on medical professionals while Senegalese caregivers initially seek spiritual guidance. Williams et al. (2019) and Kim et al. (2020) reveal that African American caregivers experience higher stress levels than Euro-American caregivers due to systemic barriers, racial discrimination, and lower resilience. Fisher et al. (2023) further explain how racial biases and unequal access to care contribute to caregiver stress, underscoring the role of systemic disparities. Similarly, Giannotti et al. (2021) compare Japanese and Italian caregivers, showing that collectivist cultures, such as Japan, experience higher stress due to societal expectations and the need for harmony, whereas individualist cultures, like Italy, emphasize personal development.

In contrast, Millau et al. (2019) challenge the notion that cultural differences always impact caregiver mental health by finding no significant difference in quality of life between immigrant and Canadian-born parents raising a child with ASD. However, they note that Canadian-born parents report greater social support and family satisfaction, while immigrant parents feel more isolated but experience higher satisfaction in parenting itself. Overall, these studies highlight the crucial role of culture in shaping stress, coping mechanisms, and access to support services, reinforcing the need for culturally sensitive approaches in ASD caregiving.

The last caregiver-specific factor reviewed was access to external support. A common theme across the studies is that access to external support, whether in the form of services, social networks, or coping strategies, can serve as a protective factor against stress. However, dissatisfaction with services can lead to increased caregiver stress (Rivard et al., 2022; Smith-Young et al., 2020). Both Zaidman-Zait et al. (2017) and Hayes et al. (2022) highlight the role of social and community support in reducing stress and increasing resilience. In contrast, Shepherd et al. (2018) point out that more intensive services may sometimes increase caregiver stress, particularly when symptom severity is high. Catalano et al. (2018) further emphasize that parent networks and stress management training can be particularly effective in reducing mental health challenges. The studies differ in their focus, with some emphasizing the role of formal services (Shepherd et al., 2018; Rivard et al., 2022), while others highlight the importance of social and personal resources (Zaidman-Zait et al., 2017; Hayes et al., 2022; Catalano et al., 2018). While all studies agree that external support can be beneficial, they collectively suggest that the quality and type of support matter more than the mere presence of services. Social support networks and targeted interventions aimed at stress management appear to have the most consistent positive impact on caregiver well-being.

Chapter 2 explores child-specific and caregiver-specific factors influencing caregiver mental health when raising a child with ASD. Child-specific factors include ASD symptom severity and comorbidities, both of which show mixed effects on caregiver well-being. While some studies link severe ASD symptoms to increased caregiver stress, others find only moderate associations, with daily living challenges and disruptive behaviors being stronger predictors than communication deficits. Similarly, comorbidities are common among children with ASD, but their impact on caregiver mental health varies, influenced by factors like caregiver gender. Overall, the literature suggests that caregiver mental health is multifaceted and shaped by both child and caregiver factors.

Caregiver-specific factors examined include gender, socioeconomic status (SES), culture, and access to external support. Gender plays a significant role, with mothers often experiencing higher stress due to primary caregiving responsibilities, though some studies challenge this assumption. SES also affects caregiver well-being, with lower SES linked to financial strain and reduced access to resources, but education, cultural factors, and gender roles shape its influence. Cultural background impacts stress levels and coping strategies, with systemic barriers and societal expectations playing a role in caregiver experiences. Access to external support—whether formal services or social networks—acts as a protective factor, but the quality and type of support matter more than its mere availability. These findings highlight the complexity of caregiver mental health, emphasizing the need for a holistic approach that considers multiple interacting factors. While this capstone was able to highlight similarities in mental health outcomes amongst caregivers raising a child with ASD, these outcomes are variable. Therefore, the next section will discuss the limitations of the research in detail.

The findings of this capstone highlight important implications for counsellors and other professionals working with this population. While working with caregivers of ASD children, it is essential to consider that this population is at higher risk of developing mental health challenges.

Further, many child and caregiver-specific factors can heighten the risk for mental health challenges. This capstone highlights the importance of acknowledging these factors and supporting each caregiver in reflecting on how their child's ASD diagnosis has impacted their life. This information may also be helpful while delivering child-focused services. For example, many service providers focus on the child and their needs; however, it is also essential that service providers assess the caregiver's mental health. According to a family systems perspective, each member of the family has the potential to impact the entire family unit; therefore, addressing these broader family concerns would be beneficial not only to the caregiver but also to the child.

Limitations

This capstone encountered limitations within the research while examining how raising a child with ASD impacts caregiver mental health outcomes. These limitations include heavy use of self-report questionnaires, differences in conceptualizations of parent mental health, unequal representation of genders within the population, and lack of representation of lower socioeconomic status counties.

As outlined in chapter 1, the diagnosis of ASD continues to increase, putting more caregivers at risk of developing mental health challenges (Alibekova et al., 2022; Begum & Mamin, 2019; Maenner et al., 2023; Marquis et al., 2020; Nadeem et al., 2024; Papadopoulos, 2021; Scherer et al., 2019; WHO, 2023). In chapter 2, a variety of research studies highlighted the variability in caregiver mental health outcomes. In terms of child-specific factors, the research demonstrated variable results whether severity of symptoms and comorbidities had a significant impact on caregiver mental health outcomes (Baykal et al., 2018; Bradshaw et al., 2021; Dovgan & Mazurek, 2019; Gardiner & Iarocci, 2015; Goyla & McIntyre, 2018; Lanyi et al., 2022; Liu et al., 2020; Martin et al., 2020; Salomone et al., 2018; Yorke et al., 2018). Research that reviewed caregiver-specific factors demonstrated more conclusive evidence that factors such as caregiver gender, socioeconomic status, culture, and access to external supports have a significant impact on caregiver mental health outcomes (Catalano et al., 2018; Cardon & Marshall, 2021; Giannotti et al., 2021; Grebe et al., 2021; Hayes et al., 2022; Kim et al., 2020; McStay & Trembath, 2014; Pickard & Ingersoll, 2016; Williams et al., 2019; Yan et al., 2023; Zaidman-Zait et al., 2017; Zhou et al., 2019). However, other research that evaluated caregiver-specific factors found only minimal to moderate impact on caregiver mental health outcomes (Ang & Loh, 2019; Giannotti et al., 2023; Green et al., 2021; Liao & Li, 2020; Mathew et al., 2019; Millau et al., 2019; Shepherd et al., 2018). Although the majority of the research suggests that mental health issues are higher in caregivers raising a child with ASD, the explanation as to why remains variable. This posed a limitation when writing this capstone, as it was challenging to narrow down the topic to specific child and caregiver factors.

As seen in chapter 2, the majority of the research utilized self-report questionnaires, which pose many limitations. Out of the five studies that evaluated the severity of ASD symptoms, all of them relied on self-report data when evaluating caregiver mental health to draw their conclusions (Baykal et al., 2018; Bradshaw et al., 2021; Gardiner & Iarocci, 2015; Goyla & McIntyre, 2018; Salomone et al., 2018). Furthermore, all studies evaluating the impact of comorbidities on caregiver mental health relied on self-report data (Dovgan & Mazurek, 2019; Lanyi et al., 2022; Liu et al., 2020; Martin et al., 2020; Yorke et al., 2018). Some studies that evaluated child-specific factors used more than one self-report questionnaire to assess caregiver mental health, with specific assessments targeting specific domains of mental health. For example, studies by Baykal et al. (2018), Lanyi et al. (2022), Liu et al. (2020), Martin et al.

(2020), and Salomone et al. (2018) all used multiple self-report assessment tools when evaluating caregiver mental health. However, other studies that evaluated child-specific factors relied on one self-report questionnaire to assess caregiver mental health (Bradshaw et al., 2021; Dovgan & Mazurek, 2019; Goyla & McIntyre, 2018). In line with studies that reviewed child-specific factors, the majority of studies that reviewed caregiver-specific factors also relied heavily on self-report data. For example, all but one of the studies evaluating caregiver gender relied on self-report data (Ang & Loh, 2019; Argumedes et al., 2018; Giannotti et al., 2023; Grebe et al., 2021; McStay & Trembath, 2014; Yaffe, 2020). Only Rafferty et al. (2020) employed a phenomenological approach in assessing the impact of caregiver gender on mental health outcomes, which involved in-depth phone interviews broken down into themes. All the studies that evaluated the impact of SES on caregiver mental health outcomes utilized self-report data (Green et al., 2021; Liao & Li, 2020; Mathew et al., 2019; Pickard & Ingersoll, 2019; Yan et al., 2023; Zablotsky et al., 2014; Zhou et al., 2019). Although the studies evaluating the impact of culture on caregiver mental health contained more phenomenological data, such as the studies by Cardon and Marshall (2020) and Fisher et al. (2020), the majority of them utilized self-report questionnaires and data (Giannotti et al., 2021; Kim et al., 2020; Millau et al., 2019; Williams et al., 2019). Lastly, most studies that reviewed the impact of access to external supports on caregiver mental health also utilized self-report data (Catalano et al., 2018; Hayes et al., 2022; Rivard et al., 2022; Shepherd et al., 2019; Zaidman-Zait et al., 2017). Only Smith-Young et al. (2020) used phenomenological data collected through interviews and then coded into key themes. Although self-report questionnaires are cost and time-friendly, they cast a broad net over symptomology and typically do not display the whole picture (Zimmerman, 2024).

Zimmerman (2024) suggests that self-report questionnaires can provide a picture of what populations are at risk; however, researchers should conduct a semi-structured interview to gather a more in-depth and accurate picture. Out of the studies discussed in chapter 2, only research by Cardon and Marshall (2020), Fisher et al. (2020), Rafferty et al. (2020), and Smith-Young et al. (2020) mentioned the use of an interview. Research by Gardiner and Iarocci (2015) did mention the use of an interview; however, the interview collected data using self-report questionnaires.

Self-report questionnaires also increase the risk of different response biases. For example, social desirability bias, which occurs when individuals are more likely to select a response that aligns with their social norms rather than statements that reflect their true feelings, is common in self-report data (Tan et al., 2021). Tan et al. (2021) suggest that social desirability bias presents a risk to the validity of research, and findings may not reflect the intended phenomenon. Recall bias is another limitation of self-report questionnaires. Recall bias refers to the tendency for individuals to overestimate or underestimate their positive or negative past experiences (Colombo et al., 2020). Colombo et al. (2020) suggest that recall bias can impact mental health self-report questionnaires as individuals with both positive and negative recall bias tend to report poorer mental health outcomes. As most of the studies discussed in this paper utilized self-report assessment data, there may be more to the picture that a semi-structured interview could collect. However, the research on this topic was heavily influenced by self-report data, as it is time and cost-efficient and provides a snapshot of the issue at hand.

Another limitation of the current research is differences in conceptualizations of key terms such as caregiver mental health and socioeconomic status. For the purpose of this research, the definition of caregiver mental health was broad and included stress, anxiety, depression, burnout, and quality of life. Depending on the sociocultural context of the studies, there were different conceptualizations of the specific construct of caregiver mental health studied. For example, research by Gardiner and Iarroci (2015) evaluated caregiver quality of life, defined as "conditions where the family's needs are met, and family members enjoy their life together as a family, have the chance to do things that are important to them, and have a sense of well-being" (p. 199). Research by Lanyi et al. (2022) evaluated parent well-being, defined as "subjective well-being, including, but not limited to physical, and emotional health of parents, coping skills, quality of life, stress, and social support" (p. 152). Research by Martin et al. (2020) assessed maternal mental health by examining health-related quality of life and maternal stress. Other studies, such as research by Bradshaw et al. (2021), Giannotti et al. (2023), Liu et al. (2020), and Zhou et al. (2019) did not outline a clear definition of caregiver mental health; instead, the methods section contained the construct of caregiver mental health measured. For example, research by Zhou et al. (2019) evaluated emotional difficulties in mothers of autistic children by using the PHQ-9 and GAD-7; therefore, the evaluation of only depressive and anxious symptomology determined the emotional difficulties of mothers. In terms of specific themes, research that evaluated socioeconomic status also had variable conceptualizations of the construct. For instance, Pickard and Ingersoll (2016) only included caregiver education level, and parents with a higher education level were associated with a higher socioeconomic status. Other studies, such as Mathew et al. (2019), utilized a more in-depth definition of socioeconomic status, evaluating caregiver occupation, education level, as well as people's access to materials and social resources. Conceptualizations of socioeconomic status varied among the studies; however, all of them included the caregiver's education level. The different conceptualizations of concepts pose concerns with the overall validity of this research.

The validity of research is what determines whether and to what extent what is being measured is true to what the researcher desires to measure (Chetwynd, 2022). Chetwynd (2022) suggests that within the scope of a literature review, such as this capstone, it is the researcher's responsibility to provide enough information so that the validity of the study can be assessed. Specifically, for a literature review, researchers must ensure that they do not exceed the scope of what is stated or implied within the research. The purpose of this capstone was to provide an overview of how child-specific and caregiver-specific factors impact the overall mental health of caregivers raising a child with ASD. Although the research analyzed in this capstone presents different conceptualizations of constructs, all are relevant to the definition of caregiver mental health provided in chapter 1. However, to increase the validity of this capstone, a more in-depth and narrower conceptualization of mental health could be beneficial.

Another limitation of the current research is that the majority of studies occurred in developed countries above the poverty line. The current research included studies from the USA, China, Australia, Canada, Turkey, the United Kingdom, Japan, New Zealand, Singapore, Switzerland, Italy, and Senegal. Out of these countries, 12 are developed, while only one is considered developing. Viljeon et al. (2021) suggest that although the clinical characteristics of ASD present themselves the same in high-income versus low-income countries, the way caregivers identify and manage the challenges related to ASD are different; therefore, stress levels amongst caregivers may vary depending on the country. This capstone addressed this limitation by evaluating the culture of caregivers; however, more studies, including those from low-income countries, would need to be included for a more in-depth evaluation of culture on caregiver mental health outcomes. Interestingly, despite reviewing data from 12 different countries, all demonstrated that caregivers raising children with ASD have unique circumstances leading to variability in caregiver mental health outcomes.

A further limitation of this research was the unequal representation of diverse gender identities. In chapter 2, research by Ang and Loh (2019), Argumedes et al. (2018), Giannotti et al. (2023), Grebe et al. (2021), McStay and Trembath (2014) and Rafferty et al. (2020) examined the impact between caregiver gender and caregiver mental health outcomes while raising a child ASD; however, within these studies, male and other gender identities were underrepresented. Specifically, none of the studies within the theme of caregiver gender included other gender identities outside of male and female. While searching for studies that included other caregiver gender identities, there was very limited research available. Any mentions of gender diversity focused on the child with ASD, not the caregivers. Tornello (2020) suggests that for cisgender heterosexual couples, childcare is typically specialized based on gender, with females doing more of the childcare duties. Within the literature discussed in chapter 2, the majority of the findings support that caregiver gender does impact mental health outcomes; therefore, future research needs to evaluate caregiver mental health outcomes with gender-diverse caregivers raising a child with ASD.

The purpose of this capstone was to provide an overview of how child-specific and caregiver-specific factors impact caregiver mental health while raising a child with ASD. This research contained limitations, including heavy use of self-report questionnaires, a broad conceptualization of caregiver mental health, limited research including lower-income countries, and a lack of representation for gender-diverse caregivers. However, this capstone was able to highlight that caregiver mental health outcomes while raising a child with ASD are variable when considering different child-specific and caregiver-specific factors on a broad scale. Further, this capstone was able to suggest that caregiver-specific factors such as gender, culture, socioeconomic status, and access to support are greater predictors of poor mental health outcomes. Therefore, the next section will discuss why it is essential to create a framework that prioritizes caregiver mental health while delivering services to this population.

Applied Practices

Through the review of current literature, this capstone highlights that caregivers raising a child with ASD face unique challenges, putting this population at an increased risk of mental health challenges. Specifically, this capstone highlighted that child-specific factors and caregiver-specific factors lead to variability in caregiver mental health outcomes. Through the analysis of the literature, multiple themes emerged that impact caregiver mental health outcomes, such as severity of ASD symptoms, comorbidities, caregiver gender, SES, culture, and access to external support. The general findings suggest that although child-specific factors such as the severity of ASD symptoms and comorbid conditions impact caregiver mental health outcomes, there is more evidence to support that caregiver-specific factors such as gender, SES, culture, and access to external supports have a more significant impact on caregiver mental health outcomes. Despite the caregiver-specific literature demonstrating more conclusive evidence that these factors have a slightly greater impact on caregiver mental health outcomes, the results were variable. Overall, the literature demonstrated that caregiver mental health outcomes while raising a child with ASD are multifaceted. Given these variable findings, this capstone proposes a new research study that focuses on the lived experiences of this population rather than relying on self-report data to understand the complexity of this issue further.

Based on the current research and limitations, this capstone proposes conducting future research to determine more conclusive results in terms of what factors impact caregiver mental health outcomes while raising a child with ASD. Further, the purpose of this future research would be to propose a culturally inclusive assessment that delivers services to this population, supporting practitioners in identifying the specific factors caregivers view as having the greatest impact on their mental health. The remainder of this chapter will propose a research study to develop such an assessment.

Study Aims

The purpose of the proposed study is to draw more conclusive evidence in terms of what factors significantly influence the mental health outcomes of caregivers while raising a child with ASD with the hopes of creating an assessment tool that practitioners can use to individualize services within this population. As the majority of current research on this topic relies on self-report data, this study will focus on the lived experiences of this population through in-depth interviews. The interview questions will answer the overarching research question: The research question guiding this capstone is: How do child-specific factors (severity of ASD symptoms, comorbid diagnoses) and caregiver-specific factors (gender, socioeconomic status, culture, access to external supports) impact caregiver mental health outcomes? For the purpose of this study, caregiver mental health will continue to be defined as subjective well-being (e.g., life satisfaction, life meaning, loneliness), emotional health (e.g., anger, guilt), mental health (e.g., depression, anxiety), and physical health in relation to the roles involved in raising, supporting, and socializing children throughout their lives (Nomaguchi & Milkie, 2020).

Theoretical Orientation

The proposed study will continue to utilize a family systems framework, believing that family relationships have a highly influential nature on one another (Keller, 2020). Further, the proposed study will examine how the biological, psychological, and social parts of the family impact one another to influence caregiver mental health outcomes while raising a child with ASD (Kim-Appel & Appel, 2021). Specifically, how child-specific and caregiver-specific factors either alleviate or aggravate caregiver well-being.

Keller and Hall (2019) suggest that utilizing family systems theory in research provides an opportunity to analyze the complex interactions and interdependencies within the family unit that impact individual functioning. Further, family systems theory enables researchers to expand their understanding and knowledge of the various interconnected factors that influence both family and individual functioning (Keller & Hall, 2019). Another advantage of utilizing a family systems approach is that it enables the researcher to examine how stress and anxiety are transmitted between family members and how these emotions affect individual functioning (Keller & Hall, 2019). Given that the purpose of the proposed study is to examine how child-specific and caregiver-specific factors interact and impact caregiver mental health outcomes, family systems theory is an effective theoretical framework for gaining a greater understanding of this issue.

Methods

Sample Selection. The proposed study will recruit 20 caregivers who are currently receiving services for their child through disability support across Canada. In an effort to obtain a culturally diverse sample, this study will recruit caregivers from multiple provinces, diverse gender identities, and various cultural backgrounds. There will be no age limitation for the caregiver; however, the caregiver must be the primary caretaker of the child. The child must have a formal diagnosis of ASD according to the DSM-5-TR criteria. living with the caregiver, and be in between the ages of 3 and 18. The hope is that the sample will be representative and inclusive of this population, supporting the development of a caregiver assessment tool that practitioners can use while working with this population.

Procedure. Similar to the study by Smith-Young et al. (2022), the proposed study will employ a qualitative research design based on the grounded theory methodology. Grounded theory suggests that human behaviour and the roles individuals play are changed in the process of interactions over time (Smith-Young et al., 2022). Grounded theory builds on concepts where similar data is grouped, organized, and categorized based on the patterns within the data (Smith-Young et al., 2022). The purpose of utilizing a grounded theory methodology is to create a new caregiver assessment tool based on the similarities and differences within the data. Participants in this study will undergo an individual, semi-structured interview to ensure that responses from other participants do not skew their answers. The interview questions will be based on the findings from this capstone and will include questions on child-specific factors (severity of symptoms and comorbidities) and caregiver-specific factors (gender, socioeconomic status, culture, and access to external supports). This study will evaluate how these factors impact caregiver anxiety, depression, isolation, social stigma, social support, sleep, self-care, and caregiver capability in relation to raising a child with ASD. Some sample interview questions could be: "What is it like taking your child grocery shopping?" "How many nights a week do you feel unrested and have little to no energy?" "Describe the impact your child's diagnosis has had on your social relationships." "How did your family respond to your child's diagnosis?" "What behaviour does your child display that you find the most challenging?" Although this interview will be semi-structured, participants will be allowed to share any other factors impacting their mental health due to raising a child with ASD.

Data Analysis. The data from the interviews will undergo three stages of data analysis based on the grounded theory methodology. The first stage is open coding, where the interview transcripts are reviewed line by line to identify key phrases and concepts (Noble & Mitchell, 2016). In this stage, data between participants will be constantly compared for similarities. In the second stage, the data will undergo axial coding, where relationships are identified between categories and connections are established by the researchers (Noble & Mitchell, 2019). Lastly, the data will undergo selective coding, where core categories are identified and integrated (Noble & Mitchell, 2019).

Data Presentation. The proposed study recommends that the findings be presented in a narrative passage within an academic journal to share the results with other researchers, practitioners, and the general public. By employing a narrative approach, the researcher can present the data using direct quotes, which provide the reader with a deeper understanding of the participants' lived experiences (Creswell & Creswell, 2017). Furthermore, presenting the data through a narrative passage allows the researcher to highlight the social, cultural, and relational contexts that shape an individual's experiences (Creswell & Creswell, 2017). The narrative passage will also highlight the themes revealed within the data, as well as how these data can inform the development of a caregiver assessment tool that can be beneficial when working with this population.

This capstone suggests that conducting the proposed research study will lead to a better understanding of the complex issue of caregiver mental health while raising a child with ASD. The findings from this capstone suggest that caregiver mental health outcomes are variable, and there needs to be more concrete data to increase understanding and support this population. Using this data, researchers can create a caregiver mental health assessment that supports practitioners in understanding where the caregiver is currently at and highlights the areas they are struggling with. Using this assessment, the practitioner will be able to provide individualized caregiver support. Conducting a more in-depth research study to create a caregiver mental health assessment tool is one way that researchers and practitioners can start to reduce mental health challenges within this population.

According to the Canadian Code of Ethics for Psychologists [CPA] (2017), psychologists practicing in Canada have the duty to be sensitive to current issues and problems of society when determining which research questions to ask and which services to develop (Section IV. 20). This capstone highlighted that caregiver mental health while raising a child with ASD is a complex, multifaceted issue that needs to be addressed as the prevalence of ASD continues to rise. This capstone also highlights the many discrepancies in the current research, highlighting the need for future research to have more conclusive results when determining the impact raising a child with ASD has on caregiver mental health.

The CPA (2017) also states that psychologists need to be sensitive and knowledgeable about the cultural vulnerabilities to both groups and individuals when delivering services to maximize benefit and minimize harm (Section II. 14). This capstone highlights that caregivers raising a child with ASD have variable mental health outcomes considering the impact of culture, gender, socioeconomic status, and access to external supports. Therefore, it would be unethical to adopt a one-size-fits-all approach, as the current research suggests the need for a personalized approach. The development of a caregiver mental health assessment tool would provide psychologists and other professionals one way to adopt a more personalized approach and meet caregivers where they are.

Reflections on Personal Learning

Prior to this capstone project, the topic of caregiver mental health while raising a child with ASD was something that I was familiar with. In my role as a Behaviour Consultant with SHINE Beyond Limits, I work closely with this population and see the impact raising a child with ASD has on caregiver mental health. Due to my personal experiences, I had some knowledge of the complexity of caregiver mental health; however, this knowledge has increased because of the capstone project. Prior to this capstone, I would have thought that child-specific factors largely influenced caregiver mental health outcomes. Although this capstone did highlight that child-specific factors such as symptom severity and comorbidities impact caregiver mental health, I was surprised to find that it was not as significant as expected. I was also surprised by the significant impact that external support had on caregiver mental health. Specifically, the impact of social support for caregivers raising a child with ASD had more of a profound impact than expected. Most recently, a mother who I work with shared her experience raising a child with ASD. She mentioned that out of all the services offered, the opportunities to meet other parents facing similar challenges were the most impactful. This conversation enabled me to connect my personal experiences with the research findings of this capstone, reflecting on the importance of social support within this population.

While completing this capstone, my passion for caregiver mental health flourished in many ways. Ultimately, this capstone reaffirmed my passion for supporting parents as they navigate the many challenges that come with raising a child with ASD. Recently, I have also started to show interest in family therapy. This capstone allowed me to look at caregiver mental health through a family systems perspective, which was very beneficial. Upon completion of this capstone, I plan to continue my work as a Behaviour Consultant with SHINE. Further, I aim to further my professional development by completing courses and training in family systems therapy. I am hoping to expand my role at SHINE Beyond Limits by adding family therapy for families and siblings impacted by an ASD diagnosis.

The purpose of this capstone was to address the research question: How do child-specific factors (severity of ASD symptoms, comorbid diagnoses) and caregiver-specific factors (gender, socioeconomic status, culture, and access to external supports) contribute to variability in caregiver mental health outcomes? Chapter 1 provided an overview of the topic, highlighting that caregivers raising a child with ASD are at higher risk of developing mental health challenges compared to caregivers raising children without ASD (CITE). Chapter 2 highlighted the clinical characteristics of ASD according to the DSM-5-TR criteria and evaluated how child-specific factors impact overall caregiver mental health outcomes. Further, chapter 2 evaluated the impact caregiver-specific factors had on caregiver mental health outcomes while raising a child with ASD. Chapter 2 concluded with evidence that both child and caregiver-specific factors impact caregiver mental health outcomes; however, the degree of impact remains variable. Chapter 3 provided an overall discussion regarding the findings from chapter 2 and highlighted some key limitations that impacted this capstone's findings. Chapter 3 also proposed a new research study to address these limitations and highlighted the development of a caregiver mental health assessment tool that can be used when working with this population. Overall, this capstone suggests that both child-specific and caregiver-specific factors can either increase or decrease mental health challenges within caregivers raising a child with ASD. However, further research is needed to yield more conclusive and consistent results.

This capstone, combined with further research, will highlight caregiver mental health challenges while raising a child with ASD. However, it also raises other issues, such as a lack of services or barriers to receiving mental health support amongst this population. There has also been a rise in discussions around ASD and its impact on family dynamics. Most notably, United States Health and Human Services Secretary Robert F. Kennedy Jr stated that "autism destroys families, and more importantly, it destroys our greatest resource, which is our children" (Braun-Silva, 2025). Many caregivers of individuals with ASD have reacted to RFK Jr's comments, sharing that these comments are disheartening and harmful to any parent of an autistic child, with one parent commenting, "Unless you are the parent of a child with autism, you cannot begin to imagine what this journey is like" (Braun-Silva, 2025). Comments like those made by RFK continue to perpetuate harmful stereotypes about autistic individuals and their impact on families. Board chair at Autism Speaks, Tom Frazier, suggests that research should focus on the needs of autistic individuals and their families (Braun-Silva, 2025). Similar to thoughts by Tom Frazier, this capstone suggests that resources and research may be better suited to evaluate barriers in providing accessible and beneficial support for caregivers raising children with ASD.

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