

**The Lived Experiences of Parents Who Have Children Diagnosed with Autism Spectrum  
Disorder (ASD)**

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## **Abstract**

This study examines the lived experience of parents who have a child diagnosed with autism spectrum disorder (ASD). The rise in the number of children diagnosed with ASD means that more parents may be adversely affected. This study chose a descriptive phenomenological design to study the phenomena around the lived experiences of these parents. This study recruited ten Canadian participants. Inclusion criteria for being selected were that the participant needed to be over the age of eighteen and the child needed to have a formal diagnosis of ASD by a health care professional. The researcher collected data through a semi-structured interview, in which participants were audio recorded. The data were processed through the software NVivo to generate transcripts. Four themes emerged from the data: participants felt a lack of support from informal and formal supports; grief over their child's diagnosis; the stigma around the diagnosis; and poor mental health. This study is important as it can aid clinicians, social workers, and other health professionals to better support parents who have children with ASD, as the research provides deeper insight into the lived experience of parents who have children diagnosed with ASD.

## **The Lived Experiences of Parents Who Have Children Diagnosed with Autism Spectrum Disorder**

The literature on autism spectrum disorder (ASD) is quite dense with knowledge as the current understanding around the disorder is becoming more and more heavily researched. While the focus of the literature is on the individual with ASD, there are gaps in the literature surrounding the experience of parents of a child with ASD. When looking at the issue systemically, it is likely that the parents are affected by their child's diagnosis, as they are the child's main support. It is essential to add knowledge regarding the effects of ASD on parents as this research can support clinicians and health professionals and possibly improve pre-existing programs or create other programs that can better support these parents. The purpose of this study is to bridge the gap in the research that surrounds parental perceptions of their child's ASD diagnosis by examining their lived experience.

ASD is classified as a neurodevelopmental disorder according to the *Diagnostic and Statistical Manual for Mental Disorders*, 5th edition (DSM-5; American Psychiatric Association, 2013). The DSM-5 helps clinicians specify symptoms and diagnose ASD. ASD's usual onset is early, often before the child enters grade school (APA, 2013). Previously, in the DSM-IV, if an individual met the criteria for pervasive developmental disorder - not otherwise specified (PPD-NOS); Rett syndrome; childhood disintegrative disorder; and autism and Asperger's disorder, they would be considered to be diagnosed with ASD (APA, 2013). The diagnostic criterion are now updated in the DSM-V, in which the following symptoms categorize a diagnosis: deficits in social understanding and communication and restricted, repetitive patterns of behaviours (APA, 2013). For deficits in social understanding and social interaction, all three of the following symptoms need to be present: deficits in non-verbal behaviours used for social communication; deficits in social-emotional reciprocity; deficits in developing and maintaining appropriate social

relationships with others (APA, 2013). Lastly, two of the following symptoms need to be present for restricted, repetitive patterns of behaviour: repetitive speech, motor movements, or use of objects; excessive adherence to routines or patterns of verbal or non-verbal behaviour, highly restricted, fixated interests that are abnormal in focus, and hyper or hypo reactivity to sensory input to sensory aspects of the environment (APA, 2013).

There is also a strong chance for a neurodevelopmental disorder such as ASD to be co-morbid with other mental health diagnoses, such as attention-deficit/hyperactivity disorder (ADHD), which can amplify the complexity of the diagnosis (APA, 2013; Panagiotidi et al., 2019). Autism is diagnosable if the clinical presentation includes deficits and delays in achieving result in interference with daily function (APA, 2013; Ornoy et al., 2016). Symptoms of excess behaviours can include repetitive actions such as stimming, hand-flapping, or rocking back and forth (APA, 2013). ASD affects a child's social interactions, communication, and behaviours (APA, 2013). Presentations of ASD symptoms vary in either gender, which is essential to consider alongside an ASD diagnosis (Mandy & Tchanturia, 2015). In addition, individuals with ASD are more prone to anxiety, depression, somatic complaints, aggression, and rule-breaking behaviour than neurotypical peers. These adverse behaviours can impact the experience parents have regarding their child's diagnosis (McRae et al., 2018; Shah, 2019).

ASD is rising steadily globally, as one in 59 children will be diagnosed with ASD (Baio et al., 2018). Currently, males are more likely to be diagnosed with ASD than females, one in 42 versus one in 189, respectively (McFayden et al., 2019; Townsend & Puymbroeck, 2017). However, there is a chance that the ratio between male and female ASD diagnoses may be closer to 1:1, as females are underdiagnosed with ASD (Baio, 2018). Discrepancies behind the lower diagnosis rate for females include a greater risk of clinicians overlooking ASD symptoms in

females. When eventually diagnosed, females begin receiving treatment later than their male counterparts (Bargiela et al., 2016).

Each diagnosis of ASD is unique, as it has a varying clinical profile among its patients (Courchesne et al., 2019). In the scientific literature, researchers have found that ASD is a multifactorial disorder that has roots in both biological and environmental factors (Ornoy et al., 2016; Oron & Elliot, 2017; Genovese & Butler, 2016). There is an established heterogenous genetic etiology for ASD, meaning that this clinical disorder can be caused by several factors rather than a homogenous genetic origin (Courchesne et al., 2019; Butlan et al., 2018). These factors can include genetic, neurological, and immunological which can be impacted by environmental influences (Diaz-Beltran et al., 2016; Genovese & Butler, 2016). These environmental influences may trigger physiological changes in genetically susceptible individuals, potentially causing the ASD diagnosis (Diaz-Beltran et al., 2016; Genovese & Butler, 2016). The genetic architecture is complex, with common and rare inherited genes, and new genetic variants that contribute to the ASD etiology (Genovese & Butler, 2016). Through research, it has been identified that ASD has origins in multiple casual factors (Courchesne et al., 2019; Oron & Elliott, 2017). However, no specific mode of transmission or cohesive model of causation has been firmly identified for the ASD diagnosis (Genovese & Butler, 2016). The complexity around the etiology of the ASD diagnosis is evident, which can prove difficult for parents that are inquiring if this means that diagnosis is heritable for them specifically, or not. Currently, clinical genetic evaluations can identify the cause of ASD in 30%-40% of cases, however there needs to be further research in the specific identification of a genetic etiology (Schaefer, 2016).

For parents who have received a new diagnosis of ASD for their child, navigating extensive information about the disorder can be overwhelming. The amount of research available on ASD is a positive aspect; however, the literature on parental experience is limited. The following literature review will explore mental health and stress, identity ambiguity, stigma, supports, grief, coping mechanisms, and dive into the different components of the parental experience of ASD.

### **Literature Review**

In the 1950s and 1960s, the child's mother was blamed if the child displayed autistic behaviours (Glazzard & Overall, 2012). Leo Kanner, the first individual to coin the term "autism," proposed that since children with ASD did not attach themselves to their mothers, the mothers were cold-hearted individuals (Hanley, 2013; Kanner, 1943).

It was thought that the child's attachment to the mother was in jeopardy, or the child was experiencing neglect as a direct result of bad parenting, leading to the diagnosis (Glazzard & Overall, 2012; Hanley, 2013). As parenting a child could be considered a transactional association, a child who does not offer communication or affection towards the parent can shape the interaction to appear "cold" (Crowell et al., 2019). During Kanner's time, Freud's psychoanalytic theory was a frontrunner in conceptualizing, treating, and diagnosing atypical behaviours (Hanley, 2013). This may have shaped how Kanner conceptualized this diagnosis, as Freud's psychoanalytic theory focused heavily on attachment between child and parent (Crowell et al., 2019; Hanley, 2013). In the 1970s, this theory was debunked by researcher Bernard Rimland, who found that autism had a neurobiological component and was not solely based on parenting (Glazzard & Overall, 2012; Hanley, 2013). Rimland himself had a child with ASD,

which led him to the pursuit of debunking the “bad parenting” myth (Hanley, 2013). At the time of the completion of this paper, there is no sole cause of ASD, and this may likely leave parents feeling that they are without answers. The lack of answers around this diagnosis may have an impact on parents in a variety of ways, such as their mental health, stress, and feelings of grief.

## **Impact of ASD on Parents**

### **Mental Health and Stress**

The impact on mental health and parenting a child with ASD primarily focuses on the relationship between stress and the child’s behaviour (Barroso et al., 2018; Keenan et al., 2016; Schiltz et al., 2018). Parenting stress can be defined as the “aversive psychological reaction to the demands of being a parent” (Schiltz et al., 2018, p. 1169). Parenting stress can be attributed to various aspects of family life, marital relationship, psychosocial well-being, and overall finances (Iadarola, 2018; Ilias et al., 2019). The onset of parenting stress could be due to cognitive dissonance between the perception of the parenting demands and support they intend to receive versus their reality, or perhaps the different domain that the diagnosis affects, such as the rise in financial cost (Iadarola, 2018; Schiltz et al., 2018). However, as parents experience stress, there is a strong likelihood of stress proliferation, which is defined as the “tendency for stressors to create additional stressors” that have an impact on parents’ mental health (Benson & Karlof, 2009, p. 350; Schiltz et al., 2018).

For example, chronic stress due to their child’s condition may cause feelings of depression, anxiety, perceived lack of confidence in their parenting skills, and thoughts of grief (Iadarola, 2018; Ilias et al., 2019; Rutgers et al., 2007). Stress can also negatively affect child attachment, as the parents are less able to be consistently sensitive and responsive to their

child's needs (Keenan et al., 2016). Parents can experience feelings of anger due to their child's behaviour that amplifies both stress proliferation and their personal mental health symptoms (Benson & Karlof, 2009). Stress proliferation may be resolved or mitigated by accessing formal or informal social support (Benson & Karlof, 2009).

Barroso et al. (2018) conducted a meta-analysis to study the relationship between parenting stress and child behavioural problems, hypothesizing that parents who have children who are at risk for behaviour problems, such as ASD or developmental delays, have a higher rate of parenting stress. The researchers' meta-analysis examined 133 studies and found that there is a higher level of parenting stress when the child demonstrates externalizing behaviour (e.g., hitting, kicking, punching) in comparison to internalizing behaviours. (e.g., irritability, not speaking, withdrawing). It is important to note that the authors' exclusion criteria tried to focus solely on the children's behaviour, thus ruling out studies that had prior mental health diagnoses, drug use, intimate partner violence, substance abuse, neglect, and child maltreatment within its participants, which may have made the results more specific to the behaviour rather than other variables in the study (Barroso et al., 2018). However, the authors did not specify differences between mothers and fathers in the sample or results section, which leads the reader to infer that high parenting stress in relation to their child's behaviours is common among both parents.

Parents of children with disabilities may also experience isolation, fatigue, depression, and elevated stress levels (Baptista et al., 2019; Lyons, 2019). Specifically, parents with children who have ASD report higher levels of parenting stress and higher frequency of affective disorders in comparison to parents who have children with other disabilities such as Down syndrome (Lyons et al., 2019; Su et al., 2018). Parents of children with ASD are more likely to have anxiety, as well as exhibit other mental health concerns such as feeling inept at taking care

of their child since they are expected to not only advocate but also to choose and navigate the best resources for their child, usually with limited information or knowledge (Keenan et al., 2016; Taylor & Warren, 2012).

Other researchers have found that the presence of anxiety or depression is based on susceptibility of individual traits from parents and not solely on the child's diagnosis (Kuusikko-Gauffin et al., 2013; Su et al., 2018; Uljarevic et al., 2016). In a study by Taylor and Warren (2012) that examined the depressive symptoms that follow an ASD diagnosis, out of 75 participants, 78.7% experienced clinically significant depressive symptoms following the result of an ASD diagnosis. These results were related to both the financial barriers associated with the diagnosis and the child's behaviour problems. However, within this study, 91% of the participants were mothers (Taylor & Warren, 2012).

It is evident that the ASD diagnosis has a strong correlation to poor parental mental health in a variety of ways, including stress proliferation depressive symptoms as a result of their child's behaviours related to the diagnosis, and cognitive dissonance around their perceptions and reality of parenthood (Baptista et al., 2019; Lyons, 2019; Keenan et al., 2016; Taylor & Warren, 2012).

## **Stigma**

Goffman (1963) defined stigma as an "attribute that is deeply discrediting" and reduces the individual "from a whole and usual person to a tainted, discounted one" (p. 3). Essentially, stigma is a form of social control, wherein an individual is perceived to have traits that are outside socially accepted, normative expectations (Bottema-Beutel et al., 2018; Goffman, 1963; Milacic-Vildojevic et al., 2012). Parents and siblings experience a phenomenon known as

“courtesy stigma” or associative stigma, because they are connected to a stigmatized group, such as people with ASD (Farrugia, 2009; Kinnear et al., 2016). It is proposed that parents struggle between wanting to detach from yet also to accept the stigma that is associated with their child’s diagnosis (Farrugia, 2009; Kinnear et al., 2015; Papadopoulos et al., 2019). The genetic factors that play into neurodevelopmental or other psychological disorders may fuel associative stigma, as it is assumed that the diagnosis lies within the family lineage (Koschade & Lynd-Stevenson, 2011; Thibodeau & Finley, 2017). Although there has been a shift from a psychoanalytic to a genetic or cognitive explanation, many of the associated stereotypes still linger (Farrugia, 2009; Kinnear et al., 2015; Kinnear et al., 2016). Currently the literature around associative stigma is based on qualitative studies conducted primarily through interviews with those who have experienced this phenomenon. While insightful, this body of literature would benefit from complementary quantitative data (Koschade & Lynd-Stevenson, 2011; Link & Phelan, 2001; Link & Phelan, 2006; Thibodeau & Finley, 2017).

## **Grief**

The two most common reactions to the challenges of parenting a child with ASD is grief and distress, especially in instances of a life-long diagnosis such as ASD (Gitterman & Knight, 2019; Wayment & Brookshire, 2018). The type of grief that may be experienced by a parent with a child diagnosed with ASD is called ambiguous loss, also known as chronic sorrow (Boss, 2010; Brown, 2016). The ASD diagnosis can trigger feelings of resentment, guilt, hopelessness, anxiety, depression, anger, or other intense emotional and psychological reactions, perhaps due to the lack of clarity around the cause of the disorder (Brown, 2016; Gitterman & Knight, 2019; O’Brien, 2007; Wayment & Brookshire, 2018). Upon receiving the diagnosis from health care professionals, some parents are usually considered to be “grief-stricken,” which is considered the

beginning of the grief process (Wayment & Brookshire, 2018). However, it is important to note that this does not occur for all parents in this journey, as some parents are prepared for an ASD diagnosis at this point of the process. For parents who do experience grief, ambiguous loss differs from normative grief as the individual they are mourning is still physically present, if not psychologically, which complicates the grief process (Boss, 2010; Brown, 2016). In this initial grief stage, it is proposed that mothers take on a tragedy discourse, which includes dismissal, confirmation, or a non-static position about the diagnosis (Brown, 2016). The tragedy discourse implies that the parent is active in their world but is attuned to the fluctuations of the feelings of grief around the diagnosis (Broberg, 2011; Brown, 2016). As parents moves past this stage, they next experience chronic sorrow, either at intervals or steadily throughout the child's lifespan (Brown, 2016; Wayment & Brookshire, 2018).

### **Identity Ambiguity**

The inability of the parents to separate themselves from their child's diagnosis is known as identity ambiguity (Boss, 1999; Wayment & Brookshire, 2018). Identity ambiguity is more prominent in mothers than fathers because mothers tend to be the primary caregiver, and some choose to stay at home, which makes taking care of the home and their children a full-time job (Wayment & Brookshire, 2018). The amount of time spent with the child could cause more identification with the child, as one is spending more time and becoming more enmeshed (Brown, 2016). In O'Brien's (2007) qualitative study, higher levels of identity ambiguity were correlated with higher levels of depressive symptoms and perceived stress in 63 mothers.

There is a call for more research around the relationship between ambiguous loss and identity ambiguity for parents who have children with ASD. Further insight into the topic could aid parents and other health professionals to navigate these complex feelings.

## **Support**

Social support is the emotional, informational, physical, and instrumental assistance that an individual takes from their social, professional, or personal networks (Lu et al., 2015; Ming-Hui et al., 2018). Support can be categorized into formal and informal (Boyd, 2002; Yulina et al., 2019). Informal support has been defined as assistance from one's social network, including assistance from friends and family members using methods such as perceived (e.g., giving advice or reassurance to parents) or instrumental (e.g., providing financial assistance, cooking meals for families) (Ming-Hui et al., 2018; Yulina et al., 2019). Formal support is from organizations and government, such as psychologists and educators (Boyd 2002; Clifford & Minnes, 2013). There may be barriers that parents face when thinking about accessing either formal or informal support. Barriers could include internalized stigmas, such as feeling as though they are a burden to their loved ones, they are not adequate caregivers to their child, or dealing with associative stigma from their child's diagnosis (Kinnear et al., 2015; Ming-Hui et al., 2018). In addition, parents are less likely to access natural community support if they have a child with ASD, as they may worry or feel apprehensive about their child's development in comparison to others (Moody et al., 2019).

Although these barriers exist, it is important for parents to access support, as it is a strong predictor for adjustment, overall happiness, lower levels of depressive symptoms, and optimism

towards their child's diagnosis (Al-Kandari et al., 2017; Benson & Karlof, 2009; Boyd, 2002; Lida et al., 2018).

### **Coping Mechanisms**

A common theme surrounding stress and parenting a child with autism is coping mechanisms. Coping mechanisms are a protective factor that help parents manage their emotions and behaviours around their child's diagnosis (Lai & Oei, 2014; Lyons et al., 2010). Parents can cope with stress with three types of coping mechanisms: task-oriented or problem-focused coping, emotion-oriented coping, and avoidance-oriented coping (Lai & Oei, 2014; Lyons et al., 2010; Vernhet et al., 2019). Task-oriented coping involves putting strategies in place to help minimize a problem's effects (Folkman & Lazarus, 1980; Lyons et al., 2010). Examples of this include finding community resources to help their child or seeking out information about their child's diagnosis to gain more insight into what steps are needed moving forward. Emotion-oriented coping involves seeking support to help parents manage their feelings, such as positive reframing around their child's diagnosis (Lyons et al., 2010; Shepherd et al., 2018; Vernhet et al., 2019). Lastly, avoidance-oriented coping is when parents avoid stressful situations by not engaging with others to help reduce stress around their situation, which is found more likely with parents who have a child with ASD (Lyons et al., 2010; Obeid & Daou, 2015). Examples of avoidance-oriented coping strategies that parents use to compensate for a lack of support is to exclude themselves from social situations, peer groups, religious/faith institutions, or communities so they can minimize the potential for associative stigma (Glazzard & Overall, 2012; Obeid & Daou, 2015; Vernhet et al., 2019). It is important to note that both the style and the amount of coping styles used are subject to change over time (Shepherd et al., 2018; Vernhet et al., 2019).

There are many factors that pertain to the lived experience of parents who have children diagnosed with ASD. These include poor parental mental health and stress, support, grief, and coping mechanisms. As the prevalence of children being diagnosed with ASD grows, the number of parents being affected grows as well, calling for more research into specific areas of literature surrounding this demographic in order to gain further insight. This study has shone a light on this area of research as it provides to mental health professionals a deeper insight into the lived experience of parents who have children diagnosed with ASD.

## **Methodology**

### **Role of the Researcher**

Prior to beginning this research, I worked with the autism population for several years, including performing roles as a behaviour therapist, private respite aide, and behaviour interventionist across various Canadian agencies. Throughout my time in these positions, I worked predominately with children who had been given this diagnosis. However, it is impossible to work with a child alone as there must be some degree of interaction with their parents or family. I was not only working alongside the child and watching their struggles, but their parents' struggles as well. I recognized the enormous difficulty of raising a child with ASD, as it was a full-time job within itself, between time needed learning in-home therapy, attending and scheduling doctors' appointments, and dealing with schools and other community involvement. As I watched and listened to parents in these roles, when the opportunity arose to select a topic for my Master's thesis, I decided to examine the lived experience of parents who have children diagnosed with ASD.

As this research design is phenomenological, the terms “reduction” and “epoche” are essential to this study. Reduction is the phenomenological term that describes bracketing (epoche), which helps the researcher gain a primary understanding of the phenomena without self-imposed bias (Given, 2008). Reduction also refers to understanding the topic’s consciousness instead of how we understand a topic based on our previous knowledge (Archer-Kuhn, 2018). When researchers bracket our preconceptions around participants’ lived experience, we experience meaning (Given, 2008). Epoche, derived from German philosopher Edmund Husserl’s work, guides researchers to engage and suspend our assumptions on the interpretations of the perceptions, as well as the experiences of others (Butler, 2016). If we do not suspend our pre-conceived notions and examine only the research, we find ourselves making false conclusions based on what data have been gathered, a situation called pseudodoxia (Butler, 2016). Both phenomenology concepts help uncover the lived experience that honours the authentic participants’ narrative within the research.

My bias was evident due to my empathy for these parents. I have seen examples of parents who work full-time, time-consuming, and stressful careers, come home and take on more tasks trying to manage their children’s behaviours. These behaviours may have included dealing with aggression, tantrums, navigating activities of daily living, and food or sensory sensitivities. Although my empathy was present while completing the interviews, I would let my participant complete their stories. For example, when participants spoke on sensitive topics, such as mental health or painful changes they needed to make in their lives, I would let them speak until they were done. The interviews with participants were an opportunity for them to narrate their stories with my questions as prompts. This interview style allowed both the participant and me to stay on the content of the research.

Throughout the process, I felt immersed in the participants' stories. I made sure to honour their time and complete only one interview per day. Giving myself the boundary of engaging with only one narrative per day gave me time to immerse myself in the narrative they chose to share with me. That boundary allowed me to suspend the previous data that I was involved in from earlier participants and remain as objective as possible. As a phenomenological researcher's primary role is to find an intersection between Husserl's intentions of this approach and my authentic self as a researcher, I needed to remain faithful to my character as an individual and a qualitative researcher (Butler, 2016).

### **Qualitative Design**

I selected a qualitative design for this research study due to its approach to inquiry (Creswell & Poth, 2018). It was essential to choose a design that focused on the participant's voices based on the nature of the research questions (Creswell & Poth, 2018). Historically, phenomenology was a major movement in thought in Europe during the 20th century (Given, 2008). The phenomenological approach is to study a "phenomenon," which allows researchers to further understand a topic (Groenewald, 2018). The approach studies a phenomenon and reduces participant experiences of the phenomenon to an essence that captures the nature of the phenomenon (Creswell & Poth, 2018). The researcher collects data from participants who have experienced this phenomenon and who describe what they experienced and how they experienced it, revealing the experience's essence (Moustakas, 1994). Fundamentally, the topic should create wonder (Creswell, 2013). When one begins to think about the topic from various angles, one can start the process of embarking on phenomenological research, as wonder and philosophy are at the core of this style of study (Creswell & Poth, 2018).

There are four major philosophical perspectives in phenomenology that researchers need to keep in mind while conducting and synthesizing this qualitative data. The first is returning to the philosophical approaches of research, which allows researchers to continue searching for data beyond empirical means (Butler-Kisber, 2010). The second is embracing epoche, the suspension of pre-suppositions of what is real, until we can find it on a more concrete basis (Stewart & Mickunas, 1990). Epoche essentially refers to researchers' ability to bracket themselves from the data they are immersed in (Creswell & Poth, 2018). The ability of researchers to bracket themselves allows for a stronger phenomenological study, as it allows for the phenomena to be interpreted solely of itself, without the researchers' pre-conceived notions (Creswell & Poth, 2018). Third, researchers need to remember that the intentionality of consciousness has a dual Cartesian nature (Creswell & Poth, 2018). Dual Cartesian nature refers to a phenomenon possibly having two perspectives, neither correct nor incorrect (Stewart & Mickunas, 1990). Finally, we address the meaning of the experience, which is based solely on the individual (Stewart & Mickunas, 1990).

### **Research Tradition**

German mathematician and philosopher Edmund Husserl was a pioneer of phenomenological research. His descriptive phenomenology is important to the current study as it is concerned with the lived experience, universal essences, and discovering insights based on those experiences and essences (Archer-Kuhn, 2018). The descriptive phenomenological approach allows both the participant and the researcher to be submerged in the research, which can be potentially transforming (Finlay, 2011). It allows the participants to have a voice and be heard, without the researcher imposing their own framework or experiences onto the data

(Finlay, 2011). This research design aims to capture the shared and personal meanings of that phenomenon, which can be so fundamental to how others view the research.

It can also create more profound and insightful understanding of the lived experience without being subjected to the phenomenon (Finlay, 2011). Another aspect of descriptive phenomenology is that it can uncover the truth of the participants' everyday life experiencing the phenomenon, which adds more in-depth insight into the experience (Archer-Kuhn, 2018). The goal is to engage and value the participants' individual experiences and thus challenge them to reflect on the events' impact and significance (Michalchuk & Martin, 2019). Engaging allows the researcher to examine personal experience accounts and isolate themes through transcripts or other data collection methods (Sloan & Bowe, 2014). It is important to note that German philosopher Martin Heidegger argued that all descriptions from the phenomenological approach could be interpretative (Adams & Van Manen, 2008).

From the methodological end, the researcher needs to collect data, interpret that data, and then report findings from that data (Sloan & Bowe, 2014). The findings that come out of this data are phenomena, specifically lived experiences of the participants who were involved in the research (Sloan & Bowe, 2014). From the researcher's point of view, it is important that both epoche and reduction be utilized to gather results that are authentic to the participants' narratives and remain authentic to descriptive phenomenology (Archer-Kuhn, 2018). The researcher needs to suspend prior pre-conceived notions and refrain from bringing in knowledge not provided by the data to help interpret the phenomenon (Giorgi, 2012). Suspending pre-conceived notions requires the researcher to focus entirely on what is stated by the participants about the phenomena, which, in this study, is the lived experience of parents having a child diagnosed with ASD (Giorgi, 2012).

The data will be analyzed through focusing on what having a child with ASD is like and the parents' direct experiences (Michalchuk & Martin, 2019). Four stages were used to help organize the data. In stage one, the interviews were transcribed and re-read, paying special attention to any observations, significant moments, or reflections that seemed to be of importance. In stage two, the transcripts were re-read and specific quotes, phrases, and segments were extracted that related to the phenomenon. This is the stage in which emergent themes and general impressions were gathered. Stage three involved clustering of the similar themes and examining emergent themes and content areas (language). Content analysis helps researchers determine the character of the data by focusing on the finer details, such as the "who says what, to whom, and with what effect" (Vaismoradi, Turunen, & Bondas, 2013, p. 400). With content analysis the phenomenon is described in a descriptive manner, allowing for more richness in fully understanding the phenomena, coupled with the thematic findings (Graneheim & Lundman, 2004). Thematic analysis involves finding common threads around the data gathered among the set of interviews (Vaismoradi, Turunen, & Bondas, 2013). Thematic analysis helps researchers categorize these common threads, helping to organize data for better interpretation (Graneheim & Lundman, 2004; Vaismoradi, Turunen & Bondas, 2013). While content analysis focuses on the finer details, thematic analysis provides researchers a nuanced account of the data collected (Braun & Clark, 2006; Vaismoradi, Turunen, & Bondas, 2013). The goal in both content and thematic analysis is to examine the central phenomena of the study through participants' narratives (Vaismoradi, Turunen, & Bondas, 2013). Both levels of analysis provide more in-depth analysis for the researcher, which adds to the depth of findings generated by a qualitative phenomenological study (Vaismoradi, Turunen, & Bondas, 2013). Lastly, in stage four, the data were depicted in a table that highlight the major themes, as well as the content extracted from the

participants in this study (Michalchuk & Martin, 2019). A table is utilized to help readers understand the data and the interpretations. Major themes are displayed in the left column, and the right column presents direct quotes from the participants in the study. All four stages were done alongside the transcript to ensure that time was taken to check meanings to distinguish between what the participants told the interviewer and the themes that were generated out of it (Michalchuk & Martin, 2019). In addition, adequate time was taken between transcripts to ensure that each participant's data were being reviewed closely.

The intention behind using the phenomenological design was due to the study's nature: the lived experience of parents who have children diagnosed with ASD. The purpose of qualitative phenomenological analysis is to highlight similar patterns that emerged from the participants' story.

### **Recruitment and Selection of Participants**

Participants referred themselves to the study from an online flyer posted to ASD agencies across Canada through various online platforms. These online platforms included Facebook, other social media outlets (Instagram, Twitter), agency websites, and newsletters. Participants were encouraged to reach out to the researcher if they wanted to participate in the study.

Participants must have met two inclusion criteria: if their child had a formal diagnosis of ASD and if the participant was over the age of eighteen. The children with ASD could be biological, fostered, or adopted and the current guardian was involved throughout the diagnostic process. Ten participants were involved in this study, nine self-identified as a mother and one self-identified as a father. There were no pre-existing relationships between the researcher and

any of the participants. The following table depicts each participant involved in the study and a brief description.

Table 1

*Participant Description*

Participant Assigned Letter	Brief Description
Participant A	Middle aged mother (36-55 years old). Had one child. Child is in grade one and was diagnosed with ASD in kindergarten. Participant was currently a stay-at-home mother. Biological parent.
Participant B	Middle aged mother (36-55 years old). Had two children. Youngest diagnosed with ASD. Divorced and works a full-time job. Biological parent.
Participant C	Later adulthood (55+ years old). Had one child with ASD and was a single mother. Biological parent.
Participant D	Identified as mother and was in later adulthood (55+ years). Had three children, two of whom were diagnosed with ASD. Was married and was currently a stay-at-home mother. Biological parent.
Participant E	Did not disclose age. Identified as a mother and had two children, one with ASD. Recently divorced. Biological parent. Worked in the field of ASD after her child's diagnosis.
Participant F	Identified as a mother. Had two children. One is diagnosed with ASD. Biological parent.
Participant G	Identified as a mother. Had two children, one diagnosed with ASD and one child currently being assessed for ASD. Is a stay-at-home mother. Biological parent.
Participant H	Did not disclose age. Identified as a single mother and had two children, one with ASD. Biological parent.
Participant I	Middle aged (36-55 years old), identified as a mother. Had three children, one with ASD. Stay-at-home mother. Biological parent.
Participant J	Middle aged (36-55 years old), identified as a father. Had one child on the spectrum and one neurotypical. Biological parent.

## Ethics

Ethics approval was obtained by the International Review Board (IRB) through City University of Seattle. The researcher notified the participants of their right to stop the audio recording during the interview or withdraw from the study at any time. Participants had the option to look over their transcripts from the interviews in order to provide them with an opportunity to redact any portion of the transcript.

Participants were aware of the risks and benefits of the study. The most probable cause of risk or harm could come from possible distress of discussing themes around ambiguous loss or grief surrounding their child's diagnosis. Any other potential risks and benefits were outlined thoroughly in the informed consent process and explained verbally to the participant. If a participant experienced distress or challenges in the interview, the researcher asked them mid-interview how they were doing. If the participant continued to be distressed, the interview would be terminated and the researcher would withdraw the participant from the study. If this occurred, no data gathered from the participant would be used in the study.

Benefits of the interviews for families and parents were that they could learn from this study's recommendations or perhaps gain a deeper understanding of the journey they had undergone. All participants were given a pseudonym throughout the interview that both parties agreed upon before beginning the audio recording. The pseudonym was to ensure confidentiality. The researcher redacted all identifying information such as agencies used, children's names, and school names in the transcription record. All the transcriptions went through the primary researcher, so there were no outside transcribers with access to the data. Data will be retained for five years.

## Data Collection and Analysis

The researcher obtained responses through a semi-structured interview. Participants were encouraged to share their stories but used the questions as prompts to help guide their narrative. Only one participant was interviewed per day to allow the researcher to immerse herself in the participant's data. The limit of one interview per day also permitted the researcher to spend time with the data, allowing bracketing to occur. The intention behind ensuring adequate time between interviews was to allow the researcher to submerge herself into the participant's narrative to gain a deeper understanding of their lived experience.

In terms of confidentiality, participants were informed that the researcher as well as her supervisor, Dr. Heather Macdonald, were the only two individuals to have access to the data. The interviews were audio-recorded and then transcribed on the data analysis software, NVivo. The data were stored on a 32-GB USB flash drive. In addition, a password-protected encrypted Dell laptop with no Internet access was utilized for the research. No data were stored on the laptop. The USB, digital recorder, and laptop were kept in a locked filing cabinet in a personal office at the researcher's residence.

The process was as follows to gather more evidence around the phenomena of the lived experience of a parent who has a child diagnosed with ASD.

1. Interviews were recorded and then uploaded into the NVivo software. In this step, the researcher processed the data to gain immersion into the participants' subjective experience.

2. Transcripts were coded and specific themes that emerged in multiple transcripts were extracted. In this step, all identifying information from the participants was taken off the record.
3. These themes and content areas were coded into NVivo, allowing the researcher to have a specific quote from the transcript.
4. Data were re-read to make sure that no new themes nor content areas emerged. Then these codes were used as themes and content in the data analysis.

The following table highlights the rationale behind the questions listed in the semi-structured interview.

Table 2

*Semi-Structured Interview Questions*

Question	Rationale
Do you identify as a mother or father?	The purpose of this question was to highlight the role in the family system that the participant played, whether it be a mother or father. This question opened the floor up to the following questions.
How many other children do you have?	This question came in two parts, as it allowed the researcher to seek out more information about the family system. Since the study was based on the child who has ASD, it was helpful to see who else was in the system.
Any other children with disabilities?	This could potentially highlight the different dynamics that they faced.
What has been your experience as a parent who has a child with ASD?	This was intended to see what a snapshot of the participant's narrative would look like. This question set the tone for the remaining questions asked.

Question	Rationale
What were your initial feelings when you realized your child has ASD?	This question gauged how their feelings around how the diagnosis had affected them, their family, and their overall life moving forward.
What are some of the positives of having a child with this diagnosis that you have experienced?	This question was chosen to reveal some of the positive experiences of having a child with an ASD diagnosis, because much of the current literature focuses on the negatives.
What has surprised you about yourself as a parent through this journey?	This question highlighted the surprises that the parent experienced throughout their journey. This could be related to parenting, community resources, or anything that they felt was relevant to share.
What are some of the negative experiences of having a child with ASD?	This question helped elicit gaps or flaws in the community support or resources that these participants experienced. In addition, this question highlighted any stressors of having a child with ASD they had experienced.
Have you felt supported as a parent throughout the process?	This question further expanded on the previous question, and streamlined the questioning to aspects outside their child that they did not view as beneficial.
What has been your experience with accessing support or resources?	The purpose of this question was to learn how funding, respite, community groups, etc. helped or hindered the participant in their journey.
What is something you would have done differently in your journey as a parent with a child with ASD?	This question sought information around parts of their journey that they realized either too late, or information they felt was vital for new parents with children with ASD should know.

## Results

The researcher followed the descriptive phenomenological method to help interpret the findings from the data. The study's findings are in both the thematic and the content areas of the data analysis and as are follows:

## Thematic Results

There were four emergent themes in the participant interviews. These included lack of supports, grief, stigma, and poor parental mental health. These four themes help uncover the study's central phenomenon.

### Lack of Supports

Participants were asked to expand on their experience with accessing support or resources in their journey of having a child with ASD. With the data collected, support networks were separated into two categories. First, personal support, such as the participant's family and friends, and second, community or resource support (agencies, government funding, support groups). Participant I stated "The support that you do get is tough to maintain. You feel like you're always up against a strong force. Example FSCD, constantly fighting, with education, too, you're fighting with. There's absolutely barely any support here"

Participants stated the following with regard to their experience with community or resource supports:

I find it's very difficult and stressful and hard to receive support and services to help your kid. Not only help your kid, but as a parent, you need support too. And there's no support for you whatsoever. I feel like there was none. You have to fight tooth and nail to get anything. Just being honest. (Participant C)

I mean, the school wasn't great. We've had some. I mean, he's been through a variety of educational experiences, but some schools have been great and others just kind of sucked. And they just carried a lot of stress and a lot of frustration to the situation that was

already pretty rough. So that wasn't helpful. You know, sometimes the hospital just wasn't helpful. (Participant H).

These participants had experienced struggle in receiving and maintaining community supports in their journey. Participants spoke to community agencies such as government funding (FSCD), schools, and hospitals. As for personal supports, participants stated the following: "We haven't had adequate support throughout his life. Yeah, just a big old challenge. We lived in constant crisis for a number of years." (Participant F). "He was 14, 15, when he started transitioning into his group home. But before that, I had him besides school. I had him 24/7. I had no other help." (Participant E)

The lack of personal support at some time in their journey as parents of children with ASD was evident by the recounts of both participants. Overall, the findings from participant interviews indicate a lack of support in both personal and community/resources. As recalled by participants, the lack of support made having a child with this diagnosis a difficult and stressful experience.

## **Grief**

Grief will be the second theme that will be discussed. In this context, grief refers to sadness the participant has felt due to having a child diagnosed with ASD. Eight participants spoke to grief in many aspects of the semi-structured interview process. The following questions asked by the researcher sparked discussion around feelings of grief from participants.

1. What has been your experience as a parent who has a child with ASD?
2. What were your initial feelings when you realized your child has ASD?

3. Have you felt supported as a parent throughout the process?

Participant C stated “And I think that was the initial [shock] and then sad, right. Because you know that it’s not going to be an easy thing to be fixed” in relation to her feelings around the diagnosis. Participant B stated “They’ll be with you for your life. Those kinds of things. So it’s depressing. But it’s still pretty tough. Those things are hard. And, you know, it’s doesn’t get better.” Participant I mentioned that she saw herself going through the stages of grief, as indicated by the following:

And then given when I was with my ex-husband at the time, and it was kind of funny because I was given at that point the five stages of grieving. And I recognized myself going through them. But then, my ex-husband was always a couple of steps behind me. But I didn’t realize that you didn’t just go through them once. It was like different points of his life where he should have been a milestone to develop into this or be doing that or be doing that. You kind of go through all this grieving process again.

Well, I was sad. Of course, I was depressed because you told you all the goals and the dreams you have for your kid. You’re kind of like, oh, I might have to put that behind me now because, basically, what the doctors tell you is really like, OK, your kid may never talk. Your kid may never graduate from school. Or be successful or whatever the case may be (Participant F)

Participants spoke to a wide variety of aspects that triggered grief feelings for them. These included the diagnosis itself, comparing their child with neurotypical milestones, and readjusting expectations they had for their child, such as the ability to talk or graduate school.

Refer to Table 3 for more specific information on grief thematic data. These feelings of grief were experienced at different intervals throughout their journey as parents with ASD.

## **Stigma**

Stigma emerged as a theme in the data. Stigma refers to perceived feelings of discrimination by others due to having a child with ASD. Participants stated the following with regard to experiencing stigma:

Another negative would be public discrimination. When you're out with your kid, you get looks, and you get stares. I have people tell me on the airplane, for example, if my kid were stimming there, people would turn around and be like, can you shut him up? So a lot of that would be negative. Just people, in general, are just some people who are just miserable. And that was indeed a huge negative for me. It's been really stressful on my marriage, on our social life. We barely had a social life. No, we don't. We only have a small circle of people who know us. (Participant D)

You know, my child has done or said something odd or, you know, just doing something that is not in line with the other children. And they just don't understand it. And then they think it's, you know, related to parenting. (Participant A)

Participant D spoke to how being out in the community or trying to interact with those outside their inner family unit created traumatic experiences of associative stigma, which made them avoid certain situations as a way to cope. Stigma extended into how the participant was parenting as well. Participant A experienced associative stigma in relation to her parenting, due

to others' lack of understanding around having a child with an ASD diagnosis. Both participants recounted experiencing associative stigma as a result of being a parent with a child with ASD.

### **Poor Parental Mental Health**

Poor parental mental health is the final emergent theme pulled from the data that will be discussed. Poor mental health refers to the deficient physical, emotional, and spiritual well-being of the parent. Participants stated the following with regard to experiencing poor parental mental health:

I really think that would have been a top thing I would have done, just got help for myself. You can't get that much support from your spouse, like, they have their issues. And my spouse especially needs support, but he denies that he needs it. So, I think no one would be for me to get help. (Participant D)

Participant J said "I think we have more stress and play with depression and a little bit more in our lives than a lot of other people."

### **Content Results**

In this section content (language) results will be discussed. The following four content areas emerged in the data: knowledge, frustration, patience, and trying. These content areas added to the depth of data extracted from participant interviews.

#### **Knowledge and Frustration**

Participants described "not knowing" and trying to find more knowledge around the diagnosis. This was due to their not feeling that they had enough information on a variety of

topics. This wording extended to not fully understanding the diagnosis or understanding how to navigate the services offered to them. Participants stated the following: “This overwhelmed sense of not knowing what to do next.” “I didn’t know. No, I didn’t know anything.” “No, I didn’t know anything about autism.” “Too much information. I don’t know what to do for him.”

Feelings of frustration surfaced as another content area. Frustration could be linked to feelings of not knowing a variety of information during their journey, or simply towards different situations that they experienced, indicated by the following participant quotes: “Stress and a lot of frustration to the situation.” “It was really rough. Probably frustrated.” “And then just the general frustration and emotional distress.”

### **Patience and Trying**

Patience was another content result, as the participants felt that they either developed or exercised patience throughout their journey. Participants said that they learned patience from their child in a variety of aspects of life. The phenomena of parents having a complicated experience was evident, as participants described their efforts to navigate a complicated system. Participants spoke to this content area in great detail when asked “what has surprised you about yourself as a parent throughout this journey” by the researcher. The following are direct quotes from participant content data: “Probably my patience. Yeah, I’m pretty frickin’ patient if I need to be. Yeah. Tolerance. Patience and probably my ability to adapt.” “And I think he taught me a lot in patience and stop and listen and pay attention to the individual.” “My patience. I’m very patient. I’ve learned to just be more patient with anything and everything.”

Trying was another content area that appeared in the results as participants noted the extent of their effort during their journey of having a child with ASD. They tried to bridge the

gap of knowledge around the diagnosis itself, contributing to the patience they exercised. This is highlighted by the following quotes: "...a period where I did try different things." "I was on a computer trying to learn what I could." "...jumped on the bandwagon and tried all this crap." "We, I mean, we have tried to educate ourselves on what supports are out there and try to make use of them." "It was very troubling trying to navigate a system."

Refer to Table 3 (thematic data) and Table 4 (language/content data) for additional information on the exact wording gathered from the participants.

Table 3

*Thematic Data*

Theme	Data
Lack of support	<p>"I find it's very difficult and stressful and hard to receive support and services to help your kid. Not only help your kid, but as a parent, you need support too. And there's no support for you whatsoever. I feel like there was. There is none. You have to fight tooth and nail to get anything. Just being honest."</p> <p>"The support that you do get is tough to maintain. You feel like you're always up against a strong force. Example FSCD, constantly fighting, with education, too, you're fighting with. There's absolutely barely any support here."</p> <p>"We haven't had adequate support throughout his life. Yeah, just a big old challenge. We lived in constant crisis for a number of years."</p> <p>"He was 14, 15, when he started transitioning into his group home. But before that, I had him besides school. I had him 24/7. I had no other help."</p> <p>"I mean, the school wasn't great. We've had some. I mean, he's been through a variety of educational experiences, but some schools have been great and others just kind of sucked. And they just carried a lot of stress and a lot of frustration to the situation that was already pretty rough. So that wasn't helpful. You know, sometimes the hospital just wasn't helpful."</p>

Theme	Data
Grief	<p>“And then given when I was with my ex-husband at the time, and it was kind of funny because I was given at that point the five stages of grieving. And I recognized myself going through them. But then, my ex-husband was always a couple of steps behind me. But I didn’t realize that you didn’t just go through them once. It was like different points of his life where he should have been a milestone to develop into this or be doing that or be doing that. You kind of go through all this grieving process again.”</p> <p>“And I think that was the initial [shock] and then sad, right. Because you know that it’s not going to be an easy thing to be fixed.”</p> <p>“Well, I was sad. Of course, I was depressed because you told you all the goals and the dreams you have for your kid. You’re kind of like, oh, I might have to put that behind me now because, basically, what the doctors tell you is really like, OK, your kid may never talk. Your kid may never graduate from school. Or be successful or whatever the case may be.</p> <p>They’ll be with you for your life. Those kinds of things. So it’s depressing. But it’s still pretty tough. Those things are hard. And, you know, it’s doesn’t get better.”</p> <p>“Everything was just really hard, getting him to do things was really hard; getting him to start things was really hard, getting him to end things.</p> <p>That’s really hard. Life was just really, really hard. And by the time he was relatively young, he was having pretty significant physical outbursts. I mean, he’d have to restrain him. So that wasn’t delightful.”</p>
Poor parental mental health	<p>“I really think that would have been a top thing I would have done, is just got help for myself. You can’t get that much support from your spouse, like they have their own issues. And my spouse, especially he needs support, but he denies that he needs it”</p> <p>“I think we have more stress and play with depression and a little bit more in our lives than a lot of other people.”</p> <p>“You know, my child has done or said something odd or, you know, just doing something that is not in line with the other children. And they just don’t understand it. And then they think it’s, you know, related to parenting.”</p>

Theme	Data
Stigma	<p data-bbox="451 275 1435 380">“We couldn’t go ‘cause, you know, go to people’s houses. We couldn’t have company over. We couldn’t go to events or things like that. But lots of things that my kids could not do.”</p> <p data-bbox="451 401 1435 548">“Probably not so much anymore, but when he was younger. A lot of people, like a lot of dirty looks. ‘Discipline your kid.’ ‘Do something with your kid,’ that kind of thing. People not understanding him or giving him an opportunity to explain himself. That’s really frustrating still.”</p> <p data-bbox="451 569 1435 716">“And usually it’s to do with social situations, you know, where, you know, my child has done or said something odd or, you know, just doing something that is not in line with the other children. And they just don’t understand it. And then they think it’s, you know, related to parenting.”</p> <p data-bbox="451 737 1435 1022">“Another negative would be public discrimination. When you’re out with your kid, you get looks, and you get stares. I have people tell me on the airplane, for example, if my kid would be stimming there, people would turn around and be like, can you shut him up? So, a lot of that would be negative. Just people, in general, are just some people are just miserable. And that was indeed a huge negative for me. It’s been really stressful on my marriage, on our social life. We barely had a social life. No, we don’t. We only have a small circle of people who know us.”</p>

Table 4

*Content (Language) Data*

Content (Language)	Data
Patience	<p data-bbox="488 1404 1421 1478">“Probably my patience. Yeah, I’m pretty frickin’ patient if I need to be. Yeah. Tolerance. Patience and probably my ability to adapt.”</p> <p data-bbox="488 1499 1421 1572">“And I think he taught me a lot in patience and stop and listen and pay attention to the individual.”</p> <p data-bbox="488 1593 1421 1650">“My patience. I’m very patient. I’ve learned to just be more patient with anything and everything.”</p>

Knowledge	<p>“I didn’t know. No, I didn’t know anything.” “No, I didn’t know anything about autism.”</p> <p>“Too much information. I don’t know what to do for him.”</p> <p>“How do you know? I didn’t exactly sign up for this.”</p> <p>“Was it guilt? You know, I feel guilty.”</p> <p>“I don’t understand; you don’t usually know.” “Something’s different. I don’t know what’s going on.” “I didn’t know at that time.”</p> <p>“Honestly, I didn’t know much about it.”</p> <p>“Well, I don’t know that we really get funding or anything for him.”</p> <p>“This overwhelmed sense of not knowing what to do next.”</p> <p>“I did not know how I let this bad.”</p> <p>“Sometimes demoralizing for parents for not knowing if you’re doing something wrong.”</p> <p>“...and called so many places knowing nothing was going to happen.”</p> <p>“Because they’re not interested in knowing what it is [diagnosis of ASD].”</p>
Frustration	<p>“And then you’ll feel frustration or anger.” “...really difficult. It was very frustrating.” “It was really rough. Probably frustrated.” “I find it frustrating.”</p> <p>“And then just the general frustration and emotional distress.”</p> <p>“Stress and a lot of frustration to the situation.”</p>
Trying	<p>“...a period where I did try different things.”</p> <p>“I was on a computer trying to learn what I could.” “...jumped on the bandwagon and tried all this crap.”</p> <p>“We, I mean, we have tried to educate ourselves on what supports are out there and try to make use of them.”</p> <p>“It was very troubling trying to navigate a system.”</p> <p>“It was not the same as you trying to accept it.” “...and it wasn’t for the lack of trying.”</p> <p>“...between trying to accept it and trying to find the therapy.”</p>

## Discussion

This study examined the lived experiences of parents who have children diagnosed with ASD. The research surrounding the experience of parents with children diagnosed with ASD

highlights the variety of factors, such as the interplay between genetics and environment, support, grief, and parenting stress. In this semi-structured interview, the findings included prominent themes such as lack of support (personal or community/resources), grief, stigma, and poor parental mental health.

This study found that the essence of the phenomena around the lived experience of parents who have a child with ASD is a complicated experience that involves both grief and trauma. Participants across the board had a complicated experience involving feelings relating to the grieving process, which had elevated their levels for both depressive and stress symptoms around their new conception of their child's identity (Brown, 2016; Gitterman & Knight, 2019; O'Brien, 2007; Wayment & Brookshire, 2018). Participants experienced higher levels of depressive and stress levels (Boss, 1999; O'Brien, 2007; Wayment & Brookshire, 2018). This could be due to the parent becoming attached with their child's diagnosis, which could be displayed as hyper-focusing on the diagnosis itself through the following: extensive researching about the diagnosis itself and potential causes of the diagnosis and finding different supports/medications to help alleviate symptoms or behaviours of the diagnosis.

Stigma was another theme that emerged in the research. Participants felt the effects of associative stigma due to their child's diagnosis (Farrugia, 2009; Kinnear et al., 2015). The associative stigma affected the way some participants viewed their parenting, which may be due to the etiology of "parent blaming" that is rooted in the history of ASD, or perhaps due to perceived covert stigma that participants experienced (Hanley, 2013; Koschade & Lynd-Stevenson, 2011; Phelan, 2005; Thibodeau & Finley, 2017). It is also possible that parents' heightened perceptions of stigma are due to struggling between accepting their child's diagnosis and rejecting their new social identity as a parent with a child with ASD (Kinnear et al., 2015;

Papadopoulos et al., 2019). It is possible that experiencing stigma over the course of years can create new trauma, such as social rejection, causing parents to adjust or create new coping strategies.

Finally, poor parental mental health was a theme that is important to the understanding of the entire study as well as the essence behind the phenomenon. Participants noted feelings of stress proliferation as a result of parenting their child that included associative stigma, the lack of knowledge around support and resources, and confidence in their parenting ability (Iadarola, 2018; Ilias et al., 2019; Rutgers et al., 2007). As parenting stress increases, depressive and anxious symptoms also increase, affecting how consistently responsive the parent can be to their child, which was found in a participant in this study (Benson & Karlof, 2009). The results around poor parental mental health are consistent with the topical literature review, as participants did report increased depressive symptoms as a result of their experience. It is unknown if this is a result of participants' susceptibility for depressive symptoms or poor mental health, or if it is a direct result of dealing with the child's behaviour. In addition, as this study was conducted during the COVID-19 pandemic, participants may have experienced poor mental health as a result of the sudden onset of full-time caregiving, a lack of support (such as respite or in-home behavioural aides) due to the lockdown, and increased anxiety over financial status such as a layoff from their job.

As parents are navigating a new territory in their lives, social support allows for better adjustment post-diagnosis; however, participants in this study did not recall positives around accessing formal or informal support (Al-Kandari et al., 2017; Lyons et al., 2010; Tan et al., 2017). Participants recalled instances when they had attempted problem-oriented coping strategies, such as accessing funding for their child, but this was a difficult process for them to

navigate. Consistent with the literature, participants practiced avoidance-oriented coping due to having little to no positive experience with seeking out these support venues.

New findings related to parental feelings such as patience, frustration, and trying emerged in this study. These findings provided more profound insight into the themes generated from the study. It gave the researcher a more raw understanding of the emotions that these participants felt during their journey, adding to the depth of analysis of all data generated from this study.

### **Clinical Implications**

Moving forward, clinicians who work with children who have ASD need to consider the stressors that the client families may be experiencing. As evidenced by the data, there are many factors to consider when aiding a parent who has a child with ASD. These can include high levels of stress, dealing with associative stigma, complicated feelings around grief, and navigating their own trauma (Boss, 2010; Brown, 2016). This study highlighted the multi-faceted experiences of parents, experiences which necessitate more compassionate care from clinicians and other health care professionals. Such care includes supporting parents' mental and psychological health by encouraging them to access the informal and formal support available to them, as positive relationships are associated with better emotional adjustment (Lai & Oei, 2014; Lyons et al., 2019). Health professionals who are involved in the diagnostic process are encouraged to take the time to aid parents along their journey through more extensive psychoeducation about the ASD diagnosis and walking them through what to expect from their child's behaviour. Finally, health professionals are encouraged to keep up to date on the literature concerning the parental experience of adjusting to an ASD diagnosis for their child, as it can provide further insight to areas where special attention may be needed.

## **Future Recommendations**

The population of parents who have a child with an ASD diagnosis is rising in our society (Baio et al., 2018). Supporting parents by creating process groups for unpacking the feelings and feeling supported in a safe community is vital, as it can allow parents to speak openly in a community where they are understood. Groups such as these will help support those parents with pre-existing mental health conditions or those whose mental health is affected by their child. Support can address parenting stress, stress proliferation, financial concerns, overall psychosocial support, and simply relating to those who have similar experiences (Iadarola, 2017; Ilias et al., 2019). Creating a safe community for parents can potentially help alleviate the stigma that parents face around their child's diagnosis. Aspects that are taboo, such as guilt or feeling incompetent as parents, can be processed in a support group with individuals who have experienced similar events. In addition, parents who lack a network of personal support can meet other individuals through the group themselves, thereby helping other parents feel better supported and less isolated.

The last recommendation is to continue adding to the research around parents who have children diagnosed with ASD, especially in areas of grief. This study revealed that the lived experience of parents who have children diagnosed with ASD is a complicated experience of grief and trauma, so it is vital that more current research be conducted to give parents better insight into these feelings. Specific areas where current research would be beneficial would be the relationship between ambiguous loss and identity ambiguity. The literature surrounding both ambiguous loss and identity ambiguity is limited. It would be beneficial for researchers to take a look at the relationship between parents who have children with a lifelong diagnosis and the impact on their identity, as this topic is not extensively covered in current research. The link

between ambiguous loss and identity ambiguity could also be an insightful relationship to explore, as grief can implicate identity.

Moreover, it could be useful for researchers to study the effect of the COVID-19 pandemic on parents. As this study was conducted in the midst of the pandemic, it was a factor to consider when interpreting the results, as it could have elevated levels of stress, stigma, or grief for parents. More research on the direct link between COVID-19 and parents with children who have been diagnosed with ASD could provide insight into the relationship between these factors.

Finally, as a researcher, my compassion for parents who have children diagnosed with ASD has been heightened. This research gave me a deeper glimpse into each participant's experience and their feelings surrounding parenting a child with ASD. Though the interviews got emotionally intense at times, I did my best to remain as objective as possible. Remaining objective meant giving myself adequate time between interviews to ensure I was not being biased to the next participant as well as not pulling in experiences from one interview to another. From a researcher's perspective, I learned how traumatic it could feel to have a child diagnosed with ASD and then be expected to navigate various environments to better support your child. This new expectation can cause parents mental anguish as the pressure of this new responsibility can feel unmanageable at times. There is also a lack of information given by professionals in the field, compounding these feelings of stress. Finally I have learned that parents who navigate this journey with their children are incredibly resilient and resourceful.

### **Limitations**

It is important to note that participants were interviewed over the phone due to COVID-19 precautions. The inability to see the participant visually eliminated any non-verbal responses

that researchers could have caught, which would have allowed more room for interpretation or expansion of the participants' answers. In addition, since this research took place during a worldwide pandemic, parents were now at home taking care of their children, limiting the number of participants who were able to partake in the research. As well, the pandemic had caused some participants to be at home full-time with their child without the support or resources they would typically have in place. These contributing factors may have affected the participants' narratives as they were undergoing a period of uncertainty and high stress. There were five people who initially agreed to participate but who withdrew due to the COVID-19 pandemic. As this study initially had more participants, the lower number may have affected the data saturation, as a higher number of participants could have yielded more data for the study.

In addition, the participants were all biological parents. Though the criteria for selecting participants included parents who fostered or adopted their children, only biological parents reached out to be involved in the study. The experience of foster or parents who have adopted children with ASD may have added richness to the study. It allows researchers to gather further insight into that particular lived experience. In terms of participants gathered, the researcher only had one father participate compared to nine mothers, which could have been a result of sampling methods (i.e., posting on social media sites and direct agency websites). The reason why this study attracted more participants who identified as mothers is unknown; however in future studies it would be helpful to gather data from participants thatwho identify as fathers.

### **Conclusion**

The lived experiences of parents who have children diagnosed with ASD is an important area of research. The themes extracted from the ten Canadian participants: stigma, poor parental

mental health, grief, and stigma are essential sub-areas for future researchers to consider. These themes provide insight into the participants' experiences in the study and give health professionals, clinicians, social workers, and parents insight into the journey of having a child with ASD. While this research adds to the current literature describing the lived experience of parents who have children diagnosed with ASD, there is a call for more phenomenological studies on this topic. As the number of children diagnosed with ASD rises, it is vital that current research is being undertaken in this area of study as it can aide a variety of populations.

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