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# Exploring the Caregiving Experiences and Challenges of Mothers of Children with Autism Spectrum Disorder (ASD) in Zhuhai City, Guangdong Province, China

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## Abstract

The aim of this research was to explore the caregiving experiences and challenges of mothers of children with ASD in Zhuhai City, Guangdong Province, China. To achieve this aim, the research employed a qualitative design and used semi-structured interviews to facilitate the collection of rich, qualitative data regarding the experiences and challenges of mothers of children with ASD. The study population comprised mothers of children with ASD in Zhuhai City, Guangdong Province, China, and purposive sampling was used to select a suitable sample of 10 mothers that was used in the study. The participants were recruited from a rehabilitation center for children with ASD in Zhuhai, Guangdong Province, while thematic analysis was used to analyze the qualitative data collected from the sample of mothers of children with ASD. Overall, the results reveal that the main social challenges experienced by mothers of autistic children in the region include stigma, inadequate social support, as well as fatigue, stress & anxiety. In addition to revealing the challenges facing mothers of children with ASD, the results also revealed the main coping strategies that can be used by mothers of autistic children in addressing the major caregiving challenges and improving their health and well-being. Thus, this research has valuable implications for both theory and practice.

**Keywords:** qualitative, autism, challenge, stigma

## 1. Introduction

### 1.1 Background to the Research

Autism spectrum disorder (ASD) is a developmental disability that commonly involves repetitive behaviors and difficulties in social communication and interaction (Bonis, 2016; Lord et al., 2018). Given the nature of ASD, parents of children with ASD tend to endure some unique challenges as the caregivers (Bekhet, Johnson, & Zauszniewski, 2012; Papadopoulos, 2021). For example, parents of children with ASD are generally required to devote a considerable amount of their time to caregiving, as the symptoms of ASD often persevere across the lifespan (Nicholas et al., 2017; Vernhet et al., 2019). Additionally, the behavioral differences exhibited by children with ASD can be challenging for parents to manage, as often, people with ASD are less capable of expressing their wants (Bekhet, Johnson & Zauszniewski, 2012; DePape & Lindsay, 2015; Chu et al., 2020). Consequently, ASD can have an extensive impact on family-life, including the parents' well-being and quality of life, and unsurprisingly, research conducted over the past decade has shown that parents of children with ASD often endure more stress than other parents (Buescher et al., 2014; Bonis, 2016; Vasilopoulou & Nisbet, 2016; Ilias et al., 2017).

Even though parents of children with ASD generally experience substantial challenges as the caregivers, research has revealed that experiences are highly variable between parents of children with ASD (Papadopoulos, 2021), with the variance in parental experiences mainly attributed to the differences in the extent of disability

and behavior problems (Patel et al., 2022). Thus, in order to better address the challenges faced by parents of children with ASD and help to lower stress and improve well-being, there is a need for detailed insight and understanding of the experiences, behaviors, and opinions of parents in specific contexts. On that account, this research focuses on exploring the caregiving experiences and challenges of mothers of children with ASD in Zhuhai City, Guangdong Province, China.

*1.2 Purpose of the Study*

The overarching aim of this research is to explore the caregiving experiences and challenges of mothers of children with ASD in Zhuhai City, Guangdong Province, China. The study aims to achieve the following objectives:

- To explore the caregiving experiences of mothers of children with ASD in Zhuhai City, Guangdong Province, China.

- To explore the caregiving challenges of mothers of children with ASD in Zhuhai City, Guangdong Province, China.

- To explore the coping strategies used by mothers of children with ASD in Zhuhai City, Guangdong Province, China.

*1.3 Approach Taken*

In terms of the research design, the research employs a qualitative design, mainly because a qualitative approach is suitable for exploring the research topic. As Aspers and Corte (2019) argue, qualitative research helps to understand people's opinions, ideas, and experiences, hence, helping researchers to obtain in-depth insights into a particular problem. Thus, adopting a qualitive design in this research facilitates in-depth insights into the experiences of mothers of children with ASD. Consistently, semi-structured interview is used as the method for collecting qualitative data mainly because this method is suitable for providing rich and in-depth qualitative data about a particular topic (Braun & Clarke, 2019). Thus, using semi-structured interviews in this research facilitates the collection of rich, qualitative data regarding the experiences and challenges of mothers of children with ASD. The study population comprised mothers of children with ASD in Zhuhai City, Guangdong Province, China, and purposive sampling was used to select a suitable sample for the study. The potential participants were recruited from a rehabilitation center for children with ASD in Zhuhai, Guangdong Province (where the researcher previously worked as a social work intern and managed to build a good rapport with the clients), while Braun and Clarke's (2019) six-step thematic analysis method was used to analyze the qualitative data collected from the sample of mothers of children with ASD in Zhuhai City, Guangdong Province, China.

## 2. Literature Review

*2.1 Autism Spectrum Disorder (ASD)*

Autism spectrum disorder (ASD) is a developmental disability that commonly involves repetitive behaviors and difficulties in social communication and interaction (Bonis, 2016). Over the past several decades, ASD has transformed from a narrowly defined, rare disorder of childhood onset to a well publicised, advocated, and researched lifelong condition, with researchers generally recognizing ASD as a fairly common and very heterogeneous condition (Lord et al., 2011; Lord et al., 2020). As a developmental disorder, ASD is diagnosed on the basis of early-emerging social and communication impairments and rigid and repetitive patterns of behaviour and interests (Frith & Happé, 2005; Devlin & Scherer, 2012).

Although there are multiple causes of ASD, this developmental disorder is mainly attributed to genetic and biological factors, with researchers indicating that ASD is among the most heritable developmental disabilities (Frith & Happé, 2005; Devlin & Scherer, 2012). In this regard, having a sibling with ASD is listed among the common risk factors, with research revealing that siblings of those with ASD are fifty times more likely to be diagnosed with ASD than the general population, while there is a 60–90% risk of developing ASD for a person whose twin has ASD (Frith & Happé, 2005). Crucially, ASD occurs in all racial, ethnic, and socioeconomic groups, while boys are four times more likely to develop ASD than girls (Devlin & Scherer, 2012). Therefore, it could be argued that research on the diagnosis and therapy of ASD is beneficial to all groups of people with ASD, including their parents, siblings, and other people providing care and support.

The description of the core features of ASD as being social communication differences along with repetitive and unusual sensory behaviours has not changed substantially since early research was conducted on this developmental condition (Sharma et al., 2018). However, recent research presents autism as a spectrum that can range from very mild to severe (Frith & Happé, 2005; Yates & Le Couteur, 2016; Sharma et al., 2018). Since the manifestation of ASD symptoms varies significantly depending on factors such as age and ability (Frith & Happé, 2005), recent researchers (Yates & Le Couteur, 2016; Sharma et al., 2018; Howlin, 2021) have acknowledged the idea of ASD as a spectrum in order to account for this variance. Still, a majority of the people

with ASD need lifelong support of some kind in order to promote more positive outcomes (Sharma et al., 2018).

However, the existing literature on the outcomes for adults with ASD generally reveals that independent of individual abilities, most of these adults are either unemployed or underemployed, with studies also showing that a large percentage of these adults do not receive any proper services related to care and therapy (Gerhardt & Lainer, 2011; Kapp et al., 2011; Friedman et al., 2013; Murphy et al., 2016). Most of the adults with ASD have had insufficient transition programs, as very little attention is often paid to service coordination (Gerhardt & Lainer, 2011; Shattuck et al., 2012). Additionally, research has shown that the absence of evidence-based practices and issues regarding staff (care providers) recruitment are among the major systemic challenges hindering the provision of appropriate services to adults with ASD (Howlin & Moss, 2012; Shattuck et al., 2012; Howlin, 2021). As a result, there is a strong need for increased attention to individual needs of adults with ASD in order to ensure a more positive quality of life for not only adults with ASD but also their primary caregivers (Friedman et al., 2013). Therefore, ASD represents a substantial economic burden, mainly due to the provision of support to adults who cannot function independently, which results in higher health-care and school costs and loss of income for caregivers (Gerhardt & Lainer, 2011; Kapp et al., 2011).

*2.2 Experiences and Challenges of Parents of Children with ASD*

ASD can have adverse effects on family life, particularly on the parents' roles and responsibilities, with studies conducted over the last two decades generally revealing that parents of children with ASD face some considerable challenges not only at home but also in the community (Altiere & von Kluge, 2009; Nealy et al., 2012; Ilias et al., 2017). Parents of children with ASD start to experience challenges in the pre-diagnosis stage, as there is usually some confusion when ASD symptoms such as repetitive behaviors first begin to show up in their children (Ilias et al., 2017). After diagnosis, most parents report feeling of loss and devastation after learning that their child has ASD (Altiere & von Kluge, 2009), with mothers specifically feeling that ASD symptoms and behavioural differences such as sleep difficulty and hyperactivity end up spoiling their wellbeing (Ilias et al., 2017). According to Ilias et al. (2017), ASD symptoms and behavioral differences, such as repetitive behaviors and difficulties in changing routine, have a negative impact on the well-being of mothers of children with ASD.

Consequently, parents of children with ASD face a greater risk of financial strain than parents of children without ASD, as there are high costs associated with caregiving services of people with ASD (Nealy et al., 2012). Additionally, parents of children with ASD are more prone to poor physical and mental health, with these parents often experiencing high stress levels along with reduced quality of life (Ilias et al., 2017). Furthermore, parents of children with ASD are generally required to devote a considerable amount of their time to caregiving, as the symptoms of ASD often persevere across the lifespan (Nicholas et al., 2017; Vernhet et al., 2019). Relatedly, some parents might be forced into changing their careers or relocating to a different location in order to ensure that they are able to meet the required costs (Corcoran et al., 2015; DePape & Lindsay, 2015; Ilias et al., 2017). Therefore, the existing literature on the caregiving experiences of parents of children with ASD acknowledges that these parents generally endure more stress than other parents (of children without ASD).

According to previous research, parents of children with ASD generally have higher rates of emotional strain and mental disorders compared to parents of children without ASD (Corcoran et al., 2015). However, as the primary caretaker in most situations, mothers of these families often assume an unequal share of the associated responsibility and burden of providing and coordinating care for the child. According to Nealy et al. (2012) the negative impacts of having a child with ASD can be classified into four major categories: emotional impact, familial relationships impact, social impact, and financial impact. The emotional impacts of having a child with ASD on parents include higher levels of stress, worry, and guilt for mothers, while the common familial challenges include the lack of time and energy to devote to their spouse or partner and in many cases, the siblings of the diagnosed child (Nealy et al., 2012). Social impacts, on the other hand, include inadequate time to spend with friends and increased isolation as a result of the potential behavioral outburst from the child with ASD, while financial impact revolves around the high cost of care along with the concern over the future cost for the child's future (Kapp et al., 2011; Nealy et al., 2012). As a result of these impacts, mothers of children with ASD often feel the need to leave or change their occupations in order to provide the much-needed care to their children (Nealy et al., 2012).

Consistently, focusing on mothers of children with ASD in Greece, Papadopoulos (2021) reveal that these mothers often experience a sense of burden (emotional, family, and social), distress, and vulnerability when raising a child with ASD. Likewise, recent research (Papadopoulos, 2021; Patel et al., 2022) focusing on Indian mothers of children with ASD confirm that increased burden is an outcome of caring for a child with ASD. According to Patel et al. (2022), the degree of burden is greater in Indian mothers mainly because in the country, mothers are generally perceived as the primary caregivers and are, thus, required to spend considerable time with the child. Correspondingly, several researchers have argued that because society generally perceived women as

the caregivers and men as the breadwinners, the burden of caring for a child with ASD might be entirely on mothers (Papadopoulos, 2021; Patel et al., 2022). Hence, it could be argued that negative effects such as increased stress and reduced quality of life might be more pervasive in mothers than in fathers of children with ASD. Therefore, even though parents of children with ASD generally experience substantial challenges as the caregivers, it could be argued that the experiences of mothers are different from the experiences of fathers in caring for their children with ASD.

*2.3 Coping Strategies Used by Parents of Children with ASD*

However, previous findings have revealed that despite the feeling of devastation often experienced in the early period after diagnosis, parents are often eager to mobilize the required resources to continue providing quality care to their child (DePape & Lindsay, 2015; Ilias et al., 2017). For example, Ilias et al. (2017) explored how mothers in Malaysia give meaning to their experiences of raising a child with ASD, revealing that acceptance, proactive mindset, character growth, spirituality, and parent support networks are among the main strategies used to cope with the difficulties involved in caring for a child with ASD. Relatedly, DePape and Lindsay (2015) explore the experiences of parents caring for a child with ASD, revealing that family life adjustment and parental empowerment are crucial measures to help parents of children with ASD to overcome the difficulties involved in caregiving. Correspondingly, recent findings propose the development of programs, services, and initiatives aimed at empowering parents of children with ASD and providing them with adequate information to help in improving their caregiving ability (Corcoran et al., 2015; DePape & Lindsay, 2015).

More recently, Chu et al. (2020) also explored the challenges and experiences of parents of children with ASD in Malaysia, revealing that even though there is a general perception among parents that speech therapy is advantageous, there are some barriers and challenges hindering the access of speech therapy, such as inadequate understanding and awareness of ASD. Thus, increasing public awareness about ASD along with formulating support groups for parents are proposed as critical strategies to help address the challenges faced by parents of children with ASD.

Focusing on mothers of children with ASD in Canada, Nicholas et al. (2016) revealed that ASD causes mothers to change their careers or career goals, while support programs and services are often inadequate to overcome the mothers' challenges in caring for their children. Focusing on mothers of children with ASD in Greece, Papadopoulos (2021) reveal that these mothers often experience a sense of burden (emotional, family, and social), distress, and vulnerability when raising a child with ASD. Likewise, recent research (Papadopoulos, 2021; Patel et al., 2022) focusing on Indian mothers of children with ASD confirm that increased burden is an outcome of caring for a child with ASD. According to Patel et al. (2022), the degree of burden is greater in Indian mothers mainly because in the country, mothers are generally perceived as the primary caregivers and are, thus, required to spend considerable time with the child. Correspondingly, several researchers have argued that because society generally perceived women as the caregivers and men as the breadwinners, the burden of caring for a child with ASD might be entirely on mothers (Papadopoulos, 2021; Patel et al., 2022). Hence, it could be argued that negative effects such as increased stress and reduced quality of life might be more pervasive in mothers than in fathers of children with ASD.

Therefore, even though parents of children with ASD generally experience substantial challenges as the caregivers, it could be argued that the experiences of mothers are different from the experiences of fathers in caring for their children with ASD. Correspondingly, research has revealed that experiences are highly variable between parents of children with ASD (Papadopoulos, 2021). The difference in parental experiences has been attributed to a number of factors, mainly the differences in the extent of disability and behavior problems (Patel et al., 2022). For example, the experiences and challenges for parents of children with advanced communication skills are likely to differ from the experiences of parents whose children are nonverbal. However, it could also be argued that differences in experience arise from the widely held perception of mothers as the primary caregivers and fathers as the breadwinners. Hence, it is important to study the experiences of raising a child with ASD from a maternal perspective.

*2.4 Research Questions*

Therefore, based on the literature review, the research will answer the following questions:

1) What are the main mental and social challenges experienced by mothers of children with ASD in Zhuhai City, Guangdong Province, China?

2) What are the views and experiences of mothers on support and strategies to help with the challenges of raising a child with ASD?

**3. Research Methodology**

*3.1 Research Philosophy and Design*

This research adopts an interpretivist philosophy that argues that reality is subjective and socially constructed (Alharahsheh & Pius, 2020). This way of seeing the world allows me to focus on a specific context — Zhuhai City in China — and examine the 'realities' of mothers of children with ASD within this context. Hence, adopting an interpretivist paradigm enables this research to explore the experiences, opinions, and ideas of mothers of children with ASD in Zhuhai City in China and identify how ASD and parenting are both socially constructed and individually experienced in one specific area of China.

In terms of the research design, this research employs a qualitative design, mainly because qualitative research is considered to be more suitable for exploratory research. As Aspers and Corte (2019) argue, qualitative research helps to understand people's opinions, ideas, and experiences, hence, helping researchers to obtain in-depth insights into a particular problem. I adopt a qualitive design in this research to facilitate in-depth insights into the experiences of mothers of children with ASD. Therefore, conducting qualitative research is consistent with the exploratory nature of the research and will, therefore, enable me to obtain in-depth insights and answer the research questions.

*3.2 Research Method and Data Collection*

Semi-structured interview was used as the method for collecting qualitative data, as I considered this method to be appropriate because of its usefulness in providing rich and in-depth qualitative data about a particular topic (Braun & Clarke, 2019). Thus, using semi-structured interviews in this research facilitated the collection of rich, qualitative data regarding the experiences and challenges of mothers of children with ASD. Crucially, using semi-structured interviews enabled the researcher to be flexible in the interview and ask follow-up questions where necessary (Adams, 2015), thus, ensuring the collection of in-depth, qualitative data regarding the experiences, behaviors, and perceptions of mothers of children with ASD.

However, because of its flexibility, semi-structured interview is often criticized for its reliability, as the discussions of the same topic can easily differ across the respondents (Kallio et al., 2016). Additionally, it is also easy for discussions to go off topic because of the flexibility of semi-structured interviews (Braun & Clarke, 2019). To address this limitation of semi-structured interview, an interview guide was used when conducting the interviews. The guide comprised a list of questions that were asked during the interview, from which some follow-up questions arose.

The research used a combination of face-to-face interviews and online interviews to collect data, though face-to-face interviews were used as the primary method of data collection in this research while online interviews were added to supplement the quality of the data collected from the participants. The face-to-face interviews were conducted in the center's professional interview room, which is usually used by social workers to interview their clients. A total of 9 participants took part in the face-to-face interviews conducted in the center's professional interview room, with each of these interviews lasting for around 30 – 45 minutes.

Although the importance of building trust and establishing a good rapport with interviewees has mostly been studied in the context of investigative interviews (Abbe & Brandon, 2013; Miller, 2017; Hoogesteyn et al., 2023), rapport is also an important aspect that should be considered when designing and conducting qualitative interviews (Drew, 2014; Brown & Danaher, 2019). Hence, establishing a good rapport with the participants in this research was useful in building a harmonious relationship with them, facilitating communication, and fostering disclosure of information (Hoogesteyn et al., 2023). Considering that an interviewer's decision-making and actions strongly influence rapport-building (Miller, 2017; Brown & Danaher, 2019), I found it important to use the CHE (Connectivity, Humanness, & Empathy) framework proposed by Brown and Danaher (2019) to guide my decision-making and actions when conducting the semi-structured interviews. Simply, I was keen to ensure that my actions prior to and during the interviews were in line with the principles of connectivity, humanness, and empathy, as, for example, I was keen to provide supportive comments to the participants, as this invites and allows disclosures (Miller, 2017). Additionally, as recommended by Hoogesteyn et al. (2023), I ensured that I use both verbal behaviours (for example, providing supporting comments) and non-verbal behaviours (for example, displaying empathy) as tactics to build rapport with the participants. After using these tactics, I evaluated whether I have successfully established a good rapport by assessing the quality of communication and information gathered (for example, the degree of cooperation and whether the participants sounded/acted confident), considering that the primary aim of rapport in research is to facilitate communication and foster disclosure (Brown & Danaher, 2019; Hoogesteyn et al., 2023). Therefore, face-to-face interviews with mothers of children with autism were useful for establishing rapport, which is crucial in attaining the goals of semi-structured interviews.

Using face-to-face interview method was also advantageous because it enabled me to exploit the benefits of field notes in qualitative research. Thus, using field notes in this research enabled me to document important contextual information and increase the rigour of this qualitative study (Deggs & Hernandez, 2018; Phillippi & Lauderdale, 2018). More specifically, I used field notes to gather information regarding the context (the

circumstances in which the interview occurred) and some non-verbal cues (for example, facial expressions, hand gestures, and general mood) that could be useful in subsequent analysis (Deggs & Hernandez, 2018), while at the end of each interview, I also used field notes to record brief summaries of the interview and outline my initial feelings about the interview and participant (Tessier, 2012). Therefore, consistent with the argument presented by researchers (Tessier, 2012; Phillippi & Lauderdale, 2018), using field notes in conjunction with tape recordings helped me to recall key information, ideas, and memories that could have easily been lost further down the research process.

In addition to face-to-face interviews, I conducted online interviews with participants who were willing to provide additional information, but could not do so at the center because of factors such as limited time and readiness or preparedness. I considered it necessary to include the option of "providing information later" because of the sensitive nature of the topic of ASD, as I thought it would be useful if I gave some mothers the chance to prepare well for the interview and create their own free time to discuss their experiences. Thus, online interviews were used to promote convenience and, importantly, this method did not lead to a significant increase in the costs because it is relatively cheaper compared to face-to-face interviews (Salmons, 2014; Weller, 2017). The online interviews were conducted via Tencent Meeting, which is one of the major online platforms commonly used for video-conferencing in mainland China. Among the 9 participants who took part in the face-to-face interviews, 4 of them agreed to provide further information through online interview, and this enabled me to dig deeper into some of the main points or issues raised by the participants during the face-to-face interviews. The online interviews lasted for around 30 minutes, which was adequate time for me to collect relevant and in-depth data that will help to answer the research questions.

*3.3 Sampling*

The study population comprises mothers of children with ASD in Zhuhai City, Guangdong Province, China, and purposive sampling was used to select a sample that was used in the study. Purposive sampling is a non-probability sampling technique that involves identification and selection of units that have the characteristics needed for the sample (Etikan, Musa, & Alkassim, 2016). Using this sampling technique is suitable for this study because I was able to select the individuals that can provide the best information required to answer the research questions. In this research, the criteria for purposive sampling was based on the range of child age, whereby the researcher will select mothers whose children are between 2 and 14 years old. According to Buescher et al. (2014), the socioeconomic costs of ASD in the UK and the US are higher for school-aged children that pre-school children mainly because of the additional costs for special education services. Additionally, Buescher et al. (2014) reveal that the medical cost of supporting a person with ASD increases with age, which suggests that there is a considerable difference between caring for a pre-school child and caring for a school-aged or teenage child with ASD. Therefore, by including mothers of children in this age bracket, the research can be able to explore any differences between caring for young children with autism and caring for school-aged children with autism.

Although purposive sampling has been criticized because of limited generalizability to the population (Etikan, Musa, and Alkassim, 2016), my research is exploratory in nature, aiming to generate detailed hypotheses about experiences and views; hence, it does not claim representativeness or generalizability. Still, I took important steps to improve generalizability, increase rigour, and promote the quality of evidence in this research, with these measures including asking similar questions across all the interviews and providing in-depth explanations of some of the hypotheses tested in previous quantitative studies.

Participants were recruited from a rehabilitation center for children with ASD in Zhuhai, Guangdong Province, where I previously worked as a social work intern and managed to build a good rapport with the clients. Through the permission of the relevant leaders and managers in the institution, an invitation message to participate in the research was pinned on the notice boards in the center. This way, parents who frequently come to the center to bring their children (with ASD) for rehabilitation would be able to see the invitation message, which included crucial information about the research and what it would mean for them to participate in the research. The invitation message also outlined the ethical code of conduct that would be adhered to in the research, assuring the potential participants of confidentiality and informing them about their rights. The invitation message included the researcher's contact information so that the potential participants who were interested in participating in the research could contact the researcher. At the same time, the researcher also went to the parent lounge of the institution, which is a room where parents usually wait for their children to complete their rehabilitation training, to advertise recruitment. Using the above methods, the researcher targeted a sample of 10 participants for the research.

*3.4 Data Analysis*

The collected qualitative data will be analyzed using thematic analysis (TA), which is one of the commonly used methods of analysis in qualitative research. TA can be described as a method of analysis that is often used in

qualitative research and works towards generating themes or patterns of meaning in a given data set (Joffe, 2011). One of the main advantages of TA is that it offers researchers a high degree of flexibility and facilitates an active process of theme development that helps in producing new insights into a particular phenomenon (Alhojailan and Ibrahim, 2012; Vaismoradi et al., 2013; Clarke et al., 2015; Neuendorf, 2018; Sundler et al., 2019). According to Braun and Clarke (2006) TA can be conducted in the following six phases: familiarization, coding, theme development, theme reviewing, theme defining and naming, and report production. Therefore, this research uses the six-step thematic analysis method proposed by Braun and Clarke to analyze the qualitative data gathered from mothers of children with autism in Zhuhai City.

In conducting TA in this research, I mostly relied on an inductive approach, which means that I allowed the data to 'tell the story' of the mothers' experiences and challenges. Although I employed an inductive approach, I also considered it necessary to situate the analysis within a guiding story rather than simply reporting the themes emerging from the data. In other words, following the recommendations presented by previous researchers (Braun, Clarke, & Hayfield, 2019; Braun & Clarke, 2022), this research used reflexive TA that considered the idea of an analytic story as a useful tool of conducting TA. As Braun and Clarke (2022) argue, without an overall guiding story, analysis can appear fragmented, as this often leads to large numbers of reported themes and homogenous results. Therefore, this research adopted reflexive TA in order to produce more nuanced results that would help in providing in-depth understanding of the research topic.

To promote convenience in the data analysis process, I used NVivo, which is a qualitative data analysis software that assists researchers to organize, analyze, and gain insights in qualitative data (Hilal & Alabri, 2013; Jackson & Bazeley, 2019). When analyzing the data using the six-step method, I started by transcribing the interview recordings, reading through the transcripts, and taking initial notes about the data (familiarization), as this initial step is useful for obtaining a thorough overview of the collected data before beginning to analyze individual items in the data (Braun & Clarke, 2019).

Coding was the next step after familiarization, and this step entailed coming up with codes to describe different phrases and sentences in the text. Coding is a crucial step in conducting thematic analysis, as codes generally provide a condensed overview of the common meanings and points in the data set (Braun & Clarke, 2019). To ensure that my coding was systematic and comprehensive, I ensured that I went through each of the transcripts multiple times, highlighting everything that appeared to be relevant or potentially interesting in the process.

The third step in the analysis process involved generating themes, which are generally broader than codes and are, hence, relevant to the research questions. After generating the main themes, the succeeding step involved reviewing the generated themes and ensuring that the themes adequately represented the data. The fifth step in the analysis process, after reviewing the themes, involved defining and naming the themes. The final step in the analysis process involved writing the report, whereby each theme was discussed in a logical manner and elaborated further to illustrate how it relates to the research topic. Thus, using the six-step thematic analysis method proposed by Braun and Clarke helped to answer the research questions. Importantly, using TA in this research incorporated many of the aspects of high-quality analysis recommended by other approaches, such as content analysis and grounded theory. The report of the analysis is presented in the next chapter.

## 4. Results

This chapter presents the results of the study, discussing the main themes that were derived from the interview data gathered from a sample of 10 mothers of children with ASD in Zhuhai City, Guangdong Province, China. The age of the mothers who participated in this research ranged from 26 years to 47 years, with a mean age of around 34 years. Each mother reported having only one autistic child, with the age of the autistic children ranging from 2 years (and several months) to 13 years, and a mean age of around 9 years. Hence, a majority of the mothers had autistic children of a school-going age, with only three mothers reporting having autistic children who were yet to start school. Table 1 shows the main themes and codes derived from the data.

Table 1. Main Themes and Codes

| Categories | Themes | Codes |
|---|---|---|
| Challenges | Stigma | Stigma |
| | | Judgements from others |
| | | Being treated differently |
| | | Myths and misconceptions |
| | | Being viewed negatively |

|  | Inadequate social support | Inadequate support from friends and colleagues |
|---|---|---|
|  |  | Lack of emotional support |
|  |  | Loss of job/employment |
|  |  | Lack of disability certificate |
|  |  | Lack of government support |
|  |  | Financial pressure |
|  | Fatigue, Stress and anxiety | Poor sleep |
|  |  | Tiredness |
|  |  | Overworking |
|  |  | Feeling demotivated |
|  |  | Very little physical exercise e.g. yoga and jogging |
|  |  | Mental stress |
|  |  | Overthinking |
|  |  | Headache |
|  |  | Worry about child's development and future |
| Coping strategies | Online social support | Social support from social media users |
|  |  | Information from social media groups |
|  |  | Use of online communities |
|  | Community social support | Joining support groups in the neighbourhood |
|  |  | Seeking help from members of the community |

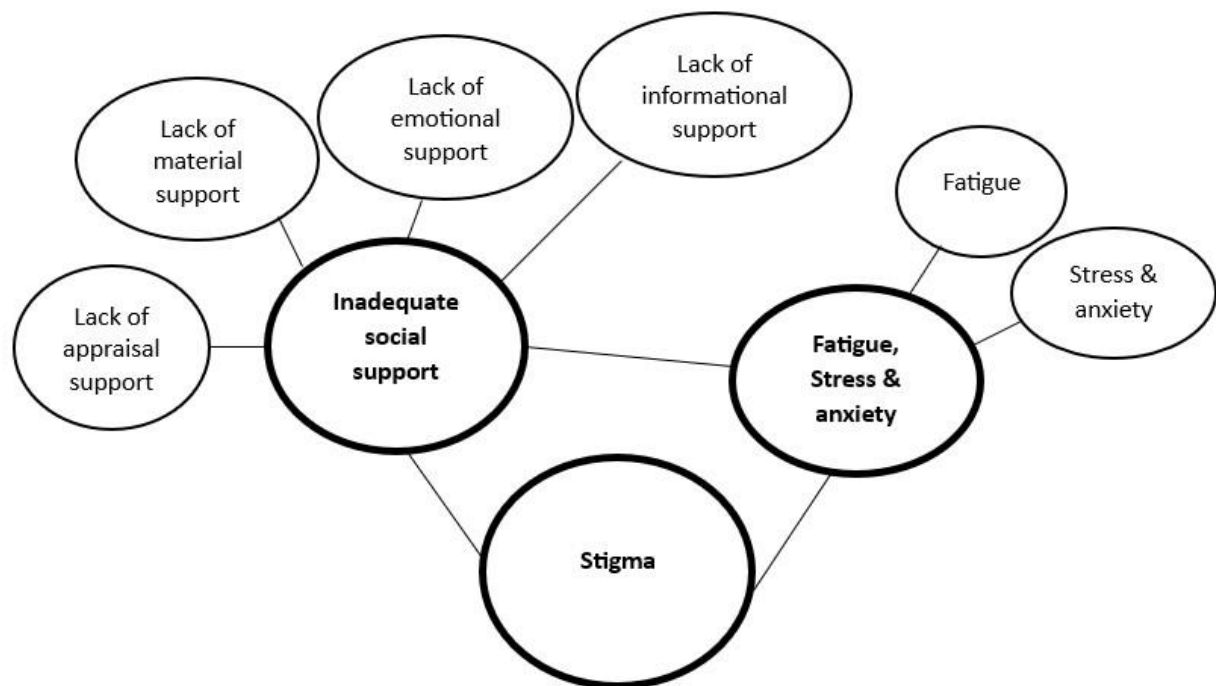Figure 1 below shows how the themes and sub-themes are related to each other.



Figure 1. Main Themes and Sub-Themes

*4.1 Challenges Facing Mothers of Children with ASD*

4.1.1 Stigma

One of the main challenges discussed in the interviews with mothers of autistic children involves the experiences of disapproval, discrimination, and judgement from some members of the general public. In the interviews, mothers confessed to having experienced different forms of disapproval and/or discrimination based on their children having been diagnosed with ASD, with a majority of them narrating how they had previously experienced judgement, stigmatization, and exclusion as a result of stereotyping and prejudice. As one of the participants narrated:

> "I don't know why, but somehow, many people seem to believe that when a child has ASD, it is because of the mother; and just like that, even without asking questions, people stick to this myth and start seeing us as outsiders and in a negative way. It is very painful honestly, because when we are giving our all to give our children the best life as possible, like any other mother out there would do, there are people who are busy telling others to avoid us because we are the problem. It's really hurting and bad, and something that people must stop doing." Participant 6, mother of 4-year-old autistic male child.

Hence, stigma was highlighted among the main themes in relation to the social challenges experienced by mothers of children with ASD in Zhuhai City, with this theme defined as the mothers' feeling or experience of disapproval or being discriminated against because of having autistic children.

In the interviews, mothers felt that stigma mainly occurs due to faulty perceptions regarding different aspects related to ASD, mostly the risk factors and causes of ASD. Specifically, mothers explained to me that they felt they were experiencing disapproval and discrimination because of the general public's judgment about parenting (mothering) as a factor that is responsible for ASD, hence, the experience of blame and judgement from the public. As one of the mothers explained:

> "Immediately they (other people) know that your child has ASD, they put all the blame on you (mothers of autistic children) and all the responsibility and they leave you alone; but they don't just leave you alone without help, they see you and treat you as a different person, and build a fence to show you that they don't want to associate with you. They don't tell it straight to your face, of course because they are not courageous enough, but it is quite clear. Suddenly, I don't get the same treatment from the shop owner and store attendants and even the delivery people. How can you explain that someone who you were having intense conversations with before does not even say good morning now? And yet I am still their customer. Even the shop assistants who used to be very friendly with me are now looking at me as if I have Covid. There is no coincidence there, all of them obviously have been told something about me that is not true." Participant 4, mother of 7-year-old autistic male child.

Hence, the mothers felt isolated and also expressed feelings of disappointment with the general public's view of them as "different" people or outsiders. Based on the mothers' sentiments conveyed during the interview, it can be said that these mothers are experiencing stigma because of having autistic children. Additionally, it has to be noted that mothers of autistic children feel that stigmatization is largely an outcome of the misconceptions and myths that some people have about ASD.

4.1.2 Inadequate Social Support

In the interviews, mothers of autistic children also explained how they felt that they were lacking the necessary support to make their lives "more manageable" and help them to cope better with the care-giving process. Specifically, most of the mothers felt that they were receiving little or no support from several parties, including their friends, members of their families, as well as the (local and national) government. The lack of support from friends was the major problem discussed by most of the mothers in the general context of inadequate support, while a few mothers also felt that they were not being supported enough by their family members. Correspondingly, the mothers explained to me that they had "no friends to talk to" and that they needed people who could listen to them and show them some "love and hope".

> "In truth, I can say that the situation has become more difficult as time has passed, and much of this I can say is because the support that I have received from others has become smaller and smaller as years have passed. Many of my close friends have drifted away from me, and my calls and messages are not being answered anymore because I think they have gotten tired of doing me small favours when I have an emergency. It's okay for them for them not to help me with their money, I totally understand them and appreciate the help they have given me in the past. But money is not all that I need from them. Sometimes I feel like I need somebody to hug me and tell me that everything will be okay, but again, I have found myself in a situation where I am always alone, with nobody to talk to about my feelings and worries." Participant 2, mother of 13-year-old autistic male child.

When discussing about social support, one noticeable point presented by the participants was their observation

that the level of social support had generally declined over time, as several participants mentioned how the current level of social support, especially from friends, is significantly low as compared to the support received in the early period after diagnosis of the child. As one of the mothers explained to me during the interview:

> "When I started this journey, I used to receive many messages of encouragement from my friends and colleagues at work, so many that others often remained unread in my phone for a long time. At the time, I didn't realize that these messages were actually helping me in some way, and it was until these messages stopped coming in that I noticed that I actually need friends to encourage me through this journey." Participant 4, mother of 10-year-old autistic child.

Therefore, based on the mothers' statements, inadequate social support was identified as a major challenge experienced by mothers of children with ASD, with social support defined as resources (material, psychological, financial or emotional) that are provided by one's social network, mostly to help in dealing with stress (Gariepy et al., 2016; Cohen and McKay, 2020). Hence, the results indicate that mothers of children with ASD feel that they are lacking the adequate social support that is required to cope better with the difficulties of raising an autistic child. Crucially, the results reveal that mothers of autistic children felt that they lacked different forms of social support, including emotional and material (financial) support. Specifically, the mothers explained to me how they mostly needed financial help (money to cater for the bills and expenses) along with people to assist in performing day-to-day duties such as house chores and also in taking their autistic children to the rehabilitation center. As one of the mothers explained in the interviews:

> "As a mother of four children, I have one hundred and one things to do (at home) on a daily basis, and you can imagine how hard it can be to find time to come here. I have been telling my husband that I need someone to help me in these duties, even in driving (my child) here. That will be very helpful. But again, where is the money to pay such a person? So, yes, it is quite a complicated problem. But I see it as fixable, and if we sort a few things, we can get the help that we need — the help that I need." Participant 10, mother of 9-year-old autistic male child.

Interestingly, some of the mothers explained that there were receiving little help from people around them, despite the presence of social support groups. As one of the mothers narrated:

> "They say that knowledge is power, that if you have all the information about your opponent, you will win the war easily. But then, we (mothers of children with ASD) are not supported enough to get the right knowledge and information about caring for our children. We are just told that in the support groups, we will get all the advice and tips that we need to manage this situation. I have been part of a number of sessions and honestly, there is not much information that I can say I have received from these talks. In as much as I see support groups to be helpful for parents like me, I don't think that the social help that we receive in reality is enough to make a big difference; this support is very small, maybe because at the end of the day, every person has his or her own problems to face." Participant 1, mother of 4-year-old autistic male child.

Moreover, the lack of adequate support was also discussed in relation to the support from the government, as the mothers explained to me how they felt that not much help was coming from the Chinese government. In the interviews, mothers complained that the government was underperforming in terms of supporting the health and wellbeing of their children, with most of the mothers specifically expressing their disappointment in not accessing the disability certificates for their children, which meant that they had to pay more than they should in providing good-quality health services to their children. As one of the mothers narrated:

> "The government has told us many times that our children will be given the best quality of education that is designed to fit their special needs, but each time we go to the offices to get the relevant documents, it is just excuses and excuses. Without that official document to certify that my child needs one or two things, no service will be given to him, and this means that I will continue to go deeper into my pockets to pay for certain services only because I have not yet received the important certificate. If you ask around, you are likely to find more mothers without the certificate than those who have it, and you will see that it is a big issue, not just for me. Week after week, month after month, we are always crying to the government to help us in this area. It is not something that is talked about often, like in the media coverage, but it is very important to us." Participant 3, mother of 3-year-old autistic male child.

Hence, the results indicate that inadequate support from the government is a key challenge facing mothers of children with ASD in Zhuhai City, China.

4.1.3 Fatigue, Stress & Anxiety

*Fatigue*

Another sub-theme that was found in relation to the challenges facing mothers of children with ASD is fatigue, defined as extreme tiredness, weariness, and lack of energy. Therefore, fatigue was considered to be a major theme in relation to the challenges experienced by mothers of children with ASD, with this theme generated after combining codes such as "tiredness", "overworking", "feeling demotivated", and "poor sleep". As one of the participants explained:

> "I feel like I have overworked myself and if I could make a wish right now, I would go for a short vacation and relax for a few days because honestly, I have very little fuel left in my tank. And when you have used up all your fuel, you obviously cannot function as normal. It is not easy, as you can imagine, organizing everything and making sure that all the important activities are conducted. I mostly get them done, but I can clearly feel the consequences of all the work that is in my schedule these days." Participant 9, mother of 10-year-old autistic child.

Hence, the results indicate that fatigue is a major challenge facing mothers of children with ASD in Zhuhai City in China.

*Stress & Anxiety*

Relatedly, the results reveal that stress and anxiety are crucial challenges facing mothers of children with ASD, whereby stress is defined as the feeling of being under pressure, overwhelmed, and/or unable to cope, while anxiety is defined as persistent, excessive worries that don't go away even in the absence of a stressor. Consistent with the aforementioned definition of stress, a majority of the participants indicated that they were feeling "pressured" by the demands of caring for a child with ASD while also constantly worrying about their child's development and future. As the mothers narrated in the interviews:

> "I cannot stop to worry that my child will end up having a completely different life to other children; my biggest headache is if he can find happiness in this unique world." Participant 8, mother of 6-year-old autistic male child.

> "I worry that if I don't do enough, I will not see my boy with a future that is full of happiness and life, but I believe that if the main issues are addressed by the government, then parents like me can have less pressure on their heads, and generally better state of mind." Participant 1, mother of 4-year-old autistic male child.

Therefore, the results of this research reveal that stress and anxiety are among the main challenges facing mothers of children with ASD in Zhuhai City in China.

*4.2 Coping Strategies Used by Mothers of Children with ASD*

In addition to revealing the challenges facing mothers of children with ASD, the results also revealed the main coping strategies used by these mothers to try to address the major caregiving challenges and improve their health and well-being.

4.2.1 Improving Social Support

Based on the findings, it can be argued that improving one's social support is necessary for mothers of autistic children to cope better with the task of caring for an autistic child. Rightly, social support from different members of the community was a key factor discussed by the mothers in the context of coping strategies used by mothers of autistic children. In the interviews, although some mothers claimed that support groups were not proving as beneficial as they should, there were other mothers who narrated how they were finding social support groups within the neighbourhood to be useful sources of social support, including emotional (feelings of love and care), material (financial help), as well as informational support. As one of the participants narrated:

> "We have this group of women, mothers like me, about 10 of us, and we occasionally meet to just talk about our lives and see where we can help each other to move forward. When we are there in the meeting, I often feel like I am sited around people who understand what I am going through and who really care for my condition." Participant 5, mother of 12-year-old autistic male child.

4.2.2 Online Social Support

While social support is often thought of as support coming from family members, relatives, friends, and colleagues, the development of social media is bringing to life a new form of social support — encouragement from users in online communities. According to several participants, the quest for social support when facing difficulty has led them to social media groups, which have been very supportive, particularly in terms of providing encouragement and advice. As one of the participants explained:

> "On WeChat, I found this group of parents who are in a similar situation to mine, and sometimes when I am not sure about something, I ask people in this group and immediately receive suggestions about the solution to my problem. Even though I don't know these people, I feel that this group has been

very helpful and has become an important part of my life for the last few years." Participant 4, mother of 10-year-old autistic male child.

Therefore, it can be said that at the very least, such online communities are useful in increasing one's perceived social support, promoting the sense that one is part of a supportive social group. Additionally, the results suggest that online communities such as social media groups can also provide actual social support to mothers of children with ASD, for example, by providing important information and advice. Hence, the findings of this research suggest that online social support can be useful for addressing the caregiving challenges and improving the wellbeing of mothers of children with ASD.

## 5. Discussion of the Findings

This chapter discusses the key findings, analyzing how these findings fit in the context of the existing literature on the topic. This chapter also evaluates the strengths and weaknesses of the research before discussing the implications for both theory and practice.

*5.1 Key Findings*

5.1.1 Mothers' Experiences of Stigma

One of the key findings of this research is that mothers of autistic children in Zhuhai City, Guangdong Province, China are experiencing stigma, which mainly occurs in the form of perceived judgements, disapproval, and discrimination from some members of the public. In the context of public health, the term stigma is commonly used to refer to the negative or discriminatory attitudes that people often develop toward others with certain illnesses (Östman & Kjellin, 2002; Schormans, 2014). Correspondingly, stigma can also be understood as undesirable signs of disgrace or discredit that set an individual or group of people apart from others, disqualifying them from full social acceptance (Stangl et al., 2019). Thus, this research reinforces the argument that stigma is a common problem experienced by parents of children with ASD (Kinnear et al., 2016; Liao, Lei & Li, 2019; Salleh et al., 2020), as the findings indicate that perceived stigma hinders the caregiving experiences of mothers of autistic children in Zhuhai City. As Salleh et al. (2020) argue, stigma is a problem that affects not only children with ASD but also the people that are close to them, such as their parents and siblings. Consistently, in the wider context of public health and mental illnesses, the existing literature concurs that stigma affects people with illnesses along with their families, with the term associative stigma used to refer to the process by which a person is stigmatised by virtue of association with another stigmatised individual (Schormans, 2014; Salleh et al., 2020).

In relation to the factors contributing to experiences of stigma, the findings suggest that lack of general understanding of ASD among the public might be a key factor contributing to the experiences of stigma among mothers of autistic children; this argument is consistent with previous research (Kinnear et al., 2016; Liao, Lei and Li, 2019) indicating that stigma manifests among autistic children and their parents when elements of labelling, stereotyping, separating, status loss and discrimination co-occur in a power situation that allows these processes to unfold. Importantly, previous research (Schormans, 2014; Salleh et al., 2020) argues that stigma can be in different forms, including public stigma, self-stigma, and institutional stigma. Public stigma involves the negative or discriminatory attitudes that others have about an illness, while self-stigma refers to the negative attitudes, including internalized shame, that people with an illness have about their own condition (Schormans, 2014). Institutional stigma, on the other hand, is more systemic, involving policies of government and private organizations that intentionally or unintentionally limit opportunities for people with certain illnesses (Salleh et al., 2020), for example, fewer ASD-related health services compared to other healthcare services. Therefore, in line with the existing literature on caring for autistic children, this research argues that stigma is one of the main challenges facing mothers of children with ASD in Zhuhai City, Guangdong Province, China.

5.1.2 Perceived Social Support

Another key finding of this research is that inadequate social support is a major challenge facing mothers of autistic children in Zhuhai City, Guangdong Province, China. In this research, social support refers to different types of resources (material, psychological, financial or emotional) that are provided by one's social network, mostly to help in dealing with stress (Gariepy et al., 2016; Cohen & McKay, 2020).

Importantly, social support can take different forms, with actions such as providing encouragement, advice, financial assistance, and empathy all categorized as social support. According to Winnubst (2017), social support can be categorized into four major types: emotional, instrumental, informational, and appraisal. Based on this categorization, it can be argued that the lack of emotional support, which involves expressions of love, empathy, caring, and hope, was discussed by the mothers, for example, in the statements "I need somebody to somebody to hug me and tell me that everything will be okay". Additionally, the lack of instrumental or material support, which refers to any tangible, material aid, or service that is provided to a person (Winnubst, 2017), was also discussed by the mothers of autistic children. Hence, the findings of this research are supported by Nealy et al.

(2012), who argue that parents of children with ASD face a greater risk of financial strain than parents of children without ASD, as there are high costs associated with caregiving services of people with ASD. Correspondingly, the findings are in line with previous studies (Nicholas et al., 2017; Vernhet et al., 2019) indicating that parents of children with ASD are generally required to devote a considerable amount of their time to caregiving, as the symptoms of ASD often persevere across the lifespan.

In addition to discussing emotional and instrumental support, the mothers of autistic children also talked about the lack of informational support, defined as any advice, suggestions, facts, or information that can help a person overcome a challenge (Cohen & McKay, 2020). Furthermore, appraisal support, defined as information that is useful for self-evaluation, is another type of social support that was also discussed in relation to the challenges experienced by mothers of autistic children. Therefore, the results indicate that mothers of autistic children are experiencing issues in relation to all the four major types of social support (emotional, instrumental, informational, and appraisal), hence, the argument that inadequate social support is among the main social challenges faced by mothers of children with ASD in Zhuhai City in China.

### 5.1.3 Lack of Disability Certificate

The results also revealed that mothers of autistic children in Zhuhai City were experiencing difficulties in accessing disability certificates for their children, with this difficulty contributing to the high costs of caring for their autistic children. While mothers of autistic children highlighted the lack of disability certificate as a key issue, they were also quick to point out that the Chinese government has helped them in some ways, which is consistent with recent reports revealing that over the past few decades, there have been noticeable improvements in China's social protection system for persons with disabilities, including the protection of children with disabilities (United Nations, 2022). Since the early 2000s, several policies have been implemented to facilitate the active integration of children with disabilities in society, as for example, the country's policies related to compulsory education state that school-age children with disabilities have the right to receive compulsory education (United Nations, 2022). Additionally, the national government has reiterated its commitment to work in conjunction with local governments to ensure that different forms of learning and education are offered in consideration of the specific needs of children with disabilities, so they can attend regular and special education classes of regular schools or enroll in special education schools (United Nations, 2022). In 2017, the Chinese government made a vow to make additional improvements to the education system for children with disabilities, with policies implemented to strengthen the foundation for special education development, actively promote inclusive education, and ensure that 95% of school-age children with hearing, visual and intellectual disabilities are enrolled in compulsory education by 2020 (Xinhua, 2020; United Nations, 2022). Moreover, the national government has been calling for local governments across the country to offer free pre-school and senior secondary education to students with disabilities facing financial difficulties (Xinhua, 2020). Therefore, it can be argued that there has been some improvement in the Chinese government's role of promoting the development of children with disabilities in the country.

However, there needs to be further improvement in relation to provision of social protection and quality education to children with disabilities in China, with the government admitting that one of the main challenges in this respect involves the lack of comprehensive, accurate and consistent information to ensure that persons with disabilities are able to access preferential policies and welfare protection services that they are eligible for and in need of. According to the State Council, although there are more than 85 million people living with disabilities in the country, only 30 million have a certificate of disability, which implies that more than half of people living with disabilities in China do not have access to fundamental welfare protection services. These statistics are consistent with the results of this research, as a majority of the mothers interviewed revealed that they had not yet accessed certificates for their children. Thus, it can be argued that the lack of certificates of disability is an issue that the Chinese government is aware about, and that this is a challenge that is faced not only by (mothers of) autistic children but also by the wider category of people living with disabilities in China.

### 5.1.4 Fatigue, Stress and Anxiety Among Mothers

Moreover, fatigue, stress, and anxiety were identified among the major challenges facing mothers of autistic children in Zhuhai City, Guangdong Province, China. In this regard, it is important to note that fatigue — the state of tiredness — is different from sleepiness or drowsiness, which only involves feeling the need to sleep and does not involve lack of energy and motivation (Thompson, Amatea & Thompson, 2014). Although fatigue is considered to be a normal response to factors such as physical activity and emotional stress, doctors warn that higher and continuous levels of fatigue can seriously hinder one's ability to do things as well as the ability to focus and think clearly (Kocalevent et al., 2011; Singh et al., 2020). Therefore, it is vital for mothers of autistic children in Zhuhai City to get enough rests and reduce fatigue in order to think and focus more clearly.

Noticeably, the results suggest that there is a close association between stress and fatigue among mothers of children with ASD, consistent with previous findings (Papadopoulos, 2021; Patel et al., 2022) that have revealed

that parents of autistic children often experience long periods of stress, which can have damaging effects on their physical and mental states, which can lead to feelings of weariness and lack of energy. Thus, this research is consistent with previous findings (Corcoran et al., 2015; DePape and Lindsay, 2015; Ilias et al., 2017) indicating that parents of children with ASD generally have higher rates of emotional strain and mental disorders compared to parents of children without ASD. Additionally, the findings of this research support the argument that mothers of autistic children often experience a sense of burden (emotional, family, and social), distress, and vulnerability when raising a child with ASD (Papadopoulos, 2021; Patel et al., 2022). Therefore, the findings of this research suggest that reducing the stress levels among mothers of children with ASD can be useful in lowering fatigue and boosting the mental and physical health of the target population.

*5.2 Strengths and Weaknesses*

One of the main strengths of this research is that it has been able to reveal the main challenges or issues that are experienced by mothers of autistic children in Zhuhai City, Guangdong Province, China. Stigma — defined as the mothers' feeling or experience of disapproval or being discriminated against because of having autistic children — was found to be one of the main social challenges experienced by mothers of children with ASD in Zhuhai City. Additionally, inadequate social support — defined as the lack of adequate resources (emotional, material, informational, and appraisal support) provided by one's social network — was identified as a major social challenge experienced by mothers of autistic children in the region. Relatedly, the results reveal that fatigue — defined as extreme tiredness, weariness, and lack of energy — is also a key challenge experienced by mothers of autistic children in the region, with this challenge found to be closely associated with stress (the feeling of being under pressure, overwhelmed, and/or unable to cope) and anxiety among mothers of autistic children.

Additionally, another key strength of this research is that it has managed to identify coping strategies that can be used by mothers of autistic children in Zhuhai City to deal with the caregiving challenges experienced in their day-to-day lives. Based on the findings, it can be argued that improving one's social support is necessary for mothers of autistic children to cope better with the task of caring for an autistic child. Correspondingly, the findings have shown that community social support can be an effective coping strategy for mothers of autistic children in Zhuhai City, with community social support referring to different types of social support and/or comfort provided by one's family, friends, and other people in the community or neighbourhood. In the interviews, although some mothers claimed that support groups were not proving as beneficial as they should, there were other mothers who narrated how they were finding social support groups within the neighbourhood to be useful sources of social support, including emotional (feelings of love and care), material (financial help), as well as informational support. Indeed, for mothers of children with ASD, social support can be useful for lessening the negative effects of stress, as material, psychological, financial, and emotional support gained from one's social network can help a person to cope with mental stress (Gariepy et al., 2016; Cohen & McKay, 2020).

However, even though this research has managed to identify the main challenges facing mothers of autistic children in Zhuhai City, one of the weaknesses of the research arises from the sample size used in this study. While the small sample size was useful in providing in-depth, detailed information regarding the experiences and challenges of mothers, it should be noted that the small sample size makes it difficult to conclude that the identified experiences are relevant to the wider population of mothers of children with ASD in Zhuhai City. That said, it is still important to note that the findings of this research are consistent with the findings presented by most of the previous studies conducted on this topic, which indicates that the small sample size was useful in providing in-depth insights into the challenges faced by mothers of autistic children in the region.

*5.3 Implications*

5.3.1 Implications for Theory

Moreover, this research plays an important role in revealing the potential of online social support as a strategy that can be used in dealing with challenges of caring for a child with ASD. Although social support is often thought of as support coming from family members, relatives, friends, and colleagues, the development of social media is bringing to life a new form of social support — encouragement from users in online communities. According to the findings of this research, the quest for social support when facing difficulty has led mothers of autistic children in Zhuhai City to social media groups, where they have found very supportive groups (online communities), particularly in terms of providing encouragement and advice. However, the existing literature on social support for parents of autistic children largely focuses on the conventional form of social support i.e., from family, friends, and members of the community, with limited research conducted in relation to social support from online sources such as social media groups. Therefore, future research on the experiences of parents of children with ASD should provide an in-depth understanding of how parents of autistic children are viewing and using online support groups. For example, in the Chinese context, future research could explore the parents' usage of WeChat groups as a strategy to address the challenges of caring for a child with ASD. Additionally,

future studies should be keen on finding out whether doctors, nurses, and other health professionals are using social media platforms to reach and communicate to parents of autistic children, as the findings of this research suggest that social media platforms can be useful in conveying important information and messages to parents of autistic children. Hence, this research has useful theoretical implications.

5.3.2 Implications for Practice

In addition to the implications for future research, this research also has implications for practice, as generally, the findings can assist policymakers in Guangdong Province, China in improving the wellbeing of mothers of autistic children in the area by addressing challenges such as the lack of disability certificate. Rightly, the Chinese government has implemented several measures over the past few years to increase the access to certificates of disability, with one of the most recent actions involving the introduction of a new online service that facilitates applications for disability certificates (Xinhua, 2020). Compared to the traditional form of application, where applicants are required to submit relevant documents in person to specific offices, the new online platform provides more convenience in the application process. In addition, the online system allows users to access other important related services, such as reporting lost certificates and replacing them (Xinhua, 2020), which shows that this initiative by the Chinese government has the potential to increase the access to disability certificates in the country.

However, the results of this research indicate that there needs to be improvements in relation to issuing disability certificates, as many mothers of autistic children are yet to receive certificates for their children long after they completed the application process. Moreover, this research revealed that mothers of autistic children still have to visit local offices to follow-up on their applications, which implies that the new online service does not provide adequate information to help users track their applications. Hence, the Chinese government along with other relevant authorities should focus on reducing the time it takes for one to receive a certificate of disability after application. Thus, this research provides useful insights that can help policymakers in Guangdong Province, China to improve the wellbeing of mothers of autistic children living within the region.

## 6. Conclusion

The aim of this research was to explore the caregiving experiences and challenges of mothers of children with ASD in Zhuhai City, Guangdong Province, China. To achieve this aim, the research employed a qualitative design mainly because this design is considered to be useful for conducting exploratory research. Consistently, semi-structured interview was used as the method for collecting qualitative data mainly because of its usefulness in providing rich and in-depth qualitative data. Thus, using semi-structured interviews in this research facilitated the collection of rich, qualitative data regarding the experiences and challenges of mothers of children with ASD. The study population comprised mothers of children with ASD in Zhuhai City, Guangdong Province, China, and purposive sampling was used to select a suitable sample of 10 mothers that was used in the study. The participants were recruited from a rehabilitation center for children with ASD in Zhuhai, Guangdong Province, while Braun and Clarke's (2019) six-step thematic analysis method was used to analyze the qualitative data collected from the sample of mothers of children with ASD. Overall, the results reveal that the main social challenges experienced by mothers of autistic children in the region include stigma, inadequate social support, as well as fatigue, stress & anxiety. In addition to revealing the challenges facing mothers of children with ASD, the results also revealed the main coping strategies that can be used by mothers of autistic children in addressing the major caregiving challenges and improving their health and well-being.

In addition to revealing the challenges facing mothers of children with ASD, the results also revealed the main coping strategies used by these mothers to try to address the major caregiving challenges and improve their health and well-being. Based on the findings, it can be argued that improving one's social support is necessary for mothers of autistic children to cope better with the task of caring for an autistic child. Rightly, community social support was a key factor that was discussed by the mothers in the context of coping strategies used by mothers of autistic children. Community social support refers to different types of social support and/or comfort provided by one's family, friends, and other people in the community or neighbourhood. In the interviews, mothers narrated how there were finding social support groups within the neighbourhood to be useful sources of emotional, material, as well as informational support. According to the mothers, social support groups within the neighbourhood are useful sources for not only financial help and information but also the feelings of love and care. While social support is often thought of as support coming from family members, relatives, friends, and colleagues, the development of social media is bringing to life a new form of social support — encouragement from users in online communities. According to several participants, the quest for social support when facing difficulty has led them to social media groups, which have been very supportive, particularly in terms of providing encouragement and advice. More specifically, the findings suggest that social support, not only from members of the community but also from online "communities" can be useful for addressing the caregiving challenges and improving the wellbeing of mothers of children with ASD. Therefore, this research has valuable

implications for both theory and practice, as the findings can be useful in terms of providing insights that can help relevant policymakers to develop effective policy actions to address the challenges of mothers of children with ASD and improve their wellbeing and quality of life.

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