

# Brazilian Grandparents in Households of Children with ASD: Roles and Experiences

Understanding the roles and experiences of grandparents in households of children with ASD in a Brazilian context.

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## **Abstract**

Grandparents play an important role in the households of children with Autism Spectrum Disorder. The goal of this thesis is to understand the roles that grandparents play within the family of children with ASD and their experiences in the family. Using semi-structured interviews, seven Brazilian grandparents shared their experiences being part of a household of a child with ASD. Data was coded inductively and deductively and key themes were identified. It was found that grandparents fulfilled several roles in the family, including providing companionship, love and affection to their grandchild, cooperating and supporting their adult child and the nuclear family unit and managing grandchild's ASD. Several aspects of experiences of grandparenthood emerged from the data. Firstly, grandparents' emotional experiences were extremely rich and a wide spectrum of emotions were reported: shock, worry and anxiety, overwhelmed and exhaustion, sadness, joy, pride and hope and optimism. Also, grandparents experienced a variety of concerns such as daily caregiving challenges, concerns for other members of the family, limited understanding of ASD and resources available for grandchild and fear for the future. Next, grandparents experienced tension that arose within the family due to differences in opinion and tension from the different roles they play within the family. Lastly, grandparents experienced an expansion of their understanding and management of ASD and openness to learn and share with other grandparents.

This article-based Master thesis comprises of two parts: an extended summary and an article manuscript. The extended summary will present the theoretical aspect of the study and contextualise the methodological aspect of the study. Next, the article manuscript, "Brazilian Grandparents in Households of Children with Autism Spectrum Disorder (ASD): Role and Experiences", written for submission to Journal of Autism and Developmental Disorders will be presented.

## **Preface**

I would like to thank the following people for making the completion of this thesis project possible:

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This project was inspired by my beautiful family. A huge note of appreciation for my parents (who received a status upgrade themselves during the course of this thesis and are grandparents to my 3 beautiful babies: Emma, Felicia and Miya). Most importantly, my grandparents (阿嬷, 外婆, 外公). Thank you for demonstrating what it is like to love unconditionally and to provide for your family in the gentlest of ways.

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# **1 Introduction**

## **1.1 Objective of thesis**

The objective of this thesis is to present a summary of literature on grandparenting a child with ASD and expand literature's current understanding of grandparenthood by increasing the diversity of voices in grandparenting literature. This thesis aims to explore the roles and experiences of grandparents through a dignified lens and close the gap between research and practice by providing an accurate account of experiences on the ground. This article-based Master thesis comprises of two parts: an extended summary and an article manuscript.

## **1.2 Connection between Extended Summary and Article Manuscript**

Firstly, the extended summary will contextualise and provide an explanation for the choices that were made for the study. This includes the background of this project, the use of a strength-based approach to understanding grandparents' experiences as well as the choice of methodology- ethnographic approach to data collection and research-tandem as a tool for reflection. Finally, the implications of the study will be discussed within the strength-based approach.

Next, the article manuscript, in accordance with the authorship guidelines from Journal of Autism and Developmental Disorders, will be presented. The article manuscript explores the roles that grandparents play and their experiences of grandparenthood within the family of children with ASD in Brazil. Also, the article manuscript discusses the findings in relation to current literature and their implications in practice, research and policy. Details of the journal's guidelines for submission can be found in the extended summary (refer to Appendix 1)

## **1.3 Journal of Autism and Developmental Disorders**

The article manuscript was written in accordance with the authorship guidelines from Journal of Autism and Developmental Disorders, ISSN (Electronic) 1573-3432, a peer-reviewed, English language, scholarly periodical that is focused on all aspects of autism spectrum disorders and related developmental disabilities. In addition to advancing the theoretical and applied understanding of autism, JADD is also endeavoured to promoting well-being of children and families by publishing scholarly papers on topics such as

advocacy, culture and society and service provision. JADD is published by Springer Science+ Business Media, LLC, part of Springer Nature.

JADD is the choice of publication due to its far-reaching and cross-disciplinary audience. The journal appeals to authors and readers from different backgrounds, including researchers, professionals and policy makers from diverse range of disciplines. Also, JADD is indexed in major bibliographic and citation databases. As such, it furthers the agenda of increasing the diversity of grandparenthood literature that this thesis hopes to achieve.

## **2 Background of Study**

This section will discuss the background of the thesis project. The Brazilian context will be presented.

### **2.1 Brazilian Context**

In the Brazilian context, life expectancy is measured at 76 years old in 2020 (The World Bank Group, 2022). Along with global trends, life expectancy of Brazilians has increased over the years. The increase in life expectancy and global aging phenomenon has ripple effects on family units and relationships, particularly intergenerational relationships. This is because grandparents are healthier and stay in the role longer than before- providing opportunities for stronger relationship with grandchild and adult children.

Mendes-Castillo and Bouso (2015) discussed that changes to the family unit as a result of the global aging phenomenon can be observed in Brazil. The likelihood of more than two generations coexisting as a family unit is becoming increasingly common. Grandparental support in the family nucleus is becoming increasingly important as the Brazilian society evolves. For example, mothers considered grandparents as the main alternative which enabled to engage in professional duties and personal activities.

Limited Brazilian studies have investigated the role and experiences of grandparents. In a study conducted among Brazilian grandparents, Matsukura and Yamashiro (2012) found that grandmothers were an important source of support for the families of children with special needs- providing instrumental and emotional support to different members of the family. Yet in the study, grandmothers interviewed conveyed their concerns for their adult child, grandchild with disabilities and their typical developing sibling. In addition, Brazilian grandmothers were reported to put aside their interests, in favour of helping the family, suggesting that their obligation to the family preceded other responsibilities.

In the international literature, research focusing on grandparents of children with additional needs such as disabilities or health issues had gained traction. As grandparents had solidified its significance as support for the family nucleus for children with additional developmental challenges in Brazil, the same trend has not been echoed in the literature. As such, Mendes-Castillo and Bouso (2015) had called for more Brazilian studies to explore intergenerational relationships when a child is ill.



### **3 Theoretical Perspective**

This section will discuss the strength-based approach to understanding grandparents of children with ASD. Firstly, the strength-based approach will be explained. Next, the importance of strength-based approach in building resilience will be discussed. Lastly, the strength-based approach will be discussed in context of this thesis.

#### **3.1 Strength-based Approach vs Deficit-based approach**

Strength-based approach to understanding grandparents cannot be understood without mentioning of deficit-based approach. In the earlier literature of understanding families of children with ASD, studies have attempted to understand experiences of family members in the context of caregiver burden, parenting stress and difficulties (Ho & Keiley, 2003; Lee et al., 2015).

In deficit-based approaches, families of children with disabilities were assumed to experience negative consequences (e.g. stress) that may arise from children's needs. Often, responses of these family members are interpreted through the lenses of pathology (Kearney & Griffin 2001). On the contrary, strength-based approaches aim to focus on the strengths of family member and use those strengths as protective factors.

#### **3.2 Importance of strength-based approach**

Strength-based approach to understanding phenomenon has often been used to investigate resilience in families. Three factors were identified to contribute to family resilience: family's ability to create meaning from adversity, encouraging one another's strengths and maintain a positive outlook and having a spiritual belief system (Walsh, 2003).

Stephan (2021) discussed and supported the use of Seligman's Wellbeing Theory, or PERMA model to understand grandparent caregiving experiences. According to the PERMA model, five factors are necessary for an individual to "flourish": positive emotions, engagement, relationships, meaning, and accomplishment (Seligman, 2011).

#### **3.3. Strength-based Approach in Understanding Grandparents**

In this project, the goal of adopting a strength-based approach is to provide a more balanced and comprehensive view of grandparents of children with ASD. As far as I know, this is the first international study regarding grandparents in households of children with ASD

in Brazil. The strength-based approach to this study attempts to set the stage for understanding the roles of grandparents from a dignified perspective for future studies.

## **4 Current Study**

### **4.1 Research Gap**

Considering the role of contemporary grandparents in the upbringing of children with disabilities, the amount of literature on grandparents has been relatively limited. Grandparents present unique opportunities for the family and development of child with ASD and consequently, may experience unique support needs as opposed to other family members (Novak-Pavlic et al., 2022). Also, much research has been focused on the Western context (i.e. North American, Australian context). As mentioned previously, Mendes-Castillo and Bousso (2015) reflected on the gap in Brazilian studies that focus on intergenerational relationships when a child is ill.

Currently there is a gap in the literature regarding the experiences of grandparents supporting households with children with ASD in Brazil. In addition, to close the gap between research and practice, an accurate account of experiences on the ground is necessary. With better understanding of the experiences of grandparents, more comprehensive support can be provided to help families with children with ASD thrive.

### **4.2 Goal of Project**

The goal of this project is to expand our current understanding of grandparents supporting families of children with ASD. By exploring the experience of being grandparents to children with ASD in a Brazilian context, this study seeks to address the gap in literature by increasing the diversity of voices of grandparents' experiences.

Using a strengths-based approach, this study seeks to give voice and shed light on Brazilian grandparents' experiences and perspectives (i.e. joys, struggles, challenges and support needs).

### **4.3 Research Questions**

This project seeks to answer the following research questions:

- (1) What was the role of grandparents in a family unit raising a child with ASD?
- (2) What was grandparents' experience of being part of the family unit?

## 4 Method

This qualitative project adopted a phenomenology approach to explore the real-life experiences of the participants and to enable researcher to understand the phenomena of being in a grandparent of child with ASD more comprehensively. A purposive sampling technique was deployed. Semi-structured discussion format interviews were conducted and participants were encouraged to share photos to supplement their sharing. Participants were provided time and space to reflect and describe their experiences of grandparenting.

The qualitative research design and discussion format of interview was meant to maximise participants' voice and agency by facilitating conversation and participant engagement. In addition, the use of photos to supplement data collected from interview questions enhanced the representation of participants' experiences.

To obtain an in-depth understanding of grandparenthood experiences among Brazilian grandparents, this project adopted an ethnographic approach. Using "research-tandem" as a device to , the ethnographic approach includes conducting field work before participants were recruited and interviewed for the study.

The next section provides an explanation of the Research Tandem programme as well as its merits and relevance to this project. Next, my positionality and reflexivity as a researcher will be presented. Further along, my fieldwork experiences in Victoria da Conquista will be reported. Subsequently, a discussion on ethics

### 4.1 Research Tandem

Research-Tandem programme within UiO's Master's programme that involves an international mobility, where students of two different countries collaborate on research project.

Xu and Marsico (2020) wrote about "research-tandem" as an innovative research device that can be especially useful in cultivating research intuition and reflection. Consisting of an insider (host) and a foreigner (guest), both sides will be exposed to a process of "defamiliarization" where guest student is exposed to a different cultural and educational context while host students will be required to respond to their curiosities and doubts. This process involves a closer examination of cultural beliefs and premises from both parties, which may have been taken for granted in daily practice. Having to suspend judgement and refraining from jumping into any conclusion, it allows a deeper analysis of the phenomenology.

Using “research-tandem” as a research device can be an effective way to combat the dominance of literature in grandparenthood in the West, as this thesis aims to achieve.

Partnering with Federal University of Bahia, Salvador de Bahia, Brazil, a host-student from Brazil- acted as my local informant and cultural mediator and worked together with me to collect data in the local field. This afforded me and my research-tandem partner opportunities to have a closer examination of grandparents’ roles and experiences in families of children with ASD that is rooted within their cultural and historical context of Brazil.

As mentioned by Tateo et al. (2018), polyphonic epistemology- where several gazes and narratives to a phenomena- adds to the richness of meaning-making process and speeds up the process of meaning-making. As such, this research device is a beneficial tool to examine this under-studied population- Brazilian grandparents in families of child with ASD.

#### **4.2 Researcher’s Positionality and Reflexivity Statement**

As one would imagine, sensitivity and reflexivity is required for research-tandem to be an effective tool for research. This section is dedicated to discussing researcher positionality and how a reflexive approach is incorporated to this project by clarifying my positionality.

Positionality refers to the lens through which an individual sees the world and the position that they adopt regarding the research task and its social and political context (Holmes, 2020; Savin-Baden & Major, 2013). Reflexivity refers to the concept in which researchers recognise and disclose their selves in their research and seek to understand their role in it or their influence on it (Cohen et al., 2011). Reflexivity requires researchers’ sensitivity to their cultural, political and social context (Bryman, 2016).

It is important to acknowledge one’s positionality as it affects the research process, the interpretations of the findings as well as how others’ research is interpreted (Smith, 2021). The importance of positionality and reflexivity extends support for research-tandem as an effective tool for research as it allows for deeper analysis of phenomenon where both insider and outsider perspectives are amplified and investigated among the pair of researchers.

#### **Statement**

As an international Master’s student from Singapore, my academic training prior to admission to UiO was grounded in psychology and special education. Singapore is small city-state with a dense population. It comprises of a diversity of ethnic, racial and religious groups. Kinship care is a common childcare arrangement option for dual-income families.

Due to its small geographic size, grandparents in Singapore are usually near to the nuclear family, making grandparental support an accessible solution for many families. In addition, it is also commonplace for three-generational families to live within the same home.

In my personal culture, grandparents play an important role in families, participating actively in activities and decisions involving other family members. This may have influenced my initial perceptions of the role of grandparents within the family. Furthermore, having worked as a Special Needs Education Officer in mainstream primary and secondary schools in Singapore, my experience with students with ASD and their families may have shaped my assumptions about grandparents' experiences being part of the family. Nevertheless, the fieldwork conducted before the start of data collection has allowed me to gain a better understanding of the needs and challenges faced by families of children with ASD on a larger scale. It provided me with a more comprehensive context in which the grandparents and their families reside in. Also, the conversations with my Brazilian research tandem partner and project supervisor supplemented me with additional information of the context. For example, it is not uncommon in Brazil for nuclear families to live apart as parents may find better work opportunities outside of the city or country. Another example is that it is not rare to find grandparents supporting grandchildren whom they are not related to by blood. This meant that I had to expand my idea of how nuclear families and extended families are defined and as such, the roles and experiences of grandparents could be different from what I had been personally familiar with.

As a Singaporean with Chinese ethnicity, English is my first language and Mandarin is my mother tongue. With no knowledge of Brazilian Portuguese, there was a potential influence of my positionality as an Asian, which is considered a foreigner in Brazil, on how much in detail participants shared. For example, some grandparents checked-in regularly with interviewers if they were answering the questions. Also, they tended to supplement their sharing with more details to provide more context to incidents that they had shared. Furthermore, my presence and position as an international student in Brazil during data collection may have influenced how grandparents perceived the importance of the research. Many grandparents expressed the importance of international research to better understand the world of individuals with ASD.

### 4.3 Field Notes

The field notes are arranged according to the organisations that were visited during my time in Victoria da Conquista, Bahia, Brazil, in order to understand the Brazilian context relating to taking care of children with ASD. The organisations visited were: Universidade Estadual do Sudoeste da Bahia (UESB) Disability Office, SEN Support Office at Colégio Estadual Abdias de Menezes and Associação Conquistense para Atendimento Especializado à Pessoa Autista (ACAEP). These field notes reflected my experiences in uncovering the context of Brazilian families and support for individuals with ASD as well as my reflections on my positionality and reflexivity.

#### 4.3.1 Universidade Estadual do Sudoeste da Bahia (UESB) Disability Office

The first organisation that was visited was the disability office situated within the state university that my supervisor taught at. The goal of the visit was to understand the function of a disability office situated within a higher education institute.

##### Physical Space

The office was the venue for the meeting. Accompanied with my supervisor and research tandem partner, we conducted the interview with one of the staff supporting students' inclusion in the university. The office consisted of two tables, adjacent to each other, with just enough standing room for the three of us. The setting was rather informal and other colleagues dropped in every now and then to check in with us and were happy to answer any questions we had. As I entered the office, I was greeted with stacks of books in braille piled up at perimeters of the office.

At this point, I had some reflections regarding the physical space I found myself in. Firstly, limited office space made me think about how the function of space and how it possesses the power to embrace or prevent people from belonging in certain spaces. In the settings that I am used to, a room will commonly be provided for meetings like this. Despite the lack of formal space, the informal space felt welcoming and intimate. Also, spaces facilitated sharing or non-sharing of information.

The next reflection I had was in relation to the braille books in the office. Staff members shared that these books were previously used by their clients with vision loss. However, as technology advances, many have adopted other forms of assistive technology such as audiobooks. It made me reflect on how the pace in which support for people with

special needs are advancing so quickly, with developments in technology moving the agenda. At the same time, there is a big risk of being left behind if there is no structure in place to ensure that professionals have the space and resources to develop professionally or get updated with new knowledge. Also, professionals need to find means to disseminate new knowledge in time before it becomes obsolete again. This reflection extends beyond professionals in the field to families of children with ASD.

### “Simpler” Special Needs

Beyond the clients with physical disabilities, staff member shared that they were currently supporting two students with ASD. Staff members noted that for students with ASD, their area of needs particularly communication issues are simpler needs as compared to other physical conditions that they were supporting. This was an interesting comment that stuck with me because I wondered what made a need “simpler”. I considered the concept of visible and invisible disabilities. Also, the consideration of cost of support came to mind. As compared to the reality that I was familiar with, physical disabilities are considered “simpler” as it can be solved more readily with financial resources.

### Challenges identified by office

Next, the office identified the following challenges to inclusion of students with disabilities in the university.

Firstly, there was generally a lack of awareness of the office and the services provided by them. Secondly, staff members acknowledged that they had limited expertise or knowledge in supporting disabilities beyond physical disabilities. Next, the expectations of support from parents and students with disabilities were limited. The absence of understanding of needs and support among parents had often resulted in unrealistic expectations of SEN office. Also, perception of support by students with disabilities was identified as a challenge. When students were unaware of their own needs, or the support they could get from the university, it created a barrier that prevented them from seeking help. Also, communication across departments of the school were limited which created a barrier for collaboration and innovation of inclusive practices. Mindset of professors were discussed as a challenge, particularly some professors were resistant to inclusive practices if it required them to adapt practices (e.g. differentiation). Lastly, there was a high turnover rate of professionals, resulting in projects and initiatives ending before they could see the impact of it.



The lack of sustainability of support structures led me to think of the conditions that need to be in place to ensure that the perception of support by students, families and professionals within the field are perceived to be supportive.

### Success Stories

Staff member shared some success stories from the office. It mainly consisted of graduates who managed to graduate and enter their professions such as law. Also, previous clients of the office were now leading associations for people with additional needs.

This question was posed because I was curious about the idea of best outcomes for people with special needs in Brazil. Success stories highlighted by staff members were of certain professions/ positions associated with prestige (e.g. law). Staff members were filled with pride when they were sharing their stories. It made me think of how people of different backgrounds and professions defined what success meant and how it looked it. I thought about my definition of success for students with special needs that may be limited by my own experience and background and considered how I could expand my definition of success to include a wider spectrum of people. It was important to be aware of such beliefs as we might risk imposing our ideas of success on others.

#### 4.3.2 SEN Support Office at Colégio Estadual Abdias de Menezes

The second organisation that was visited was the disability office situated within a secondary school at Colégio Estadual Abdias de Menezes. The goal of the visit was to understand how students with special needs were included in the mainstream school. The visit started with a tour of the school and special rooms where special classes were conducted.

### Physical Space

The first scene that greeted us was the border between the school and the outside world. I felt some discomfort entering the space due to the heavily reinforced gates and windows within the school. Fig 1 shows images of the school premises and entrance. Yet, an observation of the students entering and leaving the premise did not suggest that they experienced any discomfort. During the tour of the school, classrooms supporting students with special needs were “open” such that we were free to enter and observe the class as it was

ongoing. Furthermore, the multi-function space was used as an office by the SEN coordinator and classroom for SEN intervention. Fig 2 shows the SEN coordinator's office.



**Fig 1 A. Windows in the classroom reinforced with metal grilles,**

**Fig 1 B. Entrance to the school where security guards and another metal gate exist behind**



**Fig 2. Multi-functional space as office for SEN coordinator**

### Challenges identified

Several challenges surfaced in the conversation with the team supporting students with SEN in the school. One of the main challenges that stuck out to me was the onus that the system placed on students with SEN and their families to be included in the mainstream school. For example, students have to put in additional efforts to catch up on classes they had missed because they have to attend therapy during school hours. Another example was how some parents had to readjust their work schedule so as to be present in school to help their

child with their toileting needs. This challenge also illustrated how policies can affect the microsystems of children with special needs.

Also, staff members discussed challenges in creating synergy between educational research and practice as educational research and practice exist as separate dual entities. Universities' lecturers had a tendency to be removed from the reality of classrooms in Brazil when delivering their classes. As a result, teachers-in-training were taught in a way that may be disconnected from reality and getting a different reality in practice

Compared to the disability office in an institution of higher education, the concerns that SEN teachers in this school aired had more direct relation to the family unit. Teachers shared their difficulties working with families of children with special needs and how home-school partnership had room for strengthening. Nevertheless, they face similar issues such as the shortage of professionals to carry out sustainable changes to support the students with special needs within the school.

Lastly, SEN coordinator shared her concerns for the future of students beyond their basic education, especially those whose abilities do not match what the mainstream idea of success entails.

### Grandparents' Role

In their work with families, teachers' point of view of grandparents' role in supporting children with special needs pointed to grandparents as compensation for gaps created by parents' absence. This could be due to different reasons such as having to provide financially or when parents are in denial of child's diagnosis.

As a special needs teacher in a mainstream school who had worked with grandparents of children with special needs, I was surprised by the specific scope of grandparents' role mentioned by the teachers. This encounter heightened my curiosity about the role of grandparents in Brazil.

### 4.3.3 Associação Conquistense para Atendimento Especializado à Pessoa Autista (ACAIEPA)

Founded by a mother whose child was diagnosed with ASD, the support group for mothers and caregivers of children with ASD was run out of the founder's home. ACAIEPA was created with other mothers of children with ASD after realising that there was a lack of information regarding rearing children with ASD.

Currently supporting twenty-five children, the organisation organised interest group for children with ASD and had therapists for mothers to provide psychoeducation and

emotional support and special education services (e.g. communication skills, stimulate cognition) for children with ASD.

### An encounter with a grandparent

During the interview with the founder of this group, a caregiver walked in. Upon knowing our role as researchers and our research interest, the caregiver- a grandparent- started sharing her story with us. She narrated her story and cried while doing so.

This encounter left a deep impression on me. It made me wonder about the availability of spaces where caregivers could turn to in order to release these emotions (in settings beside the official therapy sessions). Also, the emotional availability of grandparent to share her experience with people she had just met made me think about the conditions that need to be present in the environment for people to feel listened to. Perhaps the mere association with the organisation that they are seeking help from or as more-knowledgeable-other (education/knowledge as credential) was enough or does it require more active-listening skills. Furthermore, I wondered if grandparents would benefit from having a space like ACAEPA.

## **5 Discussion**

This section will extend the implications of study by discussing the possibility of using grandparents' narratives as a tool to enhance well-being of grandparents, enabling them to thrive in their role of grandparenting a child with ASD.

### **5.1 Grow as We Go**

Lee et al. (2015) conducted a study that looked into the use of mothers' narratives of their parenting journeys to redefine the meanings that mothers give to the process of care "giving" a child with disabilities. In this study, mothers transformed their perspectives of the role they play as caregivers over time using a deliberate reflective process.

Unintentionally, the premise of this thesis project sets a similar stage for grandparents to use their narratives to redefine the meaning they have attached to grandparenting a child with ASD. Also, this project highlighted the importance of having a platform for grandparents to share their experiences and for the reflective process to take place.

### **5.2 Strength-based Approach**

In addition to fulfilling its goal of increasing the diversity of voices in grandparenting literature, this thesis adds on to the strengths-based approach by contributing empirical results to suggest that grandparents experienced growth and development. Despite the challenges of raising a child with ASD, grandparents' experiences of supporting families of children with ASD is largely positive.

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## **Attachments to the extended summary**

### **Appendix 1. Instructions for Authors**

#### **Editorial procedure**

*Double-Anonymous Peer Review*

#### **MANUSCRIPT FORMAT**

All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins. Please disregard the suggestion of 10-point font in the Text section below.

#### **APA Style**

APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-anonymous review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
- The anonymized manuscripts containing no author information (no name, no affiliation, and so forth).

#### **Types of papers**

Articles, Commentaries Brief Reports, Letters to the Editor

- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been



published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.

- Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.
- A Brief Report: A Brief Report: About 8 double-spaced pages with shorter references and fewer tables/figures. Must meet the demands of scientific rigor required of a JADD article but can be preliminary findings.

### **Review your manuscript for these elements**

#### 1. Order of manuscript pages

Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

Anonymized Abstract, manuscripts and References without contact information

Appendix

Figure Caption Sheet

Figures

Tables

### **Manuscript Submission**

#### *Manuscript Submission*

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

#### *Permissions*

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print

and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

### *Online Submission*

Please follow the hyperlink “Submit manuscript” and upload all of your manuscript files following the instructions given on the screen.

### *Source Files*

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

## **Title Page**

### *Title Page*

Please make sure your title page contains the following information.

### **Title**

The title should be concise and informative.

### **Author information**

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the

Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.

### *Abstract*

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

- Purpose (stating the main purposes and research question)
- Methods
- Results
- Conclusion

### *For life science journals only (when applicable)*

- Trial registration number and date of registration for prospectively registered trials
- Trial registration number and date of registration followed by “retrospectively registered”, for retrospectively registered trials

### *Keywords*

Please provide 4 to 6 keywords which can be used for indexing purposes.

### *Statements and Declarations*

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- **Competing Interests:** Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

### **Text**

#### *Text Formatting*

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

### *Headings*

Please use no more than three levels of displayed headings.

### *Abbreviations*

Abbreviations should be defined at first mention and used consistently thereafter.

### *Footnotes*

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

### *Acknowledgments*

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

## **Body**

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
- Introduction (The introduction has no label.)
- Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
- Results (Center the heading.)
- Discussion (Center the heading.)

## **Headings**

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

## **Footnotes**

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the

footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

## References

### *Citation*

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson, 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author's name). However, if authors shorten the author group by using et al., this will be retained.

### *Reference list*

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

If available, please always include DOIs as full DOI links in your reference list (e.g. “<https://doi-org.ezproxy.uio.no/abc>”).

- Journal article Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. *Psychology of Popular Media Culture*, 8(3), 207–217. <https://doi-org.ezproxy.uio.no/10.1037/ppm0000185>
- Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient

rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? *American Journal of Physical Medicine & Rehabilitation*. Advance online publication. <https://doi-org.ezproxy.uio.no/10.1097/PHM.0000000000001435>

- Book Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.
- Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), *Media effects: Advances in theory and research* (4th ed., pp. 115–129). Routledge.
- Online document Fagan, J. (2019, March 25). *Nursing clinical brain*. OER Commons. Retrieved January 7, 2020, from <https://www.oercommons.org/authoring/53029-nursing-clinical-brain/view>

### **Tables**

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
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Attach the authors' manual / instructions to authors from the relevant journal

Attachments vary according to the type of master thesis and could include any relevant ethical approvals, information letters, interview guide or newly developed material used for data collection.

Appendices are relevant for most empirically based theses and may include elements such as interview guides, consent forms, permissions, etc.



**Article Manuscript**

**Brazilian Grandparents in Households of Children with Autism Spectrum Disorder  
(ASD): Role and Experiences**

Meihua Wang

For submission to Journal of Autism and Developmental Disorders

URL: <https://www-springer-com.ezproxy.uio.no/journal/10803>

## **Abstract**

Grandparents play an important role in the households of children with Autism Spectrum Disorder. The goal of this study is to understand the roles that grandparents play within the family of children with ASD and their experiences in the family. Using semi-structured interviews, seven Brazilian grandparents shared their experiences of being part of a household of a child with ASD. Data was coded inductively and deductively, and key themes were identified. It was found that grandparents fulfilled several roles in the family, including providing companionship, love and affection to their grandchild, cooperating and supporting their adult child and the nuclear family unit and managing grandchild's ASD. Several aspects of experiences of grandparenthood emerged from the data. Firstly, grandparents' emotional experiences were extremely rich and a wide spectrum of emotions were reported: shock, worry and anxiety, overwhelmed and exhaustion, sadness, joy, pride and hope and optimism. Also, grandparents experienced a variety of concerns such as daily caregiving challenges, concerns for other members of the family, limited understanding of ASD and resources available for grandchild and fear for the future. Next, grandparents experienced tension that arose within the family due to differences in opinion and tension from the different roles they play within the family. Lastly, grandparents experienced an expansion of their understanding and management of ASD and openness to learn and share with other grandparents.

**Keywords:** grandparent; experience; roles; qualitative research; ASD; Brazil

# **Brazilian Grandparents in Households of Children with Autism Spectrum Disorder (ASD): Role and Experiences**

Autism Spectrum Disorder (ASD) refers to a spectrum of neuro-developmental conditions that affects one's ability to communicate and interact with others. It is characterised by three core impairments: abnormalities in social communication and social interaction skills and repetitive stereotypical behaviours and/or unusually restricted interests and activities (American Psychiatric Association, 2010). Receiving an ASD diagnosis places plenty of stressors on a family unit (Kahana et al., 2015). With the broad spectrum of behaviours and characteristics associated with an autism diagnosis, caring for a child with autism presents a unique set of challenges for the family. A knowledge base about parental functioning and coping with a child with disability within the household has been well-established in the literature (Kahana et al., 2015; Pisula & Porębowicz- Dörsmann, 2017). Beyond parents, other members within the household may experience stress and other emotions from the autism diagnosis. Grandparents of children with ASD possess unique experiences of grandparenthood due to the exceptional caregiving challenges associated with ASD. This paper aims to adopt a strengths-based approach in understanding the roles of grandparents in households of children with ASD and their experiences of grandparenthood.

## *Bioecological Perspective*

One of the most extensively developed family ecological theories that can be used to examine the complex interactions and experiences of grandparents raising children with ASD is Bronfenbrenner's bioecological model of human development. The theory posits that development and growth of an individual is the result of interactions between the individual and the environment. Specifically, development is shaped by the interactions among an individual's immediate environment (microsystem), interconnections between elements of the

microsystem (mesosystem), societal support and institutions (exosystem) and cultural ideologies (macrosystem) (Bronfenbrenner & Morris, 2006).

Along the same line, the ecological theory of Autism posits that individuals with ASD lie in the heart of the environment that influences their development (Zigler & Stevenson, 1993). Many layers of the environment, ranging from immediate factors within the individual's environment (microsystem) to distant factors beyond the individual's influence (macrosystem), interact with the individual with ASD overtime to shape the outcomes of development.

Children with ASD are embedded in their microsystem- their immediate daily environment and network of relationships. This includes the family, school, external agencies, and professionals actively engaged in the support of the individual. Proximal processes refer to the reciprocal interactions between the child and the environment overtime (Bronfenbrenner & Morris, 2006). Many families rely on grandparents for additional support for the family. At the microsystem level, grandparents exert influence over grandchild's development through the relationship they have with their grandchild as well as how they manage their ASD traits and behaviours. In addition, grandparents exert influence over children's development on the mesosystem level by influencing the players in the children's microsystem such as supporting adult children.

#### *Grandparents in Brazil*

As with global trends, life expectancy of people has increased over the years. In Brazil, life expectancy is measured at 76 years old in 2020 (The World Bank Group, 2022). The increase in life expectancy and global aging phenomenon has ripple effects on family units and relationships, particularly intergenerational relationships. This is because grandparents are healthier and stay in the role longer than before- providing opportunities for stronger relationship with grandchild and adult children.

Mendes-Castillo and Bousso (2015) mentioned that grandparents in Brazil are increasingly a significant source of support in the family nucleus. Matsukura and Yamashiro (2012) found that grandmothers were an important source of support for the families of children with special needs- providing instrumental and emotional support to different members of the family. Yet in the study, grandmothers interviewed conveyed their concerns for their adult child, grandchild with disabilities and their typical developing sibling. In addition, Brazilian grandmothers were reported to put aside their interests, in favour of helping the family, suggesting that their obligation to the family preceded other responsibilities.

### *Roles of Grandparents*

In the literature, grandparents were reported to interact with their grandchildren with disabilities in different forms- from providing attention, affection, positive support to educational and therapeutic activities. Grandparents can provide intergenerational support through proactive adaptations, with focus on stress-related adaptive tasks. Specifically, grandparents could support coping efforts of parents through proactive disorder management, social support regulation and social role management (Kahana et al., 2015). Grandparents were perceived to be important source of practical, emotional and/or financial support for their adult children and family- including providing practical help around the household such as cooking, cleaning, baby-sitting as well as participating in taking their grandchild to educational and therapy services and providing simple therapy techniques for the child's development and education (Lee & Gardner, 2015). Also, it was reported that grandparents play an important role in supporting the mental well-being of adult children and alleviated parenting stress and other stresses related to nurturance of the child with disability (Crettenden et al., 2018; Lee & Gardner, 2015). Specifically, Crettenden et al., (2018)

reported that mothers who lacked support from their own parents are vulnerable to psychological distress.

From the grandparents' perspective, they saw their primary role as support for the family nucleus at the micro- and mesosystem levels. At the microsystem level, grandparents provided informal support through their interactions with the child. At the mesosystem level, grandparents provided financial and emotional support for their adult children (Yang et al., 2018).

Taken together, the literature suggests that grandparents play an important role in households of children with ASD. Nevertheless, apart from the study conducted by Yang et al. (2018), little is known regarding how grandparents perceived their roles within the family.

#### *Experience of Grandparenthood*

In addition to the important role that grandparents play in the family, grandparents of children with ASD have unique experiences of grandparenthood.

#### *Emotional Journey*

It was found that grandparents experienced an intense emotional journey when their grandchild was diagnosed with a disability, where they transited from anger to acceptance and their experience of "double grief"- grandparents' sadness about the forsaken possibilities for their adult child and grandchild (Woodbridge et al., 2009). It was consistent in the literature that grandparenthood was a mixed bag of negative and positive experiences. Typically, grandparents expressed joy and positivity in the role as grandparents by having a strong bond with their grandchild, sharing physical affection, admiration for their adult child's effort and pride and celebration for grandchild's incremental progress and reaching developmental milestones (Hillman et al., 2017; Hillman & Anderson, 2019).

#### *Challenges*

In the literature, grandparents generally described challenges to grandparenthood as the negative experiences to grandparenthood. Grandparents reported discrepancies between their initial visions of grandparenthood and their experiences (Yang et al., 2018). In the literature, challenges reported by grandparents included (1) unmet desire to connect with grandchild due to the absence of verbal communication and ASD-related traits and behaviours such as severe meltdowns and poor social skills, (2) instrumental concerns such as residing far away from grandchild, financial costs of interventions, and activities of daily living (i.e. meal preparation, sleep), (3) insufficient systemic support that reduce or deny grandchild's access to care, (4) concerns for their grandchild and adult children's future, (5) coping with their emotions, such as exhaustion and despair and (6) lack of formal support for resources on supporting their grandchild with disability (Hillman et al., 2017, Yang et al., 2018; Novak-Pavlic et al., 2022).

### *Tensions*

Using Lee and Gardner's (2015) analogy of the philosophy of yin and yang- opposites clashing and cooperating, grandparents' support in households of children with ASD could be perceived as a stressor to their adult children. Mothers reported that stress stemmed from grandparents' differing perceptions of disability- their denial of grandchild's disability or inappropriate information regarding disability- as well as their over-involvement in decisions about child's education.

Yet in other studies, grandparents found themselves drawing role boundaries- between parent and grandparent- and were careful to maintain their position as grandparent (Yang et al., 2018).

In addition to negotiating the demands of the different roles they fulfil within the family, grandparents had to manage ASD-related conflicts and tensions that may arise within the family unit or the extended family. Family conflicts included lack of tolerance of

grandchild's ASD-related traits and behaviours from other family members, resentment over grandchild's use of grandparents' time and financial resources and differences in opinion over the cause and treatment of ASD. (Hillman et al., 2016; Yang et al., 2018). These conflicts cause tensions and threaten family dynamics and relationships with members of the extended family. Many grandparents felt obligated to maintain this intergenerational harmony, ensuring that all members of the family, nucleus and extended, received. Such kin-keeping activities required significant work from grandmothers as they managed the needs of multiple family members, while masking their own emotions.

### *Growth*

Another notable experience of grandparents in households of children with ASD is their experience of growth. It was reported that grandparents displayed resilience despite their worries and the conflicts they experienced (Hillman et al., 2016). Specifically, using their positive experiences in grandparenthood and focussing on their pride for the family's ability to overcome setbacks, grandparents developed resilience against the challenges they encountered in this unique grandparenthood. Also, grandparents built resilience through giving back to their communities and by supporting others who were new to childhood disabilities (Novak- Pavlic et al., 2022)

As ASD became more embedded into their family lives, grandparents were reported to experience transformative insight to their grandparenthood (Hillman et al. 2017). Also, grandparents were actively learning and familiarising themselves with the systems of support available for their grandchild (Moffatt et al., 2019). Furthermore, grandparents of children with ASD were reported to advocate for children with ASD through educating others in both altruistic and instrumental ways as well as supporting community services that aided them (Hillman et al., 2017; Novak-Pavlic et al., 2022)



Taken together, the literature suggests that grandparents of children with ASD possess unique and rich experiences of grandparenthood in different aspects. Despite the differences in their circumstances, grandparents across different contexts had similarities in their experience of grandparenthood of a child with ASD. Nevertheless, grandparents of children with ASD remains an under-researched group. Specifically, grandparents from Brazil were not represented in the literature.

### *Research Gap*

Considering the role of contemporary grandparents in the upbringing of children with disabilities, the amount of literature on grandparents has been relatively limited. As such, it is important to understand the experience of grandparents in households of children with ASD. Grandparents present unique opportunities for the family and development of child with ASD and consequently, may experience unique support needs as opposed to other family members (Novak-Pavlic et al., 2022). Also, much research has been focused on the Western context (i.e. North American, Australian context), with exception of Lee and Gardner (2015). This concern is echoed by Mendes-Castillo and Bouso (2015), who reflected on the gap in Brazilian studies that focus on intergenerational relationships when a child is ill. With better understanding of the experiences of grandparents, more comprehensive support can be provided to help families with children with ASD thrive.

### *Purpose of Study and Research Questions*

The purpose of this study was to explore the experience of being grandparents to children with Autism Spectrum Disorder (ASD) in a Brazilian context. This study sought to address the gap in literature by increasing the diversity of voices of grandparents' experiences. In addition, this study sought to give voice and shed light on Brazilian grandparents' experiences and perspectives (i.e. joys, struggles, challenges and support needs).

The research questions of this study were: (1) What was the role of grandparents in a family unit raising a child with ASD? (2) What was grandparents' experience of being part of the family unit?

## Method

### *Research Design*

Design, test materials and procedures were approved by Norwegian Agency for Shared Services in Education and Research (SIKT). This qualitative study adopted a phenomenology approach to explore the real- life experiences of the participants and to enable researchers to understand the phenomena of being in a grandparent of child with ASD more comprehensively. A purposive sampling technique was deployed.

Semi-structured discussion format interviews were conducted. Participants were provided time and space to reflect and describe their experiences of grandparenting. The qualitative research design and discussion format of interview was meant to maximise participants' voice and agency by facilitating conversation and participant engagement. In addition, the use of photos to supplement data collected from interview questions enhanced the representation of participants' experiences.

### *Participant*

Interviews were conducted with seven grandmothers from Bahia, Brazil. The criteria for participation include (1) having a grandchild with ASD and (2) either staying with their grandchildren or self-reported participation in grandparent support (e.g. babysitting).

Participants were recruited through organisations and agencies serving people with disabilities in the city of Vitoria da Conquista, Bahia. These organisations and agencies included general school departments (secondary school and university) supporting students with special needs, clinic for psychological treatment (i.e. SEMEAR) and non-governmental organisation supporting caregivers of children with ASD (i.e. ACAEPA). Referrals were provided by these organisations and agencies and information letter and informed consent forms were handed to potential participants. Phone calls were then conducted to elaborate on the purpose and procedures of the study. Table 1 summarises the additional details of the

grandparents. Personal data (of adults and children) were pseudonymised to ensure that the identity of participants was kept confidential.

#### *Data collection*

Semi-structured discussion format interviews were conducted individually online or at the organisation of referral. Semi-structured interview questions were designed to understand grandparents' perceptions of (1) the role they play within the family and (2) being part of the family unit raising a child with ASD. Interview questions were translated from English to Brazilian Portuguese. Examples of interview questions can be found in Table 2.

In addition to the interview, participants were invited to share photos along the following themes: (a) photos of their typical interactions with their grandchild; and (b) photos of objects, events, or activities that symbolise their role as grandparent; and (c) photos of something significant or dear to them around the theme of being a grandparent or what being a grandparent meant to them. Photos was used as secondary data to supplement the data retrieved from interviews. This data collection method is adapted from the study conducted by Yang et al. (2018).

#### *Interview procedures*

Interviews were conducted individually at the convenience of participants. They took place online via video call or facilities associated with their grandchild's therapy services (i.e. SEMEAR). A quiet room was provided by the facility for confidentiality and to facilitate audio recording. Personnel of SEMEAR were present during the interviews conducted at the facility.

Firstly, participants were greeted, and researchers present were introduced. Subsequently, the purpose of study and interview process was explained to the participants. Informed consent was obtained and permission was sought for interview to be audio-recorded. Participants were invited to share photos to supplement their sharing. Photos shown to researchers were not saved and details of the photos were recorded. Participants were

encouraged to express their honest views and were given ample time to respond to interview questions. Before proceeding with the guided question, participants were asked if they had any questions. Interviews were conducted by local researchers in participants' native language, Brazilian Portuguese. The interviews lasted from 25 to 60 minutes.

Out of 7 participants, 5 grandparents supplemented their sharing with photos and videos. A total of 5 videos and 20 photos were shown. Details about the photos are presented in Table 3.

#### *Data analysis*

Interviews were recorded, transcribed, and translated from Brazilian Portuguese to English. Data was handled with Nvivo, a qualitative data analysis software. Inductive and deductive coding were used. Firstly, transcripts were reviewed for accuracy and open-coded paragraph-by-paragraph. Some examples of open codes include (1) optimism and hope, (2) provide practical assistance, (3) differences in opinion. Next, using key concepts and ideas from research questions and theoretical framework, codes were categorised and grouped based on their themes. Examples of categories include (1) grandparent role; (2) emotional experience; (3) tensions experienced; (4) grandparent's concerns. Throughout the analysis process, faculty supervisors on the projects were consulted to discuss the emerging findings.

## Results

The purpose of this study was to explore the experience of being grandparents to children with Autism Spectrum Disorder (ASD) in Brazil. The key themes that emerged from the study include: (1) the roles of the grandparent in the family, (2) the experience of grandparenthood, and (3) grandparents' concerns.

### *Grandparent's Role*

Consistent across participants, grandparents perceived their role to provide companionship, love and affection to their grandchild. Also, grandparents spoke extensively about their role in collaboration with the grandchildren's parents- to cooperate and support their adult child and the nuclear family unit. In addition, several grandparents discussed their role in the management of grandchild's ASD.

### *Companionship and love for grandchild*

Grandparents reported that they partook in caregiving responsibilities because they did not want their grandchild with ASD to be left with a caregiver whom they were unfamiliar with. Grandparents talked about their love and pride for their grandchild. Grandparents saw their role as pampering their grandchild and showering them with love and affection: 'Since the father and mother educate, the grandparents does not educate, so grandfather and grandmother is to give affection to the children.' (#4) As one grandparent put it: 'The only thing I can do is to give her affection' (#2), referring to grandparents' role in providing affection as the role of caregiving were fully fulfilled by parents.

### *Supporting adult child and family unit*

For grandparents, their role in supporting their adult children and family unit was equally important. This support included practical support for the family unit, supporting adult children and sharing knowledge on parenting.

Firstly, all grandparents reported providing some form of practical support in raising their grandchild with ASD. This support included transporting grandchild to school or therapy sessions, babysitting while parents were working full-time. In addition to supporting the daily administrative of caregiving, other grandparents reported rendering financial help to the family unit. Acknowledging the cost of intervention sessions as well as the general cost of living, grandparents who were employed contributed financially to the expenses of the family: ‘Nowadays, a house cannot be kept with only one (family member) working. Two or three adults working are required to meet the general needs of the household’ (#1).

Next, grandparents fulfilled an important function for their adult children by providing encouragement and emotional support as adult children navigate the complex emotional journey of raising a child with ASD.

And when [my daughter] asks me, sometimes she has a meeting, I say I can, I never say "no" because I know she needs it. The mother is always there for her children when she needs it. (#4)

Also, an important perspective from grandparents regarding their role in supporting their adult child was that it created more space for their child to take care of their grandchild. Grandparents reported taking care of miscellaneous chores around the household so that their adult child can focus on parenting and taking care of themselves. Grandparents recognised the considerable effort required to manage grandchild’s ASD and tried to relieve their adult child’s caregiving responsibilities periodically.

Because, like, the parents need to go out, right? They also need to have fun ... And then one day we had to be with [grandchild] and that's where we realised how much [adult child] go through ... But you could see how much they had to work. (#7)

Next, grandparents reported sharing nuggets of parenting wisdom with their adult children. For example, as one grandmother commented:

Some things I say, like advice, like what I think will not work, but it is a tip. Not to tell how to raise, because this is something each one discovers their own rhythm. There is no right formula, there are some tips that we can improve. (#3)

Even so, grandparents were aware of their support role in raising their grandchildren and drew boundaries between being a grandparent and parent:

The difference is that I am the grandmother. I do not have to do as much as the mother, because the bigger job has to be the mother's. She has had this job with him, I only cooperate. (#5)

#### *Management of grandchild's ASD*

Grandparents took on a supporting role in managing grandchildren's ASD through different means such as finding additional information and resources to support the needs of their grandchildren, advocating for their grandchild and supporting other members of the family.

Firstly, grandparents shared that they contributed to the family's management of grandchildren's special needs by sourcing for additional information to support their grandchild's ASD. For example, one grandparent shared that 'his grandfather is coming with us to run after more information on how we will deal with (grandchild's problem behaviours in school)' (#1). For this grandparent, she played an intermediary role of dealing with schools' special arrangements before the family adjusted to the new schedule. Specifically, she had to make changes to her work schedule so that she could send her grandchild to school or stay home with her grandchild while she sought therapy support for her grandchild's challenging behaviours.

On occasions, grandparents took on the role of researching that their adult children might not had the time for:



I see a lot; I go on Google ... I get information, sometimes there are things that I send to his parents, you know, I go online, I get the link, I send the parents, to the mother as sometimes maybe they do not have time. (#7)

Next, grandparents found themselves taking on the role of advocate for their grandchildren and ASD. Grandparents encountered situations within the extended family where they had to help others understand the traits of ASD and their grandchildren's needs:

I would like to try to show people that autism is not a disease ... I get so sad when I see people looking and sometimes pointing. After we discovered [grandchild]'s autism ... I would like to try to show people that this is something natural. That we have to live, to try to love them more naturally, and to welcome more of these people. (#4)

In addition, grandparents played a role in supporting others in the family by resolving conflicts that arose among different members of the family. A grandparent shared that she had to manage the discussion between her two daughters regarding parenting strategies:

My oldest daughter ... thinks (grandchild)'s mother is wrong. She is trained in psychopedagogy ... When you have an idea different from what we're following, ... it always generates a polemic ... I'm between these two, I keep seeing the knowledge of the other and I keep seeing [grandchild]'s mother. (#5)

### *Experience of Grandparenthood*

There were several aspects of experiences of grandparenthood for grandparents raising a child with ASD that emerged from the data. It includes (1) grandparents' emotional experience, (2) grandparents' concerns, (3) tensions that grandparents experienced and (4) grandparents' growth and development.

### *Emotional experience*

Grandparents of children with ASD experience a rich spectrum of emotions along their grandparenthood journey. These emotions include (1) shock, (2) worry and anxiety, (3) overwhelmed and exhaustion, (4) sadness, (5) joy, (6) pride and (7) hope and optimism.

Despite grandparents' suspicion of grandchild's atypical development, most grandparents reported shock when their grandchild was first diagnosed with ASD:

Right at the beginning it's a shock, I won't say that we have received it happily, grateful ... It's a diagnosis that you didn't expect in your life, so we were taken by surprise.” (#1)

With an ASD diagnosis, most grandparents reported worry and anxiety in dealing with grandchild's behaviours that were associated with ASD. Most grandparents were unsure of the best way to manage their grandchild as echoed by a grandparent: ‘because we were like, how do we deal with it? What is the best way?’ (#6).

In addition, some grandparents reported that they felt overwhelmed and exhausted by having to care of their grandchild's additional needs and pay closer attention to them when they are around: ‘I had to give the right food, the bath at the right time, and he's fussy, he's running ... When my daughter comes and takes him, I feel like, take it I'm exhausted, I'm deadly tired’ (#4). For grandparents who were working, they expressed being overwhelmed with the juggling their job and caregiving responsibilities: ‘There are times when I feel so much that I feel incapable. When it is too much overload, overload, because I work’ (#1).

As grandparents gained more understanding about ASD, they experienced sadness and regret during their parenthood journey. For instance, a grandparent shared about the sadness she experienced as she realised that her grandchild lacked the communication skills necessary to be understood: ‘He doesn't know how to ask, like the other children. So this is very sad’ (#5).

Also, a grandparent shared her sorrow for not understanding her son for displaying similar behaviours in his childhood. It was recounted with regret:

Then I simply did not care about the schedule, and explained when I got him, that I took him to school, but he was against it, we saw him crying... so today I try to get it, what I could not do for him, when he was little, I did not know, I do it for my grandson. (#6)

Despite the challenging emotions, grandparenthood was not without joy. As mentioned by a grandparent: 'I'm not saying there's no sadness, there are more joys than sadness' (#1). All grandparents were able to recount happy memories with their grandchild. Consistently, photos and videos shared by grandparents consisted of happy memories they shared with their grandchild and adult children. Happy memories ranged from sharing simple moments with their grandchild and family to celebrating specific milestones of their grandchild.

Despite their developmental delays, several grandparents shared the milestones of their grandchild with ASD with pride by describing: 'everything she can do, we consider a victory' (#2) and 'When he spoke for the first time- Grandma. You know what it's like to win the lottery? The feeling was like that' (#4). Besides sharing their pride for their grandchild, grandparents also related how proud they were of their adult children. Some grandparents spoke about how their adult child had risen to the challenges of being a parent to a child with ASD: 'She is out of the ordinary, she is wonderful. It's not because she's my daughter, but she is an exemplary mother' (#4).

In addition, grandparents conveyed hope and optimism for their grandchild's future. Hope was evidently present as grandparents witnessed grandchild's progress through therapies and interventions: 'Today I have hope, hope to see the best, to achieve. The feeling of hope, to see him improve, to see him grow' (#5). Instead of grieving over the loss of the life they had expected for their grandchild before ASD diagnosis, grandparents were optimistic about the

future: “We had so many plans with (grandchild), so much, and we found out that he is autistic, then we got more” (#5) and the role they can play in their grandchild’s life:

I don't feel incapable, I feel more like a lioness to defend, a lioness to help. Something that is a challenge that you don't want to lose, that you want to win, that you embrace the cause, that you say that this cause is mine too. I feel like a person who didn't retreat, who is willing to deal with this situation. (#1)

### *Grandparents' Concerns*

There were several concerns that were identified by grandparents. These concerns were closely related to their emotional experience of grandparenthood. Grandparents’ concerns can be categorised into the following themes: daily caregiving challenges, concerns for other members of the family, limited understanding of ASD and resources available for grandchild and fear for the future.

Firstly, grandparent experienced daily caregiving challenges. These challenges included demands surrounding the management of grandchild’s symptoms of ASD (e.g. food sensitivities, communication skills), concerns about their safety and health and helping them learn boundaries.

Several grandparents shared extensively about grandchildren’s food sensitivities as a challenge that they faced: ‘It is the grandmother who worries the most about the food issue’ (#6). Selective food preferences in children with ASD troubled grandparents to a large extent. Food selectivity created excessive demands on grandparents as they had to find food alternatives. Grandparents also reported concerns for grandchild’s health due to these food sensitivities:

Today we have the difficulty of feeding. He is selective, food selective. He only eats crunchy things. He doesn't eat anything soft ... This bothers me a lot, just giving him these things, this type of [fried food]. I really want him to eat more fruits, more

vegetables ... because of the lack of vitamins that come from vegetables ... so that worries me. (#5)

Other grandparents shared concerns about their grandchild's ability to communicate their needs and preferences verbally: 'My biggest concern with (grandchild), I really want her to talk' (#2) and 'It is not easy to know that your grandson, your only grandson is autistic, that he doesn't know how to express himself, he doesn't know how to communicate' (#5).

Also, concerns about safety were discussed by many grandparents. Grandchild's journey towards independence were not necessarily an easy time for grandparents. When discussing about her grandchild's gaining autonomy by going to school independently, she shared that she experienced a lot of fear: 'We are very afraid that something like this will happen, that she will get lost. There is always this fear' (#2). Another grandparent shared that she wanted her grandchild to enjoy physical activities despite his later development in walking: 'I worry a lot about him getting hurt, when he's running, I'm always close to him. Afraid he might get hurt, I'm afraid' (#4).

Lastly, grandparents shared concerns regarding disciplining their grandchild, particularly helping them learn boundaries: 'The biggest challenge for me today is for (grandchild) to understand "No"' (#1).

Secondly, grandparents share concerns for other family members. Specially, grandparents were concerned about how their adult children and other members of the family were managing their grandchild's behaviours and news of their grandchild's diagnosis. For instance, a grandparent shared her concern regarding her daughter-in-law due to their differences in parenting style: 'For me, sometimes it is more difficult to deal with this adult (grandchild's mother)' (#3). Another grandparent shared about the way she had to educate a member from her extended family about her grandchild's ASD: 'Now, there is rejection, people

who are in the (extended) family ... (extended family member) doesn't get this story well. And with that, she ends up excluding' (#2).

Also, grandparents were concerned about how their adult children were coping with the caregiving responsibilities. When taking over caregiving responsibilities, a grandparent (#7) shared her realisation regarding the load of caregiving her adult child and his wife were shouldering.

Thirdly, grandparents shared their concerns regarding limited understanding of ASD and the accessibility of services for children with ASD. Grandparents shared a desire to learn more about the process of managing their grandchild, without necessarily knowing where they could get this information: 'I want to have more understanding of things. Why he does it. I feel very weak yet in the process, I don't know... I want to understand more how to deal' (#4). Also, grandparents were concerned about the financial burden of interventions as well as availability of resources in schools to support the total participation of their grandchild. Grandparents discussed the cost of interventions: 'It is also a very expensive support. There is no way to pay these professionals' (#2) and that concern was echoed by another grandparents: 'We have no financial conditions to maintain the treatment' (#5). In the meantime, the grandparent was also concerned about the resources available to create an inclusive environment for her grandchild: 'We are in a public school, teachers are interested, but we see that it is so difficult (to get a caregiver) in the public school, for the children' (#5).

Lastly, grandparents reported concerns regarding their grandchild's future. Specifically, grandparents discussed the society's acceptance of people with disabilities as well as grandchild's ability to gain independence. For example, a grandparent shared the fear that her grandchild will not be fully included:

And the family, we suffer because we see that the people out there that the world is not prepared for them. Not prepared to accept it. We suffer from that because we know that

their future, we do everything we can to help, but out there, they are not welcomed as they should. So that is our suffering: to know that our grandchild can suffer there. (#4)

### *Tension experienced by grandparents*

An essential aspect of grandparenthood experience includes the need for grandparents to negotiate the tensions that arise within the family due to differences in opinion, as well as tensions that arise from the different roles they play in the family.

Firstly, tensions arose from differences in opinions. Grandparents acknowledged that disagreements were inevitable in any household and related instances of differing opinions with their adult children. These differences were attributed to disagreement on parenting styles—mainly what should be allowed for the grandchild and what should not be allowed. To negotiate this tension, grandparents were likely to take a step back and acknowledge the differences:

So I avoid it, sometimes when I don't listen I go out to not talk, because if I stay I know I'm going to end up talking ... Sometimes we just want to love, just want to make (grandchild) happy, and sometimes it gets in the way. So I have to back off and say: You're right. (#4)

I stay neutral, because she is a mother, and I do not like to take authority, by no means. That is her moment ... if they are complaining and I'm not liking it, I try to get away, because for me, it does not interfere neither one side nor the other, it does not contradict or hurt anyone. (#6)

Also, there is conflict between their collaborative role in disciplining their grandchild with their adult child and their perceived role of pampering their grandchild as a grandparent: 'Sometimes we [grandparents] just want to love, just want to make him happy, and sometimes it gets in the way' (#4).

Next, grandparents were required to juggle the demands that their different roles impose. A prominent example is grandparents who had to juggle the role of being a

grandparent and being in employment. Grandparents who were employed reflected on the sacrifices that they had to make to adjust to ad-hoc caregiving responsibilities. As mentioned previously, a grandparent (#1) had to make prompt changes to her work schedule to accommodate her grandchild's schedule. As a result of this role strain, grandparents who had to adjust their work commitments to accommodate their grandchild's evolving needs reported feeling overwhelmed and exhausted. On the other side of same coin, a grandparent wished she was able to do more for her grandchild and the family. However, her job did not allow her to move closer to her grandchild and be more present in grandparenting responsibilities.

Within the family, grandparents may also encounter tension when their role of being a parent to adult children and grandparent to grandchild contradicts. For instance, a grandparent shared how she had to put on a strong front for her grandchild instead of comforting her adult child:

About two or three times, [daughter] called me to cry. And I didn't allow it, I said, you're not allowed to cry. Because if the mother is you, imagine what it's like for her, huh? And I did, then I knew she cried a lot.” (#2)

As a parent, she had wanted to be present for the emotional experiences of her daughter. It presented a tension for her as she wanted to take on the role of a parent to comfort her child and acknowledge the pain that she was going through. However, as a grandparent, she felt that her child did not have right to despair as her grandchild will be facing all the hardship without the awareness and capabilities to solve these problems:

I'm not going to let (adult child) cry, you have no right. The only person who should cry, if she could, was (grandchild), but she doesn't even have the condition to know that. So you who have this awareness, no, you're not going to cry. (#2)

Grandparents emphasised their role in supporting the family unit and that the primary responsibility of the grandchild belonged to the parents. Grandparents were mindful not to



cross the boundaries and overshadow the authority of the parents. As reflected by several grandparents: 'I stay neutral, because she is a mother, and I do not like to take authority, by no means. That is her moment' (#6) 'I could take care of everything, but I didn't want to. What I could do for (grandchild) are the things that the grandmother can offer' (#2) 'When the mother says "no", we know we can't pass over the mother, and the grandmother says "no"' (#3).

Nevertheless, a grandparent (#4) recounted an instance when she crossed the boundaries and disciplined her grandchild in the presence of the parents. That incident left grandparent feeling guilty and upset with herself.

### *Grandparents' growth and development*

In face of the difficulties that grandparents faced in their grandparenthood, grandparents reflected on their personal growth and development in the following areas: understanding and management of ASD and openness to learn and share with other grandparents.

Consistent across all grandparents, knowledge of ASD increased when their grandchild was suspected of or diagnosed with ASD. Some grandparents reported having no knowledge of ASD: 'Before (grandchild), I did not know anything ... nor the word "autism", it was zero' (#6). Nevertheless, grandparents' understanding of ASD were enriched by living and caring for their grandchild and they were able to connect grandchild's behaviours to neurodivergence accounted for by ASD. For example, a grandparent was able to differentiate her grandchild's verbal utterance as echolalia instead of speech: '... as she doesn't speak, she is not verbal, and it's echolalia, right? She repeats things like that.' (#2) and another grandparent was able to attribute her grandchild's toe-walking and food selectivity to sensory dysregulation.

In addition, grandparents held plenty of information regarding grandchild's developmental trajectory and strategies to manage grandchild's special needs. For example, grandparents were able to list the functions of different professionals and therapies as well as augmentative and alternative communication systems that their grandchild were using.

Furthermore, grandparents picked up these communication systems (e.g. gestures and other technological devices) in order to facilitate communication with their grandchild.

Next, grandparents' understanding of ASD extended beyond the management of their grandchild, influencing the way they viewed and managed neurodivergence in their communities. For instance, a grandparent (#3) shared that she is more attentive to the children in the extended family who had displayed traits of ASD. Another grandparent shared:

If (grandchild) is laughing, but they are sounds that I imagine that must be very annoying for a person in the classroom...Because it's repetitive... I'm saying this because I have a colleague like that ... He talks like a cartoon character ... I thought he was trying to annoy people when he got mad, but then I realized it was his problem, and I started thinking the following: my letter must be bothering him. (#2)

Also, several grandparents shared about their willingness to learn more about dealing with their grandchild's ASD through reading and experiences with their grandchild. "It's something new to be experienced every day. Every minute is a discovery to deal with (grandchild)" (#1).

Finally, grandparents expressed their wish to contribute and help other grandparents understand the condition and gather the community in support of families of children with ASD.

## Discussion

The key purpose of this study was to explore the experience of being grandparents to children with Autism Spectrum Disorder (ASD) in a Brazilian context. Using semi-structured interviews, several key themes that emerged across seven participating grandparents were presented in this paper.

With regards to the first research question, this study found that grandparents played several roles in the family raising a child with ASD. This myriad of roles included providing love and companionship for grandchild, supporting adult child and family unit and managing grandchild's ASD. This study replicated the finding from Yang et al. (2018) where grandparents supported the development of grandchildren through the micro- and mesosystem levels, ensuring that grandchildren had access to the most inclusive and conducive environment that was within their control. Also, the findings of this study supported the role that grandparents play in social support regulation and social role management (Kahana et al., 2015; Lee & Gardner, 2015).

Across most participants, the Brazilian saying, "Os pais educam, os avós deseducam" was mentioned. This statement translates to "Parents educate, grandparents uneducate". The essence of this saying implies that parents fulfil the role of bringing up the child (i.e. education, caregiving) while grandparents fulfil the role of being permissive, pampering the child. Usually with a negative connotation attached to it, this study suggest that this saying is largely a misstatement. This saying guided grandparents' drawing of boundaries between the role of a parent and grandparent. Nevertheless, grandparents participated actively in other roles beyond providing love and affection for their grandchild. When necessary, grandparents were assertive in disciplining their grandchild with ASD- even when they did not agree with the parenting method.

Grandparents played an important role in connecting the different microsystems and maintaining equilibrium within these systems. When there was a disruption in the microsystem, grandparents took it upon themselves to help the family adjust to the new situation. Also, grandparents connected the nuclear family unit to the extended one, taking on the role of maintaining close ties with the extended family, to ensure that their grandchild will be able to access the support that the extended family affords. Grandparents, through their lived experiences and networking, possessed far-reaching connections beyond the family unit that may benefit their role in advocating for their grandchild with ASD.

The second research question was addressed in this study with (a) grandparents' emotional experience, (b) grandparents' concerns, (c) tensions that grandparents experienced and (d) grandparents' growth and development.

In this study, it was found that grandparents' emotional experiences of grandparenthood were extremely rich. It was evident that grandparents were driven by their intrinsic love for their grandchild. This finding echoed the literature where it was reported that grandparents experienced a wide spectrum of emotions being part of the family raising a child with ASD. (Hillman et al., 2017; Hillman & Anderson, 2019). As opposed to the "double-grief" reported by Woodbridge et al., (2009), it was striking that grandparents in this study remained optimistic and hopeful of the future despite all the challenging emotions reported.

Also, this study found that grandparents had several concerns. Consistent with the literature, grandparents' concerns occurred on several levels. At the microsystem level, daily caregiving challenges related to ASD which include challenges to communicating with grandchild and selective food preferences affected them (Hillman et al., 2017, Yang et al., 2018). In this study, selective food preferences in children with ASD troubled grandparents to a large extent. A possible reason could be due to grandparents' perceived role of pampering grandchild and contributing to their well-being through food and ASD posed challenges for them to be

able to execute that role effectively. With their lived experiences, grandparents possessed wisdom with regards to how factors in the wider environment beyond grandchildren's influence may affect their grandchild's development. As a result, grandparents' concerns extended to their current assessment of the macrosystem and exosystem. Specifically, grandparents were concerned that the exclusion of people with disabilities in the society and lack of services for people with ASD respectively may be detrimental for their grandchild's future. Also, it was interesting to note that grandparents in this study were aware of the need to strengthen their understanding of ASD and how to manage it. While they were keen to know more, they had limited avenues to get more information.

Next, this study found that grandparents experienced several tensions as grandparents to children with ASD. Consistent with the finding reported by Yang et al. (2018) and Hillman et al. (2016), grandparents had to draw role boundaries and manage ASD-related conflicts and tensions that arose within the family (nucleus and extended). Furthermore, these findings suggest that grandparents did not merely fulfil one role at a time. Instead, grandparents were taking on several roles at the same time. Grandparents were constantly negotiating the tensions that arose in the roles they play. Even as this paper dissected the roles and experiences of grandparenthood into different themes, it is important to note that these roles and aspects of experiences are intricately linked. Specifically, grandparents' emotional experience of grandparenthood was tied to the roles they had to play in their lives and the tensions that arose from these roles. The tension that resulted from conflicting demands may place role strain on grandparents. When coping capabilities are compromised as a result of the overwhelming stressors, grandparents may experience exhaustion.

Despite the challenges associated with supporting families of children with ASD, this study found that grandparents experienced growth and development during their grandparenthood. The findings of this study support the literature on the growth and resilience

of grandparents through their grandparenthood (Hillman et al., 2016; Merrick, 2020). As mentioned previously, grandparents were sensitive to the needs of the child's microsystem. As a result of this attunement, grandparents may be susceptible to stress when there are acute changes in the microsystem. Nevertheless, this study showed that grandparents were quick and resourceful to gain control of the situation and to maintain equilibrium in these systems. Grandparents were able to identify their needs and the family's needs in a timely fashion and sought out information necessary for them to fulfil their roles within the family.

#### Limitations of study

A limitation of this study is the sample of the study as participants in this study were self-selected. Grandparents who volunteered to be part of the present study reported to participate in grandparent support of a child with ASD. This implied that the sample has accepted the legitimacy of the diagnosis. On the other hand, there is a possibility that grandparents who were not coping well with a grandchild with ASD or in denial of grandchild's ASD might have chosen not to participate in this study. Also, no grandfather was interviewed for this study. This limitation is consistently reported in grandparenting literature (e.g. Hillman et al., 2016) where grandfathers were less likely to report involvement in providing grandparent support. In addition, this study did not collect additional demographic data on grandparents as well as structure of the nucleus and extended family that may influence grandparents' experiences of being part of a household raising a child with ASD. Nonetheless, the findings from this study provide important insights to the importance of grandparental support and grandparents' experiences of supporting a child with ASD in Brazil. Next, a methodological limitation of this study is the absence of data from other perspectives. Future research may strengthen the understanding of the role of grandparents in supporting children with ASD by including the perspectives of adult children and particularly, the perspective of grandchild with ASD.

## Implications of Study

Despite the limitations of this study, the findings reported in this study are relevant for practice, future research and policy.

A key implication of this study is a perspective-shift of the informal role of grandparental support for households of children with ASD. Intrinsically motivated by their love of their family, grandparents have shown to be a consistent and reliable resource that can be drawn on for formal support. As such, practitioners can consider formally including grandparents' voice in planning of support for grandchildren. Also, grandparents have the potential to be involved in supporting individuals with ASD at the exosystem level. Using their wealth of experience and connections, grandparents can provide support for each other by providing emotional support and connecting each other to the support necessary. Another key implication of this study is that there is a need of stronger systemic support for grandparents who are supporting households of children with ASD. The implication for practice is to take into consideration grandparents' capacity to support the family as well as the information they may require in order to perform their different roles effectively. In addition, it is also necessary to provide specialised emotional support (e.g. grandparent support groups, therapy) for this group of grandparents as they are likely to experience a wider range and higher intensity of emotions during their grandparenthood.

To gain a more in-depth understanding of grandparents' needs, future studies can analyse grandparents' experiences at different stages of grandchild's development. As illustrated by the participants of this study- from seeking an understanding of grandchild's atypical development to the moment of grandchild's ASD diagnosis and successful intervention- grandparents experienced a myriad of emotions and their needs changed along the way. With better understanding of their changing needs at different points of their

grandchild's developmental journey, different coping strategies can be taught to grandparents to help them deal with the challenges of grandparenting a child with ASD.

Lastly, the findings of this study suggest that the financial cost of supporting a child with ASD can generate ripples of stress across generations. As such, on the macrosystem level, policies can look into reducing the cost of living for multi-generational families in order to create a more inclusive environment for families raising children with ASD.



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## Appendix

**Table 1. Summary of participants**

<b>Grandparent</b>	<b>Mode of Interview</b>	<b>Length of interview</b>	<b>Source of referral</b>	<b>Living in the same household</b>	<b>Relationship to child with ASD</b>
1	Online	31:35	ACA-EPA	Yes	Stepmother to mother of boy with ASD
2	Online	59:02	Personal	No (different house in the same neighbourhood)	Maternal grandmother of girl with ASD
3	Online	26:15	Personal	No	Maternal grandmother of girl with ASD
4	Online	33:05	Personal	No	Maternal grandmother to boy with ASD
5	Face to face	31:02	SEMEA R	Yes	Maternal grandmother to boy with ASD
6	Face to face	49:43	SEMEA R	No	Paternal grandmother to boy with ASD
7	Face to face	25:53	SEMEA R	Yes	Paternal grandmother to boy with ASD

**Table 2. Examples of Interview Questions in relation to Research Questions**

<b>RQ 1) What is the role that grandparents play in the family raising a child with ASD including different family structures?</b>
<ul style="list-style-type: none"><li>• What are some ways that you contribute to the family?</li><li>• Would you like to do more?</li></ul>
<b>RQ2) What is grandparents' experience of being part of the family unit raising a child with ASD?</b>
<ul style="list-style-type: none"><li>• What does your typical day look like?</li><li>• Tell me about a favourite memory with your grandchild.</li><li>• What are some challenges that you face while taking care of your grandchild?</li><li>• What are some happy memories that you share with your grandchild?</li><li>• What is your relationship with your children before and after your grandchild was diagnosed?</li><li>• What were some tense moments/disagreements in the family regarding the upbringing of your grandchild?</li><li>• How do you navigate these disagreements?</li><li>• Do you ever feel overwhelmed?</li><li>• How does having a grandchild with ASD affect you?</li><li>• How much did you know about ASD before your grandchild was diagnosed with ASD?</li><li>• Where did you get your information on ASD from?</li><li>• Did you know where you could get more information and support?</li><li>• What resources do you need to help you feel more competent in raising your grandchild?</li></ul>

**Table 3. Photos and Videos Provided by Grandparents**

Participant	Details of Images/Videos Shown
1	<p>(1) The whole family, the mother, the grandfather, the great grandmother and the young boy smiling for a picture taken by the mother;</p> <p>(2) The grandfather holding the young boy on a pool, they both have a smile on their faces;</p> <p>(3) Young boy smiling, looking away from the camera, holding a car toy on both of his hands;</p> <p>(4) Young boy sits on the ground and plays with dirt with both hands with a football ball by his side;</p> <p>(5) The grandmother kisses the head of a young boy sleeping on her arms;</p> <p>(6) Video: a young boy with a backpack walks holding hands with his grandfather on the sidewalk;</p> <p>(7) The grandmother holds the camera to herself and a young boy on his pajamas, smiling for the picture and holding his finger to his mouth</p> <p>(8) Video: A young boy plays with a magic cube while says words and fall a bit to the side of the sofa;</p> <p>(9) Video: A young boy plays with the gym equipment while the grandmother jokes about him working out, he smiles to the camera;</p> <p>(10) Video: The grandmother films a young boy on a brazilian football team's uniform playing with a ball, shooting the ball to the grandma and she runs back to him playing together on a football field;</p> <p>(11) Video: The grandmother films a young boy in a Brazilian football team's uniform riding a kid's bike on a football field.</p>
2	<p>(1) Grandmother carrying a toddler on her arm. Grandmother looking at toddler with a smile on her face</p>
3	<p>NA</p>
4	<p>(1) The grandfather is laid on the grass, holding his young grandson on his belly, with a car beside them. The boy looks to another direction and the grandfather looks at him;</p>

	<p>(2) A baby boy dressed on a yellow shirt and denim jeans smiles and look at another direction;</p> <p>(3) The grandmother is smiling to the camera, holding a new born grandson in her arms;</p> <p>(4) The grandmother is smiling to the camera, holding a new born grandson in her arms, the is the youngest brother of the first young boy she held on the first picture;</p> <p>(5) The grandmother holds the back of the grandfather that holds a baby boy on his arms, they are both smiling;</p> <p>(6) A grandfather holds a baby on his hands, that smiles for another direction, the grandmother smiles for the picture, while holds a young boy, that also looks for another direction;</p> <p>(7) A grandfather and a grandmother are sitting on a rock on a beach, smiling for the picture while holding a young boy on his hands;</p> <p>(8) A couple of grandparents smiles to the picture, while their daughter holds a young boy that looks to another direction, another woman is smiling on the pictures, they are all wearing the same blue shirt.</p>
5	<p>(Phone wallpaper)</p> <p>(1) Young boy sitting on a stool with his grandmother in front of a house, beside the door. Boy looking away from the camera, smiling.</p>
6	NA
7	<p>(1) Young boy playing along with colourful blocks at a play area in the house. Boy concentrated on blocks and not looking at the camera.</p> <p>(2) A pair of twins' boys (dressed in matching onesies- one in blue, one in orange) sitting beside a two-tiered cake. Boys dipping fingers into cake. Boys had cake on their faces.</p> <p>(3) Young boy looking at the camera, eating lollipop at the beach</p>

