

## Reasons, Commitments, and Meanings: A Phenomenological Exploration of Grandparents' Parenting of a Child with Autism Spectrum Disorder

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### Abstrack

This study aimed to explore the reasons, commitment and meaning of grandparenting in families caring for grandchildren with ASD aged 2-6 years. This study used a qualitative, phenomenological approach. Data were collected through semi-structured interviews with seven primary caregivers of children with ASD. They were analysed using content analysis and therapeutic and occupational science frameworks to reveal patterns of caregiving, adaptation, and subjective meaning. This study resulted in three main themes being identified: 1) motivational reasons for becoming the primary caregiver, which included a sense of responsibility to the family and concern for the child's safety and well-being; 2) the forms of caregiving work commitments undertaken by grandparents, including time management, adjustments to parenting strategies, and handling behaviours typical of ASD; and 3) the meaning of the emotional dimension of this role, which was characterised by long-term commitment, a sense of moral responsibility, and a deep bond of affection.

**Keywords:** grandparenting, autism spectrum disorder, parenting, phenomenology

### Abstrak

Penelitian ini bertujuan untuk mengeksplorasi alasan, komitmen, dan makna peran kakek-nenek dalam keluarga yang merawat cucu dengan ASD berusia 2-6 tahun. Penelitian ini menggunakan pendekatan kualitatif dengan metode fenomenologis. Data dikumpulkan melalui wawancara semi-terstruktur dengan tujuh pengasuh utama anak-anak dengan ASD dan dianalisis menggunakan analisis konten serta kerangka kerja ilmu terapi dan ilmu pekerjaan untuk mengungkap pola pengasuhan, adaptasi, dan makna subjektif. Studi ini menghasilkan tiga tema utama yang diidentifikasi: 1) alasan motivasional menjadi pengasuh utama, yang meliputi rasa tanggung jawab terhadap keluarga dan kepedulian terhadap keselamatan dan kesejahteraan anak; 2) bentuk komitmen pekerjaan pengasuhan yang dilakukan oleh kakek-nenek, termasuk manajemen waktu, penyesuaian strategi pengasuhan, dan penanganan perilaku khas ASD; dan 3) makna dimensi emosional peran ini, yang ditandai oleh komitmen jangka panjang, rasa tanggung jawab moral, dan ikatan kasih sayang yang mendalam.

**Kata Kunci:** peran kakek-nenek, gangguan spektrum autisme, pengasuhan, fenomenologi

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## INTRODUCTION

Currently, family structures in Indonesia are undergoing complex transformations due to socio-economic dynamics, urbanisation, and changing work patterns (Ferine et al., 2023; Murliasari et al., 2023). One obvious consequence of this transformation is the increasing prevalence of kinship caregiving, which is a family-based pattern of caregiving that involves not only biological parents but also extended family members or individuals with strong emotional attachments, such as grandparents, uncles, aunts, or even close family friends (Anving et al., 2025; Yang et al., 2025). This phenomenon developed in response to economic pressures and geographical mobility, where many parents have to migrate or work in big cities to make ends meet (Yang & Xie, 2024). In such situations, children are often left behind in their hometowns and cared for by grandparents, who practically take over daily caregiving roles (Notara et al., 2024).

The role of grandparents in this context is no longer merely complementary but primary, with full responsibility for the child's physical, emotional, and educational well-being. Their caregiving activities include providing basic care, discipline, learning assistance, and reinforcing cultural and spiritual values (Kavitha & Siva, 2025; Kikuchi et al., 2025; Long et al., 2025; Waugh et al., 2025). This phenomenon indicates a shift in intergenerational roles in the Indonesian family system that is increasingly adaptive to social change (Tian et al., 2025). Furthermore, the increase in life expectancy in Indonesia provides elderly individuals with more time to fulfil this role (Saigh, 2025). National life expectancy continues to increase each year, indirectly reinforcing older adults' presence as alternative caregivers in modern family structures (Razjouyan et al., 2025). Therefore, understanding the dynamics and burden of caregiving experienced by grandparents is crucial, especially in the context of children with special needs such as autism spectrum disorder (ASD), which requires sensitive and structured approaches to caregiving (Çoruh Kınalı et al., 2025; Jalilvandi et al., 2025; Nascimento et al., 2025).

The division of roles and responsibilities in the care of a child with ASD is a complex phenomenon. It is influenced by various family socio-economic, medical and structural factors (Liu & Zhang, 2024). In many cases, the decision to transfer caregiving responsibilities from parents to grandparents is not solely the result of an emergency, but also internal family negotiation and consensus (Chandra et al., 2025; Othman et al., 2024). Factors such as substance abuse, chronic health problems, or legal involvement that preclude parental roles often prompt grandparents to take over full caregiving. In addition, divorce, economic pressures, and parental workload increase the likelihood that this role will be transitioned to the older generation (Hou et al., 2024; Luo et al., 2025; Sigar et al., 2025).

In the context of parenting a child with ASD, grandparents are not simply surrogate parents, but are also key actors in shaping adaptive parenting that is oriented towards the child's specific needs. This role often serves as a medium for older adults to find new meaning in their ageing phase, both as a form of social contribution and as a process of forming a meaningful personal identity (Lazzaro et al., 2025). However, intensive involvement in the care of children with ASD also poses complex challenges, particularly in relation to emotional distress and physical exhaustion. Children with ASD generally require a strategically tailored approach, as their characteristics include communication limitations, difficulties in social interaction, and a tendency towards repetitive behaviours (Hsu et al., 2025; Kwong et al., 2025). In reality, in large families in Indonesia, the allocation of caregiving roles is often determined by internal family dynamics, resource availability, and the emotional readiness of family members.



Although the general norm places parents as primary caregivers, in certain situations, especially when social support is minimal, grandparents can play an active, and even dominant, role in caregiving (Carvalho et al., 2025).

In recent decades, there has been a significant increase in research on the role of grandparents in childcare, particularly in the context of families facing social challenges such as poverty, divorce or mental health crises. Studies in Western countries have identified grandparents' contributions as a form of kinship care that plays an important role in maintaining children's stability and well-being (Bağcı et al., 2025; Kamal et al., 2025; Kaur et al., 2025; Omori, 2025). These studies generally highlight the psychosocial aspects, emotional distress, and institutional support needs experienced by elderly caregivers. Other research suggests that grandmotherly care of grandchildren can negatively impact physical and psychological well-being, especially when not accompanied by adequate social and professional support (Choi et al., 2024; Le et al., 2025).

In the context of parenting a child with ASD, studies such as those by Cipriani et al (2025) and Zhao et al (2025) show that grandparents play an active role in supporting child development interventions, both directly and indirectly. They make therapy decisions, assist with daily activities, and manage children's emotions. The global literature has also begun to examine intergenerational dynamics in families with children with special needs and how these experiences shape grandparents' occupational identities (Hu, 2025; Jang, 2024; Kloc-Nowak & Ryan, 2025).

While many international studies address the role of grandparents in parenting in general, there is limited research that explores explicitly grandparents' experiences as primary caregivers for children with ASD, especially in the Indonesian cultural context. Most of the literature focuses on the experiences of parents or therapists. At the same time, the role of grandparents is often considered secondary, without an in-depth examination of the dynamics and subjective meanings they experience. Few studies have utilised phenomenological approaches and occupational science frameworks to understand how older adults interpret and engage in their caregiving activities as meaningful occupations. This gap points to the need for contextualised research examining caregiving experiences in large Indonesian families, which have distinctive kinship structures and collective values that differ from those of Western cultures.

This study aims to fill this gap by exploring in depth the experiences, meanings and forms of adaptation lived by grandparents as primary caregivers of children with ASD. Thus, this study not only enriches the national literature in child education and occupational therapy but also opens a space for reflection for the design of social policies that are more inclusive of elderly caregivers. The conceptual framework of this study rests on occupational science and occupational therapy, which position individuals as occupational beings, i.e. active agents who shape, choose and carry out meaningful activities in their lives (Brose et al., 2024; Rybski & DeMott, 2024). Occupational activities do not occur in a vacuum; they always happen within the context of complex physical, social, and cultural environments. Therefore, grandparents' involvement in the care of children with ASD needs to be understood as a form of occupational work that is integrated with the identity, meaning of life, and dynamics of the environment in which they are located.

Based on this explanation, this study formulates three main questions to be answered: a) What are the reasons why grandparents become primary caregivers? b) What are the forms of commitment of grandparents in primary care? and c) What is the meaning



of the grandparents' role in this role? Therefore, the objectives of this study are a) to analyse the reasons why grandparents become primary caregivers; b) to examine the forms of commitment of grandparents in primary care; and c) to explore the meaning of the role of grandparents in this role.

## **METHOD**

### **Study Design**

This research is a qualitative study with a phenomenological approach that aims to explore the forms and meanings of grandparents' caregiving experiences for grandchildren diagnosed with autism spectrum disorder (ASD) aged 2 to 6. Semi-structured interviews were the primary method of data collection (Yin, 2016).

### **Participants and Research Location**

The inclusion criteria for participants in this study included: 1) being a biological grandparent of a child who has been diagnosed with ASD aged 2-6 years, 2) having primary responsibility for the care of the grandchild consistently for at least one year, 3) being the primary caregiver with the most time allocation, 4) being able to understand and use Indonesian or Javanese fluently, and 5) willing to participate in the entire research process.

Before the study's implementation, ethical approval was obtained from Universitas PGRI Semarang through the Institute for Research and Community Service. This procedure was conducted to ensure that all research activities adhered to the applicable principles of research ethics. Once approval was obtained, a purposive sampling technique was used to select participants based on the depth of information they could provide. The research site was located in Purbalingga Regency, Central Java, and the study was conducted over three months from October 2024 to December 2024. Baseline data were obtained from Mutia Centre, the first special needs children's therapy centre in Purbalingga, which offers various therapies for children with autism. Information about the study was conveyed to the relevant families at the research site. The primary researcher obtained informed consent from the potential participants who agreed to participate, and scheduled the interviews according to their time and place of residence. All participants chose to be interviewed in person at their respective homes.

### **Research Instruments**

The main instrument in this study was a semi-structured interview guide. The interview questions were developed based on the literature review, including theories in occupational science, the Model of Human Occupation, and Occupational Adaptation theory (Grajo et al., 2024). Each interview was audio-recorded and transcribed verbatim. The transcripts and field notes were then coded, categorised and analysed to identify key themes in the data. The semi-structured interview question guide is presented in Table 1.



**Table 1.**  
Semi-structured Interview Question Guide

Key Questions	Probing Questions
What led you to take on the role of primary caregiver in caring for your grandchildren?	When did you start taking on this role? What are the main reasons you are involved in this caregiving role?
What is your role as a grandparent in caregiving?	What activities do you do with your grandchildren on weekdays and weekends?
How do you care for or educate your grandchildren on a day-to-day basis?	How do you handle them when they are sick? Do you take them to health facilities? What are the important activities you teach them at home?
What is the meaning or significance of your role in raising your grandchildren?	How important do you think your role is in your grandchildren's lives? How does this involvement make you feel?

Detailed field notes play an important role in recording observations made during interviews to describe the emotional atmosphere and the context of interactions between researchers and participants (Denzin & Lincoln, 2018). The transcription process was conducted after all interviews were completed. While listening to the audio recordings, elements such as pauses, changes in intonation, laughter, and non-verbal expressions of the participants were systematically recorded through transcription to maintain the authenticity of the lived experiences' context (Miles et al., 2014). All participant data were managed with due regard for confidentiality, and participants' identities were kept anonymous in accordance with the research ethics protocol.

### Data Analysis

Data analysis was conducted concurrently with the data collection process. This approach allowed the researcher to focus on the collection of information better and explore issues that arose during the interview process. This study analysed data using the content analysis method (Michel, 2011). The analysis process was continuous and iterative, starting with the principal researcher familiarising herself with the transcripts' content through repeated active Reading. Next, the researcher labelled units of meaning within each transcript, which were then used to develop codes, categories and themes.

Once the core categories were thoroughly identified, the researcher explored the themes that emerged from the coding process. All themes and relationships between categories were then interpreted and validated by the researcher. At this stage, concepts from occupational therapy and occupational science that emphasise the form, function and meaning of human activities were used as the basis for data interpretation and in answering the research questions.

To ensure the credibility of the research results, various data validation strategies were applied. These included interview recording, verbatim transcription and checking the accuracy of the transcripts. In addition, a semi-structured interview guide validated by the researcher was used as a triangulation method during data collection. Peer examination was also conducted as part of data triangulation to increase validity (Yin, 2018).





## RESULT AND DISCUSSION

### Result

All seven participants in this study live in Purbalingga Regency, Central Java. Three of them were grandmothers from the maternal lineage, while the other four were from the paternal lineage. The participants' ages ranged from 46 to 62 years, with an average age of 54 years. Their duration as primary caregivers ranged from 10 months to 3 years. All the grandchildren were boys.

Table 1 presents the demographic profiles of the seven participants who served as the primary caregivers for their grandchildren diagnosed with Autism Spectrum Disorder (ASD). All participants were grandmothers aged 46-62 years (average 54 years) residing in Purbalingga Regency, Central Java. Three participants were from the maternal lineage and four from the paternal lineage, with caregiving durations ranging from 10 months to 3 years. This demographic profile illustrates the diversity of caregiving experiences within extended family contexts in rural Central Java.

**Table 2.**  
Participant Profile

Participant Code	Age (years)	Gender	Family Relationship	Length of Care
P1	46	Female	Paternal grandmother	10 months
P2	50	Female	Maternal grandmother	1 year
P3	52	Female	Paternal grandmother	1.5 years
P4	54	Female	Maternal grandmother	2 years
P5	56	Female	Paternal grandmother	2.5 years
P6	58	Female	Paternal grandmother	3 years
P7	62	Female	Maternal grandmother	3 years

In this study, three main findings were found that describe the grandmothers' experiences in caring for grandchildren with autism spectrum disorder. The three themes include: (a) the reasons why grandparents become primary caregivers; (b) how grandparents' commitment to primary caregiving is shaped; and (c) the meaning of grandparents' role in this role.

### Reasons for Deciding to Become the Primary Caregiver

The grandmothers who participated in this study expressed their reasons for taking on the role of primary caregiver for a grandchild with autism spectrum disorder under two main subthemes: doing it for my adult children and doing it for my grandchild. In both cases, the grandmothers saw their role as an important contribution to maintaining the family's stability and continuity. With their involvement, the family can face the situation together, and the grandchild can receive appropriate care and treatment.

This subtheme shows that grandmothers decided to take on the role of primary caregiver for a grandchild diagnosed with autism spectrum disorder due to the work responsibilities of their adult children. The decision was generally driven by two main reasons: first, because their daughters or daughters-in-law had to return to work after their maternity and childcare leave ended; second, because they needed to resume business activities to support the family's economy.

The grandmothers' decision to take on the caregiving role was made quickly as a means of supporting the family's economic sustainability. This commitment was also linked to the need to generate income to cover the household's overall needs.



One participant, P1, stated:

“My daughter-in-law wanted to go back to work and earn an income. So, I decided to help take care of her son.”

P2 explained a similar situation:

“It was time. Initially, my daughter wanted to go back to school to finish her studies after giving birth. However, because we had to bear many expenses, she decided not to continue her studies and returned to work. Even though I am sick and have resigned from work, I am still the main caregiver for my grandchildren.”

P5, another participant, expressed this reason:

“No one can take care of my grandson. His parents have to work for a living. So, I have to raise him because my adult children have to work to make ends meet.”

In addition to economic reasons and their children’s jobs, some participants also revealed that their decision to become primary caregivers was based on concern for the health and well-being of their grandchildren with autism spectrum disorder (ASD). Concern for their grandchildren's future and safety prompted the grandmothers to take on the role voluntarily.

P3, one of the participants, shared her experience with an emotional tone:

“When my grandson was one and a half years old, his parents divorced and separated. My adult daughter told me about it and asked me to take care of her son. I immediately said, ‘Yes, I’ll take care of him.’ I knew they probably would not last long. At first, my son said he would take care of him himself, but then he left his son with us. I feel very sorry when I see news on television about children being abused by stepfathers. I was afraid that something similar could happen to my grandchild. Therefore, I decided to take care of him completely.’

P4 also expressed similar feelings:

“I was very afraid that he would be beaten or bullied. I wouldn’t be able to accept it. It would be very difficult for me not to take care of her. Uh... so I decided to raise her.”

Overall, the findings suggest that grandmothers’ participation in raising grandchildren is motivated not only by a sense of responsibility towards their adult children but also by a strong emotional urge to protect and ensure their grandchildren’s well-being. This role allows them to ensure their grandchildren receive safe, continuous care and affection.

### **Forms of Grandparents’ Occupational Commitment**

The second theme in this study revealed three main forms of work commitments made by grandmothers as primary caregivers, namely: (1) allocating time to fit the daily demands and needs of the grandchildren, (2) adjusting parenting methods to support the child’s development, and (3) addressing the child’s behaviour related to ASD symptoms.

After deciding to take on the primary caregiving role, participants had to adjust their daily schedules and routines to meet their grandchildren’s needs. P2, for example, explained that almost all of her daily activities were with her grandchild. She continues to be involved, either directly or indirectly, in all her grandchildren's activities, including



playing and guiding them. When her grandchild has difficulty completing a task, P2 provides support and instruction to improve the child's basic skills, such as social communication.

"In the morning, we have breakfast together and chat. In the afternoon, we usually watch the news on television. While I am eating, my grandson plays with his toys. If he doesn't play properly or doesn't know how, I will teach him. We also learn to read letters, recognise colours, or say the names of animals. In the evening, we watch the news and soap operas, then go to bed together."

Many of the participants already have chronic health conditions such as hypertension and diabetes. Therefore, they also have to manage their time to maintain their health. P3 said:

"I will not let my health condition interfere with other responsibilities. Because I have to raise my grandchildren, I have to make sure everything is okay. If I feel any health problems, I immediately take medicine to prevent or relieve them."

Some grandmothers expressed concern that one day they would no longer be able to care for their grandchildren due to illness or physical decline. In addition to paying attention to their physical health, grandmothers also realise the importance of maintaining their mental health. They use their free time to engage in activities that can help relieve stress. P7 stated:

"I often go to a place of worship to participate in religious activities. I set aside time for these activities for my mental and spiritual health. I usually bring my grandchildren too."

The findings show that grandmothers made adjustments in their parenting methods to meet the developmental needs of children with ASD. In many cases, grandmothers were the first to recognise developmental differences or delays in their grandchildren, and the importance of seeking medical help and adjusting parenting approaches to support the child's development. P3 recalls her experience:

"I felt something was off. I wondered what was going on and figured out what I should do. When I told my daughter, we agreed to take the child to the doctor. However, her husband did not agree. He said, 'No need to see a doctor. If the child can't talk yet, leave it alone.' But I still begged for the child to be examined."

After a long discussion with the family, the child was finally taken to a child psychiatrist and later diagnosed with ASD. From then on, the family began to adjust their parenting practices based on professional advice. P4 shared her experience:

"Before my grandson was diagnosed, I often opened YouTube to watch ABC and children's songs. I thought it was fun and could help with language development. But he didn't respond to verbal commands or start talking. Now, I am more careful and avoid things that could make him even more passive. I watch less TV and follow the doctor's advice because I want my grandson to thrive."

Adjustments to parenting patterns also involve efforts to train grandchildren's independence in performing daily activities. Another participant shared her experience in training her grandson's toilet training skills:





“I taught him to take off the nappy. If he wants to pee, he signals me or takes me to the bathroom. Now he only wears nappies at night.”

These adjustments in parenting methods reflect the grandmothers’ commitment to gradually guiding and directing their grandchildren’s development, with the hope that the child’s functional abilities will continue to improve over time.

One of the biggest challenges grandmothers face as primary caregivers is in dealing with their grandchildren’s behaviours related to ASD symptoms. Some recurring quotes emerged from the participants, such as: ‘I raised my children. None of them behaves like my grandson, or “This is different from my son,” and ‘I don’t know why he keeps doing that behaviour.’ These sentences reflect a sense of confusion and uncertainty in dealing with the behaviour of a child with ASD who is perceived to be different from the children they have previously cared for.

The interviews showed that most grandmothers experienced difficulties in managing their grandchildren’s tantrums and inappropriate behaviour, especially when in public places. P6 expressed:

“Not like my child. My grandson behaves differently. I don’t know how to deal with it.”

Most participants tried to develop their own strategies for dealing with the behaviour, such as distracting themselves or removing the stimuli that triggered it. P4 shared her experience:

“I take him out for a walk if he starts to lose control. But sometimes it does not work. He runs so fast that I can’t catch him, and other people have to help. Sometimes I have to lock him in his room because carrying him is too difficult. He also used to bang his head on the floor. I tell him to stop, but he doesn’t listen. I have to pull him out or remove objects that trigger his behaviour.”

However, the strategies used were not always successful. In some cases, grandmothers admitted to using physical means, such as spanking, as a form of behaviour control. They realised this was not the ideal solution, but did so due to limited knowledge and skills to handle the situation.

### **Role Meaning as a Grandparent**

When participants were asked to describe the meaning of their role as the primary caregiver for a grandchild with ASD, they expressed two important dimensions that coloured the experience: duty and commitment, and bonds of love.

For grandmothers, being a primary caregiver is a responsibility undertaken consciously and with commitment. P2 said that raising her grandchildren is part of the great task she carries out in family life. P2 said:

“I think this is my duty. I have to raise him. That’s what I have to do. And now, I feel I have to do it the best I can.”

The participants saw themselves not only as supporting figures but also as the main figures in shaping their grandchildren’s lives and futures of their grandchildren. P4 expressed her happiness:



“I was very happy when I had a grandson. I feel like my family has grown. Even though taking care of him takes a lot of energy, I still feel happy. He is part of my offspring. One day, when I am gone, he will still be there. He is a part of me.”

The grandmothers described the caregiving process as a form of direct responsibility, from fulfilling basic needs to providing emotional support—the more intense their involvement, the deeper the attachment.

In explaining what it means to be a grandmother, the participants used simple yet emotionally charged words, reflecting the depth of love and affection for their grandchildren. P5 answered the question, ‘What does being a grandparent mean to you?’, with a spontaneous answer:

“I love him. He’s my grandson. I love him very much. I can’t even find the right words to describe my feelings.”

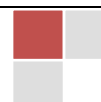
P1 described an emotional attachment that grew naturally:

“My grandson is my love. I don’t know when exactly the bond started. All I know is that I love her very much. When I had my first child, the feeling of parenthood came naturally. However, when my grandson came to live with me, I had no idea that love could form such a deep connection. My son sometimes jokes, ‘Oh... Mum loves grandchildren more than her own children.’”

Many participants initially took on the role of carer out of moral responsibility and blood relations. But over time, emotional involvement developed, forming deep and meaningful bonds of affection. To facilitate understanding of the research results, a summary is presented in Table 3 below.

**Table 3.**  
Summary of Major Themes and Subthemes

Theme	Subtheme	Description of Findings
Reasons for Becoming Primary Caregiver	For adult children’s needs	Grandmothers take over childcare to help their adult children return to work or study and maintain family stability.
	For grandchild’s safety and well-being	Grandmothers voluntarily assume caregiving out of concern for their grandchild’s safety, health, and emotional security after family disruption or divorce.
Forms of Grandparents’ Commitment	Time management and routine adjustment	Grandmothers reorganize their daily routines to accommodate their grandchildren’s therapy, meals, and activities while maintaining their own health.
	Parenting adaptation	Participants modify parenting styles to meet the developmental and behavioral needs of children with ASD, often seeking medical or professional advice.
	Managing behavioral challenges	Grandmothers develop coping strategies such as distraction, removing stimuli, or physical restraint to manage tantrums and repetitive behaviors.



Meaning of the Caregiving Role	Moral and familial duty	Participants view caregiving as a personal and moral responsibility, seeing it as part of their role within the family.
	Emotional bond and identity	Deep emotional attachment develops through caregiving, shaping their sense of identity and purpose as grandmothers.

Table 3 summarises the major themes and subthemes identified through the phenomenological analysis. The findings revealed three overarching themes: (1) the reasons behind grandparents' decision to become primary caregivers, (2) the forms of commitment and adaptation in caregiving activities, and (3) the personal meaning derived from the caregiving role. Each theme encompasses distinct subthemes that reflect motivational, behavioural, and emotional dimensions of the grandmothers' experiences.

## Discussion

This section elaborates on research findings regarding the forms of occupational work undertaken by grandparents in caring for grandchildren with autism spectrum disorder (ASD), with an emphasis on their relevance to theories in occupational therapy and occupational science (Casteleijn et al., 2024; Davis et al., 2024). This study derived its main strength from an in-depth exploration of the subjective experiences of seven grandmothers who served as primary caregivers within their families. The phenomenological approach utilised enabled the identification of the nuances of the roles and adaptation strategies participants undertook within the framework of meaningful daily occupational activities.

The first finding showed that the grandmothers' decision to take over the caregiving role was not solely driven by situational compulsion, but rather reflected a complex interaction among personal motivations, family values, and social norms (Shi et al., 2025; Wang et al., 2024). Within the Model of Human Occupation (MOHO) framework, these actions can be interpreted as the result of volition, i.e. internal drives and values that influence individual activity choices, which are then concretised in habituation through the establishment of consistent routines and caregiving roles (Rybski & DeMott, 2024). Their performance as caregivers also demonstrates high occupational capacity despite many limitations in age, physical health, and resources (Riyadi et al., 2023).

Previous literature, such as that by Cipriani et al (2025), suggests that shifts in modern family structures often make grandparents central figures in maintaining the continuity of the care system, especially in conditions of family crisis or dysfunction (Kloc-Nowak & Ryan, 2025; Li et al., 2024; Wei & Wang, 2024). In the context of families with children with special needs, such as ASD, the presence of grandparents not only fills the void of parental roles but also contributes to the emotional stability of the family through the presence of an affective and functionally reliable figure.

The second finding underscores that grandmothers' caregiving cannot be seen as a passive activity or simply an extension of the maternal role, but rather as a form of occupational work that demands high adaptability and behavioural flexibility (Hu, 2025; Jang, 2024). Actions such as daily time management, adjustments to learning methods, and the development of behaviour management strategies demonstrate that this role is carried out with a level of complexity equivalent to professional work, although not always formally recognised. From the perspective of Occupational Adaptation theory, the



grandmothers' response to this role change reflects an active attempt to reorganise the structure of their life activities to accommodate the ongoing demands (Ceo-DiFrancesco et al., 2025; Grajo et al., 2024).

The changes made are not limited to technical modifications in caregiving patterns but also involve transformations in self-perception and the construction of a new identity as a primary caregiver. In the context of occupational science, these dynamics show that caregiving activities do not merely fulfil the external needs of children, but also affect the internal dimensions of the individuals who live them (Asmarany et al., 2024; Casteleijn et al., 2024). This is reflected in the meaningful forms of occupation that participants maintain, adapt, and develop over time, as well as in changes in the condition of the children they care for.

The Occupational Adaptation Model emphasises that individuals are constantly engaged in a process of adjusting behaviours, strategies, and environments to maintain or enhance their capacity to perform meaningful occupations (Casteleijn et al., 2024; Davis et al., 2024). These adaptations can take place across various dimensions, including modifications to role demands, restructuring of the physical and social environment, adjustments to task performance methods, and the utilisation of relevant assistive devices (Brose et al., 2024). In the context of this study, grandmothers demonstrated tangible occupational adaptations by reorganising daily routines, adjusting their time, and adopting flexible parenting approaches in response to the behavioural challenges of children with ASD. Their ability to spontaneously innovate, prioritise and remain emotionally present in caregiving reflects a complex adaptive process integrated into the fabric of their daily lives (Nascimento et al., 2025; Riyadi et al., 2023; Rybski & DeMott, 2024).

The third finding highlights the meaning participants internalised from their caregiving role (Yang et al., 2025; Yang & Xie, 2024). Their experiences show that engagement in the primary caregiver role is not only functional but also contributes significantly to identity formation, routine structure, and the regulation of daily behaviour (Jalilvandi et al., 2025; Razjouyan et al., 2025; Waugh et al., 2025). Affective dimensions such as love, commitment and loyalty to grandchildren provide an emotional foundation that reinforces the sustainability of this role, even in the face of physical or psychological limitations. Caregiving is understood not merely as a moral obligation, but as an authentic and meaningful expression of affection (Chandra et al., 2025).

Literature such as Zhao et al. (2025) confirms that affectionate impulses and relational responsibilities are key motivators for grandparents to engage in intensive caregiving. Although these findings come from different cultural contexts, the underlying principles remain relevant in describing the affective mechanisms underlying caregiving commitment across generations. This view is reinforced by Bruner's constructivist theory, which holds that individuals constantly construct narratives of their actions and roles as they seek meaning in life (Bruner, 2005). Within this framework, taking on the role of primary caregiver not only addresses the family's external needs but also serves as a means for grandmothers to form a new identity that carries symbolic and existential meaning in the occupational realm.

## CONCLUSION

This study highlights the significant role of grandparents, particularly grandmothers, as primary caregivers for grandchildren with Autism Spectrum Disorder (ASD), emphasising their contribution to family stability and child development. Their



caregiving is not merely supportive but represents meaningful occupational engagement shaped by cultural values and intergenerational responsibility. Through adaptive strategies, time management, and emotional resilience, they reconstruct their daily routines and identities to meet the complex needs of children with ASD. These findings align with occupational science and occupational adaptation theories, showing how caregiving becomes a process of self-meaning and purposeful activity. Practically, this study suggests the importance of structured training and counseling programs that empower elderly caregivers in managing ASD-related challenges. Policy interventions are also needed to ensure access to health care, psychosocial support, and community-based initiatives for older adults in caregiving roles. Future research should include grandfathers' perspectives and explore the long-term psychological and physical impacts of sustained caregiving on elderly family members.

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