The Unique Experiences Encountered by Grandparents of Children with Autism Spectrum Disorder (ASD) and the Ongoing Journey of Navigating This Situation

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Abstract

This study looked into the unique experiences encountered by grandparents of grandchildren with autism spectrum disorder (ASD) and the ongoing journey of navigating this situation, focusing on the dynamics between the grandparents, parents, and the grandchild, as well as their interactions with society. The study aims to understand the emotional journey of grandparents, their knowledge and awareness of autism, and the impact of societal judgments on their behaviour and attitudes. Using Interpretative Phenomenological Analysis (IPA), this research analysed data from six in-depth interviews with grandparents, revealing their initial shock, the process of acceptance, and the proactive steps taken to educate themselves about ASD. The findings highlight the significant challenges faced by grandparents, including public judgment and the fear of taking their grandchild out in public. The study also underscores the unifying effect of the diagnosis on the broader family unit, emphasising collective efforts to support the grandchild.

Keywords: Grandparents, unique experiences, Autism, Ongoing Journey, meaning

Dedication

To my dear daughter Meg, whose arrival during this journey has filled my life with so much joy and inspiration. Your presence has been a constant source of motivation and strength every step of the way. This dissertation is dedicated to you, with all my love and gratitude, for the hope and happiness you bring to my life.

I also dedicate this to my family, for your unwavering support and encouragement throughout this journey. Your love and belief in me have been my foundation.

To my partner Omar, for your patience, understanding, and constant motivation. Your presence has made this challenging process more bearable and meaningful. Thank you for being my rock.

And to my beloved grandparents, whose love, wisdom, and guidance continue to inspire me every day. Though you are no longer with us, your memory lives on in my heart and in this work. This thesis is dedicated to you, with deepest gratitude and eternal love.

Declaration

I, the undersigned, hereby declare that the work in this dissertation titled ‘The Unique Experiences Encountered by Grandparents of Children With Autism Spectrum Disorder (ASD) and the Ongoing Journey of Navigating This Situation’ was carried out by myself. Otherwise, appropriate citations were included when referring to studies by other authors.

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List of Abbreviations

ASD	Autism Spectrum Disorder
APA	American Psychiatric Association
CDC	Centers for Disease Control and Prevention
IAN	Interactive Autism Network
IFT	Institute of Family Therapy
IPA	Interpretative Phenomenological Analysis
LSE	Learning Support Educator
NGO	Non-Governmental Organisation
TA	Thematic Analysis

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Chapter One: Introduction

The field of autism research has mostly concentrated on the immediate family unit, especially parents, but the involvement of grandparents in the lives of children with ASD is relatively underexplored. Grandparents, as key members of the extended family, frequently give essential support and care while navigating a complex web of emotional, social, and practical issues with their children and grandchildren. This dissertation seeks to shed light on the unique experiences of grandparents with grandchildren with ASD, delving into the multifaceted journey they undertake.

According to the American Psychiatric Association (APA, 2013), ASD is a developmental condition characterised by challenges in social interaction, communication, and repetitive behaviours. The condition has become increasingly common in recent decades, impacting almost one in every 54 children in the United States alone (Centers for Disease Control and Prevention [CDC], 2020). As families adjust to the demands of a child with autism, grandparents frequently find themselves in an essential but challenging role. Their engagement might range from emotional support and respite care, to advocating for their grandchildren’s needs in educational and healthcare systems (Hillman, 2007; Seligman and Darling, 2007).

Generational viewpoints, societal expectations, and personal life stages all have a unique impact on grandparents’ experiences. All these factors influence their perceptions of autism, coping skills, and strategies for supporting their families. Furthermore, grandparents must balance regulating their own emotional responses with providing stability and comfort to their children and grandchildren (Hastings, 1997). This dual position may be both fulfilling and stressful, especially when dealing with the unexpected nature of ASD (Margetts, Le Couteur & Clements, 2006).

The challenges grandparents face are compounded by cultural beliefs and stigma surrounding autism. Public misunderstanding may lead to feelings of isolation and frustration as grandparents try to advocate for their grandchildren while simultaneously seeking acceptance and understanding from their communities (Gray, 2002). Furthermore, grandparents must frequently balance their supportive role with other duties and personal health issues, complicating their caregiving efforts (Griffith et al., 2010).

In contrast, the presence of grandparents can provide opportunities for positive family dynamics and resilience. Their presence helps build a feeling of continuity and legacy by providing a broader viewpoint and an abundance of life experience that contributes to the family's collective coping strategies (Findler, 2000). Furthermore, grandparents frequently function as cultural and family anchors, instilling beliefs and traditions while adjusting to their children's changing demands (Kahana et al.,1999).

Aims and Objectives of the Study

The objective of this research project is to contribute valuable insights to existing literature by examining the experiences and reactions of grandparents of children diagnosed with ASD. While extensive research has been conducted on the impact of autism on parents, the specific topic of grandparenting a child with ASD remains understudied. Therefore, this study aims to fill that gap by exploring the nuanced experiences of grandparents and their coping strategies.

This study aims to investigate the reactions and coping strategies of grandparents of children with ASD. The research has adopted a qualitative approach to capture the depth and complexity of these experiences. Semi-structured interviews, lasting between 45 and 60 minutes, were conducted with six grandparents. The interviews consisted of open-ended questions to allow participants to share their stories and perspectives freely. These interviews were audio-recorded and transcribed for detailed analysis.

To gain a deeper understanding of the lived experiences and the meanings behind grandparents' reactions to the news of their grandchildren's ASD diagnosis, the study employed Interpretative Phenomenological Analysis (IPA), which is suited for this type of research as it focuses on how individuals make sense of their personal and social worlds (Smith et al., 2009). This approach enabled a thorough exploration of the grandparents' emotional responses, coping mechanisms, and the impact of their grandchildren's diagnoses on their lives.

Participants for this study were purposefully sampled from individuals with first-hand experience with a grandchild's autism diagnosis within the past 10 years. The sample included both male and female participants to ensure a diverse range of perspectives. Purposeful sampling was ideal for this research as it allowed for the selection of participants who could provide rich, relevant, and diverse insights into the phenomenon being studied (Patton, 2002).

This study aims to shed light on the experiences of grandparents and their unique perspectives regarding autism. This knowledge will expand our understanding of how grandparents cope with the challenges and demands associated with having a grandchild with ASD. Additionally, the insights gained from this research will offer valuable information for families and professionals supporting individuals with ASD.

Personal Interest in the Subject

My personal interest in this subject stems from my profession as a learning support educator (LSE). Over the years, I have had the opportunity to work with numerous students on the autism spectrum. I am constantly charmed by how these children, each in their unique way, exhibit such beauty and individuality. Every student has left a lasting impact on me, shaping who I am today, often without them even realising it. I care for these students as if they are my own children; additionally, now I am a mother myself, I have a deeper understanding of the parents' or caregivers' desire to provide the best for their children.

Throughout my career, I have observed the significant role that grandparents play in the lives of their grandchildren, whether they are on the spectrum or not. Many grandparents are involved in daily activities, such as taking their grandchildren to and from school and caring for them after school until their parents return from work.

My curiosity has always been triggered by how grandparents react upon learning that their grandchild is on the autism spectrum. This initial question, along with their understanding of autism, drove my interest in this research. A few years ago, autism was not commonly recognised, which made me wonder about the grandparents' understanding of the condition. The presumption that the experience of discovering their grandchild has ASD might be negative is based on my own assumptions and the judgments I have encountered in various situations.

One particular experience that significantly influenced my interest was meeting a great-grandmother who was caring for her grandchild's child with autism. I was deeply impressed by her ability to manage and understand the child's challenging behaviours. She often shared her feelings and narrated the child's behaviours at home. This made me question whether she genuinely understood autism or if her understanding was based solely on her grandchild's behaviours. This encounter highlighted the need for more knowledge on this understudied topic and became a pivotal reason for my interest in pursuing this research.

Chapter Two: Literature Review

Grandparenting a Child on the Autism Spectrum

Grandparenting a child on the autism spectrum involves unique challenges and opportunities. Many grandparents do not have prior knowledge or understanding of autism. This lack of awareness can lead to confusion and feelings of helplessness as they try to understand their grandchildren's unique needs and behaviours (Hillman, 2007). Additionally, older grandparents might find it physically challenging to care for a child with autism, especially if they exhibit behaviours that require a lot of energy to manage. The physical demands can be particularly taxing if the grandparents are the primary caregivers (Hillman, 2007).

Supporting a grandchild with autism requires understanding their specific needs, fostering patience, and actively participating in their development. Grandparents can play a crucial role in providing emotional support to both the child and their parents, contributing to a nurturing and inclusive family environment. Learning about autism, staying informed about effective therapies, and embracing open communication are essential aspects of grandparenting a child on the spectrum. Additionally, creating a supportive, accepting atmosphere helps the grandchild thrive and enhances the overall family dynamic.

Grandparents may face generational differences in attitudes towards disability and autism, which can cause friction when discussing how to approach their care and development. These differences can result in disagreements with the child's parents over treatment approaches and caregiving practices (Sicile-Kira, 2014).

Since ASD presents unique challenges to families, understanding the role of grandparents in supporting these families is of growing importance. Becoming a grandparent is one of the roles taken on later in life – typically assigned rather than willingly chosen;

additionally, individuals have limited to no control over the timing of this role. However, according to Clarke and Roberts (2003), it is, overall, perceived as significant and fulfilling.

Grandparents' Role

The role of grandparents is constantly evolving due to shifts in demographics and changes in family structures. This evolution implies that the previously established norms linked to grandparents have become progressively unsuitable (Merrick, 2020).

There is limited knowledge about the expectations and attitudes of grandparents. Various aspects of the role, such as timing, the number of grandchildren, and the frequency of interactions, are beyond their control. Despite this, both grandparents and their adult children harbour certain expectations associated with the role. Typically, grandparents anticipate spending time with their grandchildren, experiencing a sense of appreciation when they have the opportunity to do so. Parents, on the other hand, expect grandparents to offer support. Meanwhile, the grandchildren themselves may look forward to hearing family history stories and receiving gifts (Kemp, 2004; Somary & Strieker, 1998).

The dynamics and agreements surrounding grandparental roles can vary based on the unique circumstances, values, and preferences of each family unit (Finch et al.,,1993; Mason et al., 2007). Indeed, the aforementioned expectations are subject to negotiation within the context of each family.

Thiele and Whelan (2008) suggested that women tend to derive more satisfaction from the grandparenting role than men. However, research indicates that these gender differences have diminished over the past few decades; moreover, they are less frequently observed in more contemporary studies (Peterson, 1999; Reitzes & Mutran, 2004).

The conduct and role of grandparents appear to be influenced by the significance the individual attaches to the role and the level of meaning they attribute to it (Miller &

Cavanaugh, 1990; Silverstein & Marenco, 2001; Sorensen & Cooper, 2010). Broadly speaking, grandparents who actively engage in their role tend to characterise grandparenthood as a more central and meaningful aspect of their identity, compared to those labelled as ‘passive’ or ‘remote’ grandparents (Merrick, 2020).

The Interactive Autism Network (IAN) conducted a study involving over 2,600 grandparents of children diagnosed with ASD. The research revealed that approximately one-third of grandparents in the United States were the first to raise concerns regarding the potential presence of ASD in their grandchildren. Moreover, 71% of them indicated involvement in making treatment decisions, while over 15% reported offering transportation services at least once a week. Additionally, about 11% said they reside in the same household as their grandchild diagnosed with ASD (IAN, 2010).

Grandparents’ Dilemmas While Caring for Their Grandchildren

Grandparents often grapple with the dilemma of how much support and intervention they should offer (Ariel & Naseef, 2006; Rice & Bellin, 2009b) while also respecting the autonomy of the parents.

They may, for instance, wish to be involved in their grandchildren’s lives by providing emotional support, caregiving and assisting in educational and therapeutic activities (Ariel & Naseef, 2006). While doing this, they should ensure their involvement does not overstep boundaries or undermine the parents’ decisions regarding the child’s care (Rice & Bellin, 2009b). This balance can be difficult to achieve since it involves careful consideration of family dynamics and communication. Because grandparents may have various notions about disability and autism based on their generational experiences, this can lead to arguments as to which are the appropriate ways for intervention and care (Sicile-Kira, 2014).

The generation gap also influences grandparenting approaches, which complicates the issue in question. Parents' chosen approaches may differ from their own parent's opinions or experiences (Hillman, 2007). Now that grandparents have a new role, switching from primary caregivers to supporting figures to their children requires clear communication and understanding (Rice & Bellin, 2009a). While still having their own process of grief and acceptance in response to their grandchildren's diagnoses, they must discover strategies to cope with their emotions while simultaneously helping their children and grandchildren on the spectrum (Hillman, 2007).

Upon learning of their grandchildren's ASD diagnoses, many grandparents immediately experience concerns about the emotional turmoil and distress in their adult children's lives. This sense of role confusion seems to be a common experience among grandparents of children with ASD (Hillman, 2007).

In a study by Margetts, Le Couteur & Croom (2006), grandparents reported experiencing ongoing shifts, characterised by three primary themes: i) the parental bond (a protective connection towards both grandchild and adult offspring); ii) seeking answers (pursuing understanding); and iii) maintaining cohesion (preserving family unity).

The dynamic relationship between grandparents and their grandchildren with autism remains an area with limited exploration in existing literature. However, grandparents have been recognised as significant in therapeutic interventions for the family dynamic within the context of ASD (Hasenecz, 2010; Hillman, 2007; IAN, 2010; Margetts, Couteur & Croom, 2006).

Autism and Stigma

Children with ASD frequently exhibit a variety of repetitive behaviours that differ in type and severity. Identifying the basic functions of these behaviours is critical, since treatments may be ineffective or even aggravate the behaviour if not selected and applied carefully (O’Neill et al., 1997). Aggression and self-injury, for example, are often used by children on the spectrum as a form of communication (Gualtieri, 1988).

A neurodevelopmental condition, ASD not only affects the individuals themselves but also significantly influences the lives of their families, who frequently deal with problematic behaviours that might hamper the child’s scholastic development, independence, and general quality of life. Besides endangering the individual’s and others’ well-being and/or causing harm to property, these actions can exclude family members from the community and society as a whole (Worcester et al., 2008). In such situations, family members may feel the need to restrict their social connections to people who understand (Gray, 2002). Furthermore, coping with unpredictable responses while also attempting to soothe their children can result in a feeling of powerlessness when confronted with impending tantrums (Pisula, 2011).

Behavioural Issues and the Lack of Public Awareness

A significant challenge faced by families and individuals with ASD is the general lack of public awareness and understanding about the condition. This information gap can lead to misunderstandings, stigma, and insufficient support for people with autism.

Many individuals have misunderstandings regarding autism because of a lack of knowledge. Common misconceptions include the idea that all people with autism are non-verbal or lack emotional intelligence. Such misunderstandings can lead to stigmatisation, in which people with autism and their families are unfairly labelled or mistreated (Autism Society, 2021). Stigma can have a significant influence on the self-esteem and social integration of people with ASD, making it more difficult for them to lead happy lives (Goffman, 1963).

The lack of public information frequently results in inappropriate reactions to behaviours shown by individuals on the spectrum. Meltdowns and repetitive behaviours, which are common in autism, are often mistaken as disobedience or inadequate parenting. This misconception can lead to unfair judgment and criticism from others (Kite et al., 2013).

The public's lack of knowledge of autism also has an impact on educational settings. Teachers and school personnel may not be adequately trained to teach students with autism, resulting in incorrect educational placements and a lack of specialised care. This can impede academic achievement and social development in individuals on the spectrum (Simpson et al., 2018).

Exclusion and Social Isolation

Another challenge is the exclusion from ordinary setups and increased social isolation for families of children with autism. These families are frequently excluded from traditional social and community settings, which leads to increased social isolation. Exclusion and isolation may have a substantial influence on the family's quality of life and mental health. For instance, children with autism may struggle to participate in – and even be invited to – daily social activities such as birthday parties, playdates, and extracurricular activities, with behavioural challenges, sensory sensitivities, and social communication difficulties often being behind the reluctance. According to Woodgate et al. (2008), this may lead families to intentionally opt out of these activities and prevent unwanted reactions from others. Additionally, public places, including parks, restaurants, and recreational facilities, may not be accommodating to children with autism. In this scenario, a lack of knowledge and acceptance in the community can result in uncomfortable or unfriendly encounters, deterring families from participating in community activities (Gray, 2002).

The challenges of caring for a child with ASD can place considerable strain on family connections and relationships. Parents may experience greater stress and exhaustion, resulting in social disengagement and poor connection with extended family and friends. Siblings may also feel abandoned or burdened by their sibling/s' autism-related needs (Myers et al., 2009). Thus, social isolation experienced by families of children on the spectrum can have a significant impact on their mental health. Parents, particularly mothers, have an increased chance of developing depression, anxiety, and other mental health difficulties, while the lack of social support and understanding may increase feelings of isolation and helplessness (Smith et al., 2018).

Families with children on the spectrum confront considerable obstacles, such as exclusion from normal settings and increasing social isolation. According to Boyd (2002), creating support groups for parents and families of children with ASD can give much-needed social and emotional support. These groups can provide a safe environment for sharing experiences, resources, and coping skills. Addressing these concerns via public awareness, support networks, and inclusive practices can help these families improve their quality of life.

Labelling

The diagnosis and subsequent 'labelling' of a child with autism can have profound effects on family dynamics. Grandparents, in particular, experience unique challenges and emotional responses as they navigate their roles within the family and society. They frequently experience a variety of emotions after learning of their grandchildren's autism diagnosis. These can include shock, denial, guilt, and grief as they come to terms with the implications of the label (Hastings, 2003).

Their initial reaction is frequently marked with uncertainty and a lack of knowledge regarding the diagnosis' implications for their grandchildren's future. Over time, however, many grandparents come to accept it and learn to adjust. This process can be emotionally stressful, especially if grandparents have misunderstandings about autism or have predetermined notions about their grandchildren's development (Krauss & Seltzer, 1999).

Labelling a child with autism can strain the intergenerational connections within the family. Grandparents' ideas regarding autism and its origins often differ from those of the child's parents, resulting in arguments or confrontations over treatment and educational techniques (Seligman & Darling, 2007). These disagreements may originate from variations in understanding or acceptance of the diagnosis and its implications.

Grandparents frequently take on caregiving tasks to help their children and grandchildren. This may be rewarding and challenging, as they must balance offering support while also managing their own emotional reactions to the diagnosis. The additional responsibilities can cause physical and emotional exhaustion, especially for those who already have age-related health issues (Hillman, 2007).

The label of autism might cause perceived stigma, influencing how grandparents engage with their social networks. They may experience a lack of understanding or acceptance from friends and community members, leading to social disengagement and isolation (Gray, 2002). Moreover, grandparents may often feel ashamed or afraid to share their grandchildren's condition, thus increasing their sense of loneliness.

One of the most significant ways grandparents can cope with the diagnosis is to research and educate themselves on autism. This can help dispel worries and misunderstandings, allowing them to better support their grandchildren and advocate for their needs within the family and community (Hutton & Caron, 2005). Some grandparents actively engage in therapeutic interventions and educational activities for their grandchildren. Their involvement may contribute to the child's development while also giving grandparents a sense of purpose and connection to their grandchild's progress (Prendeville & Kinsella, 2019).

Parental Stress and Social Perception of ASD

The study of parents' experiences with their children with ASD has become broader. Parents of children on the spectrum may endure severe pressures beyond those faced while raising children with other chronic diseases or medical disorders (Hayes & Watson, 2013). When a child develops indications or is diagnosed with ASD, the entire family's everyday activities and financial circumstances may alter drastically, prompting considerable modifications in family relations (DePape & Lindsay, 2015). Indeed, the defining traits of ASD, such as difficulties with social contact, reciprocal communication, and the appearance of restricted or repetitive behaviours, frequently cause stress for parents (APA, 2013).

Individuals with ASD often appear typical in appearance, which can perplex onlookers when they exhibit unusual behaviours. Some people may struggle to accept or recognise that a child has ASD because of their normal outward appearance (Moyson & Roeyers, 2011). Without awareness of the child's condition, these behaviours are often misinterpreted as challenging, while understanding the child has ASD generally fosters greater tolerance (Chambres et al., 2008; Huws & Jones, 2010). Consequently, those with ASD and their families frequently face societal criticism based on actions that challenge normative assumptions of behaviour and development.

The Stigma and Social Perception of Autism Spectrum Disorder (ASD)

Erving Goffman's significant book, The Theory of Social Stigma, described stigma as a perceived negative deviation from societal standards and principles (1963). The research he conducted helped provide a paradigm for analysing stigmatising conditions. According to Goffman, stigma may have a significant influence on the quality of life and welfare of those with disabilities, as well as on their close friends and relatives. This is known as *courtesy stigma*. Goffman's study remains a key theoretical basis for understanding stigma, although recent research has expanded on the topic (Farrugia, 2009).

Parent participants in a study by Neely-Barnes et al. (2011) suggested that the general public often struggles to recognize autism, as they typically only notice a child's disruptive behaviour. According to Gray (1993) a mix of widespread impairment and apparent physical normalcy gives the stigma encountered by families with children on the autism spectrum its particular aspect.

Indeed, Broady et al. (2017, p. 228) observed that parents often experience negative comments from the general public, school and even their own family members about the behaviour of their child with ASD, giving examples such as "that child just needs a good smack on the bum", or "some people shouldn't be parents".

Social Isolation in the Context of Autism

Social isolation may include *subjective* and/or *objective* components (Zavaleta et al., 2014). *Objective social isolation* refers to an individual's real quantity of social interaction, such as fewer regular interactions with others, fewer individuals in a social circle, as well as living alone (Holt-Lunstad et al., 2015). *Subjective social isolation,* on the other hand, pertains to an individual's perception of the adequacy or quality of their social connections and encompasses aspects such as perceived social support (Wang et al., 2017). Loneliness, for example, is a type of subjective social isolation described as a poor emotional state caused by a disparity between one's actual and desired social interactions (Peplau & Perlman, 1982).

In the following chapter, I will delve into research conducted in the past to better understand the historical context and evolution of knowledge in this field. Loneliness has received little attention in the autism research area, partly because initial definitions of autism emphasised how autistic individuals prefer to stay alone. Kanner (1943), for instance, described one of his clients on the autism spectrum as someone who is at their happiest and most delighted when left on their own, noting that individuals on the spectrum have a "powerful desire for aloneness" (p. 249). Furthermore, Asperger (1944, p. 38) stated that, while "human beings normally live in constant interaction with their environment and react to it continuously … autists" have poorly disrupted and significantly reduced contact.

Loneliness in Grandparents

Many grandparents experience loneliness due to the loss of friends and peers, either through death, relocation, or decreased social interaction as they age (Victor et al., 2004). Social circles naturally diminish over time, leading to increased feelings of isolation. Physical health problems can limit a grandparent's ability to engage in social activities, further isolating them from their community and social networks (Coyle & Dugan, 2012). Indeed, chronic illnesses and mobility issues are common barriers to maintaining an active social life.

Retirement often reduces daily social interactions that were previously a part of working life, contributing to feelings of loneliness. The lack of a daily routine and the sense of purpose that work provides can be difficult adjustments (Dorfman, 1995). Changes in family dynamics, such as children moving away or being preoccupied with their own families and careers, can leave grandparents feeling neglected and lonely. This sense of abandonment can be profound, especially if grandparents were previously heavily involved in their children's lives (Bengtson, 2001).

Grandparents may find themselves isolated from their peers who do not fully understand the challenges associated with raising a grandchild with autism. This can lead to feelings of alienation and loneliness (Hillman, 2007). The responsibility of caregiving can limit their ability to participate in social activities and maintain social connections, further exacerbating their sense of loneliness (Hastings, 2003).

Commonalities in Loneliness for Grandparents and Their Grandchildren on the Spectrum

Both grandparents and children with autism may feel isolated from typical social settings. Grandparents might avoid social gatherings due to caregiving responsibilities, and children with autism might be excluded from social activities due to their behaviour (Bauminger & Kasari, 2000; Hillman, 2007). The emotional strain of dealing with the challenges associated with autism can lead to profound feelings of loneliness for both grandparents and children.

There is a growing interest in studying loneliness and isolation in individuals with autism. Studies have found that children and adolescents on the spectrum experience loneliness more profoundly and more often than their typically developing peers (Bauminger & Kasari, 2000; Bauminger et al., 2003). Youngsters with ASD tend to feel loneliness in a qualitatively different way than their classmates. For instance, past research has shown that children with autism tend to equate loneliness solely with physical isolation, whereas children without autism describe loneliness in terms of emotional and social-cognitive aspects (Bauminger & Kasari, 2000).

For typically developing children, loneliness involves a deeper emotional experience, including feelings of sadness, rejection, and a lack of meaningful social connections. They understand loneliness as not just the absence of physical company but also as the absence of emotional intimacy and supportive relationships (Bauminger & Kasari, 2000).

Children with ASD often face challenges in social communication and interaction, which may limit their ability to form and maintain relationships. This can result in a more concrete, less nuanced understanding of social experiences. While non-disabled children are more adept at interpreting social cues and understanding the emotional subtleties of relationships, children with ASD might struggle with these aspects, leading to a more simplistic view of loneliness. This difference in perception underscores the importance of tailored social skills interventions for children with ASD, aiming to enhance their understanding and management of social and emotional loneliness (Bauminger et al., 2003; White & Roberson-Nay, 2009).

Further studies suggested the absence of friendships as an essential indicator of loneliness (Bauminger & Kasari, 2000; Locke et al., 2010), with many children on the spectrum having an inadequate degree of friendship quality as well as hovering on the fringes of their educational network of friends (Calder et al., 2013; Locke et al., 2010).

While loneliness does not appear to be linked to a recognition of friendship between children with or without autism (Bottema-Beutel et al., 2019), inadequate levels of quality of friendship and/or residing on the outskirts of one's educational social networks can result in social withdrawal, isolation, and loneliness in adolescence (Sumiya et al., 2018; White & Roberson-Nay, 2009; Whitehouse et al., 2009).

Family Stressors

Families typically prepare for changes before the birth of a new child. However, they cannot fully grasp the extent of these changes until the baby arrives. As the delivery date approaches, the tangible effects of the impending addition become more apparent. Financial adjustments, shifts in parental roles, and even potential alterations in living arrangements are anticipated.

Having a child with a disability poses additional and significant challenges for parents and other family members, with each disability and child presenting unique characteristics that shape the nature of that challenge (Norton & Drew, 1994). Certain disabilities, like ASD, exhibit extreme variations in ability and behaviour, introducing heightened diversity to the challenges faced by family members (Norton & Drew, 1994).

Having a child with a disability has a profound influence on family relations, sometimes resulting in unfulfilled ambitions, and may also affect the parents' relationship. The substantial differences in skills and behaviours linked with autism provide distinct and diverse issues that can exacerbate emotions of loss and disappointment among parents. Dreams of a 'normal' upbringing and a bright future for their child may give way to concerns about the child's growth, independence, and societal acceptability. This shift in expectations can cause a strain on marriages or relationships as couples are forced to deal with the emotional and practical challenges thrust upon them. Additionally, growing stress and the need to constantly attend to the child's needs can reduce parents' time and energy for each other, potentially leading to reduced marital satisfaction and intimacy (Hartley et al., 2011; Risdal & Singer, 2004).

Furthermore, the ongoing concern and financial burden of caring for a child with a disability can intensify tensions and lead to arguments within the couple, thereby impacting the quality of their relationship (Karst & Van Hecke, 2012). Moreover, autism frequently places significant demands on grandparents, requiring them to take on their parental obligations to assist both their grandchildren and their own children. Demands may require grandparents to pitch in as supplementary caregivers to help manage the child's requirements (Hastings, 1997). This extended engagement may indicate that grandparents are more actively involved in caregiving duties well into what would normally be their retirement years, essentially extending their parental roles. This extended caregiver role may also entail providing stability and consistency for the child, which is crucial given the structured surroundings that children with autism frequently demand (Skarin & Mohr, 2002).Indeed, research by Rodrigue et al. (1990, as referenced in Dunn et al., 2001) found that families with children with ASD tend to avoid public events because they are irritated by strangers' reactions. Furthermore, according to Brill (2001), they may also harbour jealousy towards other families whose children are typical developers.

Family Dynamics and Grandparental Support in Autism Care

Koegel et al. (1983) discovered no variations in stress levels or psychological functioning among families with disabled children and those without. Indeed, according to Akerley (1984) and Kazak and Marvin (1984), parenting a child with special needs can actually strengthen couples through teamwork and shared purpose.

Furthermore, the involvement of grandparents can assist in minimising overall family stress levels. According to Hastings (1997) and Hillman (2007), grandparents may greatly improve the family's resilience and stability by engaging in caregiving and providing advice based on their own parenting experiences. The teamwork necessary to care for a child on the spectrum may build a better intergenerational family dynamic, with grandparents feeling more respected and included into the family's functioning.

Studies have identified a variety of distinct coping methods and tools employed by families with children with special needs to ensure effective adaptation. Social assistance in the form of parental education initiatives, for instance, helps families educate their children on the spectrum by modelling functional skills as well as appropriate behaviour (Bondy & Frost, 1994; Harris & Handleman, 1994; Lovaas, 1981; Marcus & Schopler, 1989; Talpins & Kabot, 1996). Assistance and encouragement from close family and friends is also vital (Randall & Parker, 1999).

According to research, mothers who express less stress also experience better support from their spouse, close and distant family members, friends, and any other involved caregivers (Bristol, 1979; Bristol, 1987; Bristol & Schopler, 1983).

Chapter 3: Methodology

Introduction

This chapter outlines the methodology employed in the study. It offers insights into the rationale behind the chosen approach, the research design, data collection and analysis methods, as well as ethical considerations, and my personal reflective journey throughout the research process.

Research Approach

I adopted a qualitative design for this study so that I could discover the major themes that emerged from the data collected, which investigated the unique experiences of grandparents of children with ASD and their ongoing journey of navigating this situation, including their reactions upon receiving the news, how they handled it, and their relationship with their children and grandchildren.

While quantitative research converts information about studied phenomena into numbers, the goal of qualitative research is to determine how and why these phenomena happen (Merriam & Tisdell, 2015). This approach is generally preferred for studies focusing on understanding specific human experiences and relationships; as such, data is typically highly subjective, stemming from individual experiences (Lewis, 2015). In contrast, a qualitative research design aims to take a holistic, comprehensive approach to the study of a phenomenon, exploring the inner experiences of participants to gain insight into the causes of the phenomenon under study (Corbin et al., 2014).

The diverse assumptions, interpretative frameworks and viewpoints of various individuals enriched the study, enhancing the depth of this approach. This enabled me to examine the phenomenon thoroughly.

Throughout this research, I was able to explore how grandparents made sense of the news that their grandchildren are on the autism spectrum, the meaning they attribute to it, and their understanding of the condition. Additionally, I examined how they collaborate with their children (the parents of the child on the spectrum), their spouses (if any), other grandchildren, and society in general.

Epoche is a crucial concept in phenomenology, especially for this qualitative study. It involves the researcher setting "aside all prejudgments, bracketing his or her experiences and relying on intuition, imagination, and universal structures to obtain a picture of the experience" (Creswell, 1998, p. 52). In this study, given my experience working with students on the autism spectrum, it was necessary to bracket my personal perceptions and preconceived ideas about the subject to gain a fresh understanding of the participating grandparents' experiences.

Choosing IPA Over Other Qualitative Methodologies

After evaluating other methods within the qualitative paradigm, including discourse analysis, thematic analysis (TA), grounded theory analysis, and narrative, I determined that IPA was the most suitable approach for this research. As described by Smith et al. (2009), IPA "provides us with a rich source of ideas about how to examine and comprehend lived experiences" (p. 10).

When I commenced this research, my specific interest was to obtain a detailed understanding of grandparents' perceived experiences and their process of making meaning. This would not be achieved had I used TA; according to Braun and Clarke (2006), TA identifies, analyses, and reports themes within data to provide insights into patterns of meaning. Narrative analysis examines stories to understand how individuals construct their identities and make sense of their experiences, capturing rich, detailed accounts of participants’ lives (Clandinin & Connelly, 2000; Riessman, 2008). On the other hand, grounded theory analysis constructs theories through systematic data gathering and analysis, aiming to generate theories that explain processes, actions, or interactions (Corbin & Strauss, 2015; Glaser & Strauss, 1967).

Rationale and Philosophical Underpinnings of IPA

As a qualitative research approach, IPA seeks to understand how individuals make sense of their personal and social worlds. This methodology is particularly suited for exploring complex, nuanced experiences, making it a powerful tool in psychological and social research. The rationale for using IPA lies in its detailed examination of lived experiences, its philosophical roots in phenomenology, hermeneutics and ideography, as well as its focus on the meanings individuals ascribe to their experiences (Smith et al., 2009).

Phenomenology, founded by Edmund Husserl, is the study of conscious experiences from the first-person perspective. Husserl’s work emphasises the importance of understanding how individuals perceive and interpret their experiences. He introduced the concept of *intentionality*, which refers to the directedness of consciousness toward objects and experiences in the world (Husserl, 1970). The chosen methodology of IPA draws from this phenomenological tradition by aiming to capture the essence of participants’ experiences. Researchers using IPA strive to understand phenomena as they are perceived and experienced by individuals, thus providing rich, detailed accounts of personal lived experiences.

Building on Husserl’s ideas, Martin Heidegger expanded phenomenology to include the importance of context and the interpretative nature of experience. Heidegger emphasised that understanding is always situated within a specific context, and that individuals continuously interpret their experiences within their world (1962). This perspective aligns with IPA’s focus on understanding participants’ lived experiences in their particular contexts and acknowledges that these experiences are inherently interpretative.

The IPA approach aligned well with the research aims of this study as it allowed me to deeply explore the experiences of grandparents of children on the autism spectrum and their ongoing journeys. It enabled me to investigate their perceived relational experiences, how they negotiated receiving the news, and their interactions with their children, their other grandchildren, their spouses (if any), and the condition itself. I delved into the relationship dynamics of grandparents with their spouses, especially those who were not separated or widowed. I inquired about how the presence of autism affected their relationship or marriage, and whether they encountered any difficulties or disagreements. Some disagreements arose around who would spend time with the grandchild versus who would continue with their daily routines. For example, participants discussed how they managed the balance of caregiving responsibilities and maintaining their own personal lives.

Hermeneutics, the theory and methodology of interpretation, is another core element of IPA. It is concerned with the interpretation of texts, symbols, and experiences. Researchers using IPA engage in what is known as a double hermeneutic process, wherein they interpret the participants’ interpretations of their own experiences (Smith & Osborn, 2003). This means that IPA involves two levels of interpretation: first, the participants make sense of their experiences; then the researcher makes sense of how the participants are making sense of their experiences.

Paul Ricoeur’s distinction between a “hermeneutics of empathy” and a “hermeneutics of suspicion” is particularly relevant here. While the former involves understanding participants’ experiences from their perspectives, the latter involves a more critical analysis that seeks to uncover deeper, often hidden meanings (Ricoeur, 1970). Meanwhile, IPA primarily utilises a hermeneutics of empathy, aiming to get as close as possible to the participants’ own viewpoint while acknowledging that the researcher’s own perspective and context will inevitably influence the interpretation.

This method allowed me to interpret the participants’ perceived relational experiences and relate them to existing literature. For example, one of the participants learned that, whenever a change is going to happen for the child, she has to prepare him beforehand. By doing so she reduces his “tantrums”, which panic her as she does not feel strong enough to calm him down at that time.

I was also guided by the multiple hermeneutics method while understanding these events. While attempting to empathise with the participants; experiences, I critically interacted with them, regardless of what they might have accomplished or were willing to accomplish (Eatough & Smith, 2008). This strategy enabled me to gain a more complete grasp of the topic under inquiry (Smith, 2004).

The third philosophical underpinning of IPA is *ideography*, which focuses on the particular rather than the general. Unlike nomothetic approaches that seek to make broad generalisations about populations, idiographic approaches are concerned with in-depth analysis of individual cases. The idiographic focus of IPA means that it involves a detailed, in-depth analysis of each participant’s unique experience before moving to more general claims. This approach ensures that the nuances and complexities of each individual’s experience are captured (Smith et al., 2009).

This idiographic commitment is reflected in the way IPA studies are conducted. Researchers typically use small, purposively selected samples to allow for a deep, detailed exploration of each participant’s experiences. This enables researchers to produce rich, nuanced accounts that highlight the uniqueness of each participant's perspective, while also identifying patterns and themes that may emerge across cases (Smith et al., 2009).

The idiographic approach in IPA allowed me to deeply examine each individual experience, identifying both similarities and differences among them to uncover participants' thought processes and interpretations (Shinebourne, 2011). While interviewing grandparents, I considered the relational dynamics between the grandparents and the grandchild on the autism spectrum, as well as between the grandparents and myself, both during the interviews and later during the data analysis within the broader context.

The rationale for using IPA in research is grounded in its ability to provide a deep, nuanced understanding of personal experiences. This approach is particularly valuable in fields such as psychology, health, and social sciences, where understanding the subjective experiences of individuals is crucial. By focusing on how people make sense of their experiences, IPA allows researchers to explore the meanings that individuals ascribe to significant events and processes in their lives.

Research Design

For participant recruitment, I selected a purposive sampling method, as it was essential to identify individuals with specific characteristics which could offer data pertinent to the research question. Using a random or representative sample would have been ineffective for examining the specific phenomenon under study. Therefore, I needed to identify a relatively homogeneous population (Smith & Osborn, 2004).

I initially contacted *Nanniet Malta,* a non-governmental organisation (NGO) via email and one of their social media platforms. When I received no response, I then turned to my family and friends, who helped me connect with grandparents they knew had grandchildren on the spectrum. Through their assistance, I was able to recruit participants. Once they agreed to participate in the study, I provided them with an information sheet (Appendix 1), available in both Maltese and English, which included all necessary details about the study and my contact information for direct communication. Participants were given the option to schedule the interview at their convenience, considering their needs.

Inclusion and Exclusion Criteria

The sample consisted of six Maltese (Gozitan) grandparents of children on the autism spectrum. I chose to focus on grandparents within the Maltese context as there is limited literature available specifically on ASD that addresses the experiences of grandparents with a grandchild on the spectrum.

It is essential to highlight the significant role grandparents play in the upbringing of grandchildren, particularly those on the autism spectrum. By sharing the experiences of the grandparents interviewed in this study, I aim to provide reassurance and a sense of community for other current and future grandparents who may find themselves in similar situations. This can help them understand that they are not alone and can relate to the shared experiences of others in similar circumstances.

I opted for a limited number of participants in my study to make the research objectives more manageable. According to Crouch and McKenzie (2006), having fewer participants can facilitate the development of closer relationships between the researcher and participants, thus enhancing the quality of information exchange. Participants were selected based on their experience with the phenomenon under investigation and their willingness to share their experiences.

The interviews uncovered the rich and distinctive perceived experiences of each individual participant. The variations, similarities, and spontaneity brought their experiences to life and added depth to their stories. Special attention was also given to how they developed common or unique themes and the negotiation processes they underwent.

Data Collection

The information was acquired via semi-structured interviews. Following IPA epistemology, I developed vast, open-ended questions with the goal of exploring the phenomena in depth rather than testing a predefined hypothesis (Smith & Osborn, 2004).

I created an interview guide for the semi-structured interviews with the participants. After consulting with my tutor and making some changes for clarity, the questions were piloted with the first participant. Because only minimal improvements were required, I chose to include the pilot findings in the research, as no significant changes were made to the question guide after the pilot.

The initial questions were designed to gather background information on the participants. I then asked about their experience when receiving the news from their children, their interpretation of it, and their perspectives on it. The questions progressed to explore the dynamics between the grandparents as a couple, their interactions with other grandchildren, and their relationship with their children who the parents of the child on the autism spectrum are. Additionally, they were asked about their views on society (Appendix 2).

The goal of these following questions was to comprehend the grandparents' reported experiences within the family dynamics in accordance with systems theory. Circular questions were employed to acquire a full understanding of the grandparents' experiences (Scheel & Conoley, 1998).

I selected the interviewing method to encourage participants to speak about their perceived experiences since it is a flexible approach that allowed me to collect an ample amount of qualitative material to address my research question. Despite the fact that the interview agenda had been planned ahead of time, I was able to delve into interesting themes raised by the participants during the interviews (Lyons & Coyle, 2008).

Throughout the interviews, I intently listened to the participants while closely adhering to the order of the pre-prepared questions. Nevertheless, I inquired for further information and explained concerns as they emerged without becoming directive. This method helped assure the data's dependability by allowing me to address any ambiguities and discrepancies in the participants' replies, assist them in retaining information (Smith, 2009), and elicit relevant and accurate data (Bailey, 2008).

This approach also enabled me to create a pleasant environment and establish a deep connection with the participants, which reduced the chance of getting socially acceptable replies (Patton, 1990). At the same time, I was cautious to avoid asking questions that reflected my thoughts rather than the participants'.

Data Analysis

The purpose of the study was to identify dominant themes from the data, focusing on issues, linguistic features, genres, and sub-themes related to the experiences of grandparents of children on the autism spectrum. The interpretive descriptive analytic process aimed to illuminate possibilities for thought and action rather than discovering absolute truths.

A summary table of superordinate and subordinate themes for each participant was created by reducing and abstracting the data to identify higher-order themes that captured the essence of each participant's experience. After analysing commonalities and differences across all cases, a final table of themes was established. These themes were used to present the study's results (Smith & Osborn, 2004).

Interviews were transcribed verbatim, and themes were elicited from each transcript using the participants' own wording. I noted my thoughts and potential biases, reflecting on how they might influence data analysis (Smith & Osborn, 2004). I also considered my positionality as a female, daughter, mother, LSE, and my personal relationship with disability.

Ethical Considerations

All the essential ethical procedures were taken to guarantee that no participants were hurt, especially considering the topic's propensity to elicit strong emotions. Because of the delicate nature of the research, ethical concerns were carefully explored at every level of the procedure. Participants were given a clear description of the study and were properly informed about the limitations and advantages of their involvement (Bond, 2004). I focused on adult participants to secure explicit consent and to prevent any additional ethical issues that may emerge when questioning youngsters about such a sensitive issue.

Details about confidentiality, data storage, and retention were specified, and participants' identities were encrypted to preserve anonymity. Before commencing the study, participants provided informed permission and were assured that they can withdraw at any moment. Each interview concluded with a quick debriefing. The study received ethical approval from the Institute's Research Ethics Committee for IFT-Malta.

Self-reflexivity

As an LSE, I have supported several students on the autism spectrum. While conducting this research, I aimed to ensure that participants shared their own experiences rather than discussing my own, though I sometimes felt I was a bit directive.

I allowed participants to choose the interview location, and most opted for their home or workplace. This unfamiliarity with the setting and meeting participants for the first time to discuss a sensitive topic like their grandchildren’s autism made me uncomfortable. However, being in their safe space helped them share their experiences more openly.

During the interviews, I felt torn between my roles as a mother, LSE, and researcher. I had to consciously stay in the researcher role, focused on obtaining information, despite sometimes slipping into my LSE role. Participants occasionally directed questions at me as an LSE rather than a researcher. Nonetheless, my position provided valuable insights, fuelling my curiosity to learn more about the phenomenon, ask deeper questions, and engage with grandparents on a deeper level.

As a mother to a 12- to 18-month-old daughter during the time of conducting interviews, my mental health was significantly impacted. Listening to participants’ stories about noticing differences in their grandchildren’s behaviours resonated deeply with me, as I thought I observed similar behaviours in my own daughter. I kept these concerns to myself but addressed them during my subsequent therapy sessions. This process helped me gain better self-awareness, as I found myself delaying interviews with participants due to the emotional toll it took on me.

During the interviews, I gained a deeper understanding of why certain parents and grandparents behave in particular ways. As an LSE, I interact with them regularly and witness their joy when they see significant improvements in their children’s progress over the course of a year. While I get to know the child only from the beginning of the scholastic year, parents and grandparents have known them their entire lives. In several interviews, participants mentioned substantial improvements in children’s communication skills, highlighting the long-term perspective they have on their development.

Conclusion

This chapter outlined the study’s methodology, covering the research design and rationale, data collection and analysis methods, as well as the ethical considerations and self-reflexivity procedures.

Chapter Four: Results

This section presents the findings based on the primary themes that emerged from the interviews and data analysis. The results are organised into themes, with superordinate themes and their corresponding sub-themes. These highlight the commonalities and differences found in the research. To protect the participants, all names have been changed. Quotations from the conversations between the participants and the interviewer are included, with the original quotes in Maltese and their English translations, as the interviews were conducted in Maltese.

The Participants

Table 1 illustrates the study participants' information.

Table 1

Participant Information

Name	Polly-Ann	Jeremy	Josephine	Celeste	Rose	Kate
Age	64	67	74	69	72	58
Status	Married	Married	Widow	Married	Married	Separated
Number of children	4	4	3	3	2	2
Number of grandchildren	4	4	3	2	4	2
Age of grandchild on spectrum	7	7	10	8	17	11
Profession	Housewife/ cleaner	Self-employed	Invoice typist/ housewife	Manager	Seamstress	Cleaner
Retired/employed	Retired	Retired	Retired	Employed	Retired	Employed

Sub-themes and Superordinate Themes

The sub-themes and superordinate themes that emerged from the data are shown in Table 2.

Table 2

Sub-themes and Superordinate Themes

Sub-themes	Superordinate themes
Relationship with the grandchild on the spectrum Relationship between the couple (where applicable) Relationship between grandparent and their children Relationship with society	Relationships
Indications that something is amiss Shock Denial Acceptance Comparison to themselves – blame	Initial indications and reaction when given the news
Communication between the adults (grandparent/s and their adult daughter/son) Communication between the child and grandparent Type of communication the grandchild use	Communication
No awareness of what autism is Knowledge Social judgements	Awareness and knowledge on Autism
Fear of the future Fear of being in the public	Fear
Satisfied seeing the child like others Included Judgement	Society

Grandparents' Initial Reaction Upon Receiving News

Regardless of whether grandparents have noticed any developmental or behavioural indications that something might be amiss, receiving the news that their grandchild has a lifelong condition is a significant moment for them.

In this study, participants described when they first began to notice their grandchildren were not developing typically. Some of the participants, like Josephine, attempted to reassure themselves and persuade their adult children that these atypical behaviours were simply unique reactions.

> *He had the letters… of the alphabet… and his father was playing with him, he sorted, sorted for him the alphabet. This boy dismantled, dismantled it… and done it by himself…he did not get one wrong. dismantled it again and re done it again. dismantled it again and redone it starting from… from "z" …this to us appeared to be a great piece of work… removed it and done the Maltese alphabet.* (Josephine)

Some of the grandparents began to notice that their grandchildren did not consistently respond when their names were called. This led them to suspect potential hearing difficulties or speech delays. Each of them hoped that, over time, the child would start speaking and the issue would resolve on its own, especially when professionals confirmed there were no hearing difficulties. Josephine explained how "they [the child's parents] thought ... that he has hearing problems. Then they started taking him for tests, then they were told non-verbal autism is what he has.." Rose, meanwhile, described how "I would call him and he wouldn't pay attention ... then I told her, I told her, 'This boy can't hear anymore?' And from there it started." Polly-Ann agreed, saying that:

Some grandparents began noticing differences in their grandchildren’s behaviour and development, especially in the way they reacted in certain situations:

> *For example, I would call him, and he wouldn’t look at me. And I would tell his mother, I told her, “Maybe he has hearing problems?” I used to tell her that, “Maybe he is deaf.” But whenever he wanted, he would listen.*

> *The first thing I do, to a baby ... a one-month-old ... I put the keys in front of her like this and see where she looks. Is she looks away, if she is looking that way and doesn’t turn around ... I mean here is the trouble.* (Jeremy)

One of the participants suspected something was amiss due to her grandchildren’s (twins) speech delay:

> *That they didn’t speak at all ... at two years old nothing, not even “Mamà” or “Papà”. And that they don’t play with each other. One plays for himself and the other plays for himself, and they never fight. Separate lives.* (Celeste)

Upon receiving the news about their grandchildren’s autism diagnoses, participants experienced a variety of emotions. Some started conducting their own research to understand the condition better, though only after they recovered from the initial shock. Indeed, Polly-Ann admitted that “at first it hits you hard ... you understand? But ... I thought maybe he doesn’t have it, maybe not that severe.” Josephine agreed, saying that “it hit me. A lot. I tell her, ‘But why?’”. Kate said that “When I was told that he’s autistic, I got a big shock”, with Celeste remarking that “they were two years old … I got a big shock obviously. I wasn’t expecting it.”

One of the participants noticed similarities between the grandchild’s behaviour and their own childhood experiences. They observed specific characteristics and behaviours in the child that reminded them of how they had acted at a similar age, prompting them to draw parallels between their experiences and those of their grandchild. This personal reflection led to a deeper understanding and empathy towards the grandchild's condition. Jeremy, in particular, reflected that, "personally ... that's how I was, just like him. A photograph."

Others compared their grandchildren to those without ASD, including their other grandchildren. For example, Polly-Ann admitted that, "not even if there wasn't another child ... we wouldn't have noticed that he has."

Participants felt that this moment of clarity allowed for a better understanding of the child's behaviour and needs, which, in turn, enabled them to seek appropriate support and interventions. The diagnosis provided a framework within which the child's unique characteristics could be recognised and addressed, offering a sense of direction and hope for the future. Indeed, Josephine remarked that "when they told us that, they told me that he is non-verbal, his autism is non-verbal ... it's like then you accept it. Difficult, very difficult but you have to accept it."

Kate, meanwhile, described receiving the unpleasant information about their grandchild's diagnosis, commenting on the inappropriate terminology or manner of communication commonly used in Malta and Gozo. "They told me that he was living in a world of his own," she said.

Awareness on Autism

Despite being explicitly informed that their grandchild has ASD, most participants admitted that they did not fully comprehend the diagnosis, as they had no prior knowledge of autism. This lack of familiarity with the condition made it difficult for them to understand the implications and the nature of the disorder. Rose admitted that "I didn't even know what it was", with Kate adding that, "I didn't know anything. Nothing." Josephine also commented that she knew “nothing” about the condition, while Polly-Ann adamantly exclaimed, “Nooo, I didn’t know about it because … I didn’t know about it.” Meanwhile, Jeremy explained that, though he knew “nothing then” because “there was no interest”, “when you have yours, the interest starts coming in.”

It was only through their own research that the condition became more understandable to them. This process of learning and education helped them grasp the implications of the diagnosis and enabled them to better support their grandchildren. Celeste, for instance, explained how “I used to just read an article ... but I never had first-hand information.”

Other participants held mistaken beliefs regarding autism. Their understanding of the condition was inaccurate or incomplete, potentially leading to misunderstandings or misinterpretations, as shown from the following statements. Jeremy explained how, “ we never called him that either. We used to say he was a naughty boy”, with Polly-Ann also admitting “I just thought he was a naughty boy.”

Another participant, Josephine, asked her daughter, who works as a learning support educator (LSE), for her opinion, saying that, “I knew something as my daughter started working as an LSA ... She told me, ‘Mum, these want everything in order.’”

> *Certain things come as well from a religious situation eh. Where because the boy is naughty … you never stood…. Did you go to doctrine? You never stood on your knees on upturned Coca-cola caps, eh? I did a couple of years on them on my knees. The situation is rebellious eh … so we don’t say because autism is this and autism is that.* (Jeremy)

Participants’ Own Perceptions on Autism

The Relationship Between the Grandparents as a Couple

Relationships between grandparents tend to suffer from some tension while caring for their grandchildren. Some limitations arise throughout their daily life, affecting their previous routines and leading to arguments and confusion. One of the greatest challenges they face is not being able to relax and continue what they were doing when their grandchild is visiting.

> *No, no, listen to me, as a relationship we fight only on this, as … look, let me tell you something, let me make it clear. She, when they are here, has to do the chores. She has to go up on the roof, wash the clothes, she wants to go on the roof to hang the clothes! Work is not a priority*. (Jeremy)

> *Look, you asked this question … sometimes we fight with each other. We fight! Sometimes we don't agree why he has this and this, has that, sometimes we don't agree. Sometimes we disagree. Eh, eh, he tells me, he tells me, maybe he does not have, as I was just like that.* (Josephine)

Other grandparent couples distribute tasks between them according to their grandchild's likes and wants. The commitment they have to take care of the child leads them to set aside things they used to enjoy doing now that they are retired, in order to take care of their grandchild on the spectrum:

> *We both knew how he is ... both of us were … helping one another … because there were times when he wanted him and there were times when he wanted me because … to feed him … He had a great task*. (Rose)

> *Their mother is Maltese ... so as grandparents it's only us here ... so, every time, we have a chat between us ... we pick up the children ... everything that needs to be done, we do it. Total teamwork.* (Celeste)

The relationship between grandparents and their adult children, who are the parents of the child on the autism spectrum, is crucial. All participants in the study mentioned experiencing a shared sense of responsibility and support within the family dynamic. The grandparents do their best to help both their children and grandchildren, especially when a grandchild is diagnosed with ASD. According to Josephine, “it’s more like you’re drawn to him. Like he needs more help than ... anyone else.” Speaking about her adult daughter, Polly-Ann said that “I help her. She tells me everything. She doesn’t hold back so I do not worry.” Jeremy, meanwhile, observed how, “The relationship has grown, in the sense because I help”. Rose agreed, saying that “I helped her [my adult daughter] as much as I could”, while Kate admitted that “she’s [my adult daughter] has become very nervous. In fact, I try to keep her as calm as possible. Support her.”

Unity and collaboration were also mentioned several times as these were more seen and felt when certain issues evolved in the presence of autism. On this subject, Josephine observed “more unity, that’s it. Even his other siblings … and the grandchildren, it seems like they have become very close.” Kate also described her relationship with her daughter as “very close and we talk.”

Society

Participants mentioned that they sometimes choose not to take their grandchild with ASD out in public to minimise potential difficulties. They worry about the child getting hurt while under their care, and this concern often leads them to avoid situations where the child might be at risk. Josephine, for example, admitted that, “to tell you the truth, I never take him out with me. I don’t go out. Because I say, because here is very dangerous.” Polly-Ann added that, “you don’t really take risks. You don’t, as even with the other grandchildren, you don’t risk. I never took mine ... as in front of people they shout even more. So, they can take what they want.”

Participants also commented that, when they take their grandchildren out with them in public, they prepare them in advance by explaining what they will be doing and where they will be going. This preparation helps reduce any potential verbal outbursts and ensures that the child is mentally prepared for the outing. Kate described how “we prepare him … for example, ‘We are going to McDonalds.’”

> *One always has to prepare him. For example, let’s say we’re going to Victoria, but i will not buy anything that you want. I think that if you prepare them, they will listen. I never used to do so with my kids. Just listen to what I say.* (Polly-Ann)

Other grandparents mentioned that they don’t concern themselves with society’s opinions about autism or the reactions when their grandchild behaves differently. They focus on the well-being and happiness of their grandchild, prioritising their needs over societal judgments. Indeed, Celeste was adamant that, “I don’t mind saying that they have autism. They are our grandkids ... I accept them as they are and everything that needs to be done, gets done.”

Some of the participants mentioned that they often leave events early or avoid going to certain places altogether. This is primarily due to concerns about potential challenges their grandchild with autism might face in those environments. Jeremy, for example, described how, “You’ll have to leave from there as if you stop again … we kept on going towards the car. From there to the car and from there back home.”

> *If you go up to the square and there is the feast, he won’t forget. He goes to the part where there are the toys, and there are no toys there. He goes there to buy toys as that’s where he bought from before. He hasn’t forgotten the street. So, you can’t go anywhere with him.* (Polly-Ann)

The participants expressed a sense of satisfaction and happiness knowing that their grandchild is accepted and included in society. Josephine happily remarked how “even in the school photos or a video there’s the children playing, running together… they include him … yes, yes … they try to include him.” Rose agreed, explaining how “there would be the Christmas procession … he would take part. He would go and dress up … he loved taking part and I was so glad that he took part.

Fear of the Future

The unknown nature and future implications of autism, which vary significantly among individuals, cause uncertainties and anxieties for grandparents. They are concerned about their grandchildren’s current and future challenges and their own ability to help mitigate these difficulties. The variability and unpredictability of the disorder contribute to their worries about how severe the condition might become and how it will affect the children’s lives.

The participants expressed that they frequently find themselves worrying about the future.

> Listen, Jack scares me ... for the future not the present. Because he is an individual who does not take a decision. He takes it immediately without any plan or thoughts on it. If he puts his mind to it, bumm! He is not scared of anything. For me, that’s the problem. (Jeremy)

Chapter Five: Discussion

In the following section, I examine the findings that emerged from the participants' experiences, relating them to existing literature, my self-reflexive process, and the selected conceptual frameworks.

Awareness and Knowledge on Autism

One of the recurring themes underlying the results is that the grandparents lacked any prior knowledge or awareness of autism before encountering it firsthand. They had never encountered information or experiences related to autism, resulting in a complete unfamiliarity with the condition. Their understanding was limited since they saw autism behaviours simply as signs of a misbehaving child rather than recognising them as manifestations of a neurological condition. This lack of awareness likely shaped their initial reactions and responses to behaviours they observed, potentially leading to misunderstandings or misinterpretations of the child's needs and abilities. Over time, as they gained more understanding and exposure to autism, their perceptions and attitudes evolved, reflecting a deeper understanding of the condition and its impact.

The lack of knowledge or awareness of autism among grandparents reflects a reductionist approach, where behaviours are oversimplified and misinterpreted as mere misbehaviour rather than understood within the broader context of a neurological condition. This perspective can hinder effective support and appropriate responses to the child's needs (Hastings, 2016). However, as grandparents gain exposure and education about autism, there is a shift towards a psycho-educational approach. This approach emphasises the importance of understanding the condition's complexities and educating family members about the underlying neurological factors, leading to more informed, empathetic, and effective support for the child (Guralnick, 2017). By moving away from reductionist views and embracing a psycho-educational framework, grandparents can better appreciate the nuances of autism and adapt their responses to meet the child’s unique needs more appropriately (Kovshoff et al., 2014).

Glasberg and Harris (1997) proposed that the differences in perceptions between grandparents and their adult children regarding the grandchild with autism might be due to the grandparents’ lack of familiarity with the child’s condition. Similarly, D’Astous et al. (2013) found that intergenerational tensions, such as criticism, poor communication, and a limited understanding of the grandchild’s condition contributed to grandparents providing less support and involvement with their grandchild with ASD. Conversely, when grandparents had a good understanding of autism, maintained positive relationships with their adult children, and were united in addressing the grandchild’s needs, they showed a higher level of commitment to their grandchild with ASD.

In this study, I looked at how grandparents, regardless of their prior knowledge about autism, ultimately committed fully to support their children and grandchildren. Whether they had some understanding of autism or had never heard of it before, they understood the increased attention, time, and patience needed to care for their grandchild. This understanding led them to devote themselves to providing the necessary support, demonstrating a willingness to learn and adapt to meet the needs of their grandchild with autism.

Stress becomes an enduring presence in the lives of grandparents as they continually face fears and the need to readjust over the long term. They frequently encounter unpredictable situations for which they are unprepared, increasing the risk of experiencing greater levels of stress and anxiety. These ongoing challenges underscore the persistent nature of their caregiving role and the emotional toll it can take, necessitating ongoing support and strategies to help mitigate the impact on their well-being.

Initial Reaction When Given the News

In this study, I explored how participants perceive the process, as well as their thoughts and understanding of their own emotions in connection to their surroundings, as defined by Creswell (2012). This entailed evaluating their personal observations and insights into their reactions to their individual contexts and circumstances.

The participants expressed how discovering their grandchildren have a lifelong condition was a significant shock. Many struggled to understand why this was happening, especially those dealing with non-verbal children. They had not anticipated such a diagnosis, often assuming the child was simply lagging behind in reaching developmental milestones or simply being ‘naughty’. Initially, they suspected the child might have had hearing problems or a speech delay. These concerns necessitated numerous medical visits and evaluations before the definitive diagnosis of autism was made. The process of ruling out other potential issues added to their confusion and anxiety, highlighting the emotional and logistical challenges they faced in coming to terms with their grandchildren’s condition.

The transition from a medical approach to a relational approach in understanding and managing autism reflects a broader shift in perspective from focusing solely on the individual’s condition to considering the entire social and relational context. Initially, the medical approach dominated the field, emphasising diagnosis, treatment, and intervention aimed at ‘fixing’ or managing the symptoms of autism. This perspective is rooted in a clinical understanding of autism as a disorder that requires medical attention and therapy, often leading to a focus on deficits, impairments, and the need for specialised interventions (APA, 2013).

However, over time, there has been a growing recognition of the importance of relationships, social interactions, and the broader environment in the lives of individuals with autism. This relational approach shifts the focus from solely treating the individual to understanding how relationships and social contexts influence their experiences and development. It emphasises the importance of family dynamics, peer interactions, and community involvement (Dawson, 2013; Siller & Sigman, 2002).

One participant drew a comparison between the child and himself, describing it as if he were looking at a photo of his younger self. This reflection was deeply emotional for him, evoking feelings of self-blame and guilt, as if he were somehow responsible for the child's condition. Another participant was told that the child seemed to be living in his own world. This description only added to her confusion, as she had no prior knowledge of autism. The use of such inappropriate terminology felt especially harsh and overwhelming for her.

Bristol Autism Support (2024) explains that grandparents often have to grapple with their own lack of knowledge about autism. They might experience confusion or feel overwhelmed by the diagnosis. This can be compounded by inappropriate or harsh terminologies used to describe the condition, which can be especially challenging for those with no prior understanding of autism.

Grandparents often grew up in an era with different societal norms and understandings of developmental conditions. Their upbringing and cultural context may not have included accurate or current information about autism. As a result, they might hold onto outdated or incorrect beliefs about the condition, making it challenging for them to accept new information or approaches (Guralnick, 2017). Long-standing beliefs about child-rearing and development can be difficult to change. Grandparents might believe that their experience and traditional methods of parenting are sufficient, leading to resistance when faced with modern, evidence-based approaches to autism that emphasise neurodiversity and individualised support (Silberman, 2015).

The diagnosis of a grandchild with autism can evoke a range of emotions in grandparents, including guilt, blame, and helplessness. They might question their own parenting practices or worry that they contributed to their grandchild’s condition. This emotional turmoil can make it difficult for them to engage with new perspectives or strategies constructively (Bristol Autism Support, 2024).

Resistance from grandparents can lead to significant tension and conflict within the family. Parents of the child with autism may feel unsupported or misunderstood, which can strain relationships. Disagreements about the best approach to care and support can create ongoing conflicts, making it harder to develop a unified and effective support system for the child (Kapp et al., 2013). Additionally, when grandparents are resistant to understanding autism, parents may feel isolated in their efforts to support their child. This isolation can increase stress and anxiety for parents, who might feel they have to navigate the challenges of raising a child with autism without the support and understanding of their own parents (Siller & Sigman, 2002).

Participants who noticed differences in their grandchildren’s behaviour reported feeling a sense of relief upon receiving the diagnosis, which they said provided them with a clear explanation, helping them understand that these differences were due to a specific condition. Although accepting this reality was challenging and emotionally taxing, over time, they gradually came to terms with the diagnosis. This newfound understanding allowed them to move forward with a better grasp of the child’s needs and the support required.

Relationship Between Grandparents and their Adult Children

Throughout the study, a notable theme that emerged was the relationship between grandparents and their children who are parents of a child with ASD. Participants often emphasised how the parent of a child with autism requires more help and attention than those without autistic children, due to the unique challenges autism presents. From the moment they learned their grandchild was on the spectrum, these grandparents dedicated themselves fully to supporting both their own sons and/or daughters and their grandchildren. This support manifested in various ways, such as being a comforting presence, accompanying them to professional appointments, helping with childcare while the parents were at work, and generally ensuring the well-being and happiness of the entire family.

For grandparents who still need to work and thus have limited time to support their families, the challenges can be particularly pronounced. The absence of their assistance means that the parents of a child with autism must seek alternative support sources. This situation can exacerbate the stress and logistical difficulties that parents face, especially when balancing numerous appointments, therapies, and daily care routines.

While grandparents might not always be available to assist due to work commitments or other responsibilities, other extended family members or close friends can step in to provide critical support. This network can offer various forms of assistance, which can significantly alleviate the burden on parents of children with autism. Extended family members or friends can help by driving the child to therapy sessions, medical appointments, or social activities. This can be especially helpful for parents who may have conflicting work schedules or other children to care for. Having reliable transportation support ensures that the child consistently attends important appointments, which are crucial for their development and well-being (Autism Speaks, 2023).

Having a support network that offers a listening ear can be invaluable for parents. Friends and extended family members can provide emotional support, offering empathy and understanding during challenging times. This support can come in the form of regular check-ins, being available to talk, or simply spending time together. Emotional support helps parents feel less isolated and more connected to a community that understands their struggles (CDC, 2023).

Many parents find solace and practical advice from support groups, both in-person and online. These groups can provide emotional support, share resources, and offer practical tips for managing daily challenges. Organisations like The Malta Autism Centre often facilitate such groups.

Many workplaces are increasingly recognising the need for flexibility among employees with caregiving responsibilities. Options such as telecommuting, flexible hours, and part-time work can help parents manage their schedules more effectively (Society for Human Resource Management, 2023). Telecommuting reduces commute time and allows parents to be more available for their children’s needs. Flexible hours enable employees to start and finish their workdays at times that best fit their caregiving responsibilities, allowing for better management of appointments and therapy sessions. Part-time work provides an opportunity to balance professional and personal responsibilities without being overwhelmed. For example, in Malta, some companies have adopted family-friendly policies, offering flexible work arrangements to support employees with caregiving duties (Borg, 2023).

Moreover, the presence of autism not only strengthened the bond between the grandparent and their child, but also fostered a deeper sense of unity within the entire family. Participants repeatedly described how family members came together to offer assistance whenever needed, creating a strong network of support. This collective effort reinforced familial bonds and highlighted a communal approach to handling the demands associated with raising a child on the autism spectrum. The study revealed that the challenges brought on by autism, while significant, also acted as a catalyst for bringing family members closer together, enhancing their collective resilience and sense of solidarity.

Similarly, Bayat (2007) discovered through qualitative analysis that parents of children with ASD reported experiencing enhanced spirituality, stronger family bonds, and an ability to find positive meaning in their child's condition. They also identified their own resources and developed a greater appreciation for life. These positive experiences align with the general theory of resilience (Seligman & Csikszentmihalyi, 2000), which suggests that individuals, including parents of children with ASD, can develop adaptations and foster positive emotions when faced with new and stressful situations (Bayat, 2007).

Relationship Between the Grandparents as a Couple

Grandparents might need to adapt their roles and expectations within the family. This adaptation process can affect their relationship as a couple as they negotiate new responsibilities and ways of supporting each other (Hillman, 2007). Shared responsibility and support are crucial as grandparents. However, the additional stress associated with these responsibilities can also lead to tension and conflict if not managed well (Margetts, Le Couteur & Croom, 2006). Sharing these emotional experiences can either strengthen their relationship through mutual support or create strain if they cope differently (Hillman, 2007).

The study revealed that married participants often experience arguments and disagreements, primarily because their daily routines are significantly impacted by their grandchildren's needs. For instance, some grandparents expressed that while one partner wants to maintain the regular housework routine, the other insists that their primary focus should now be on caring for the grandchild, considering the child's condition as the top priority. This difference in priorities can lead to friction between the couple.

Grandparents might reflect on their own parenting practices and feel that they lacked the knowledge or resources that are available today. The evolution in understanding autism can lead them to believe they might have missed out on key aspects of nurturing their children, contributing to feelings of inadequacy (Hastings, 2016). Engaging actively in the care and support of their grandchild with autism can be seen as an opportunity for redemption. Grandparents might feel that, by providing extensive support now, they can atone for any perceived failures in their earlier parenting. This drive can result in them prioritising their grandchildren's needs over their own relationships or personal well-being (Goodman & Silverstein, 2002).

The psychological burden of guilt and the desire to redeem past actions can lead to stress and strain within relationships between grandparents. This can manifest in various ways, including disagreements about the extent of involvement, allocation of time, and the emotional toll of caregiving (Hastings, 2016). The dynamics between grandparents, their children, and their grandchildren can become complex. Grandparents might overcompensate by being overly involved, which can sometimes lead to tension with the parents who might feel undermined or judged (Goodman & Silverstein, 2002).

Additionally, some participants mentioned that denial of the child's condition by one partner can be a major source of conflict. When one grandparent struggles to accept and understand the grandchild's autism, it creates emotional and practical challenges within the relationship. These differing perspectives on the child's condition can lead to misunderstandings and stress, potentially straining their relationship.

On the other hand, several participants highlighted the importance of coordination and teamwork in managing their responsibilities. These grandparents described how they collaborate effectively, dividing tasks related to their grandchild's care. For example, one grandparent might take charge of feeding while the other handles different aspects of care. This division of labour allows them to reach an agreement that satisfies both partners and benefits the child. By working together and supporting each other, these couples are able to create a harmonious environment that promotes the well-being of their grandchild and strengthens their own relationship.

The Relation to Society

Research by Rodrigue et al. (1990, as cited in Dunn et al., 2001) discovered that families with children with ASD often avoid public events due to the negative reactions they receive from strangers. Since children with ASD do not have distinguishing physical characteristics, they are expected to adhere to social norms by those unaware of their condition (Chambres et al., 2008). Some people make comments such as, “With a little discipline, I could turn her around” (Smith, 2011, p. 117), believing the child is simply poorly behaved. As a result, families feel pressured to either disclose their child’s special needs to reduce discrimination (Chambres et al., 2008) or ignore the comments and focus on their child (Brill, 2001).

In addition, participants in the study expressed significant concerns about taking their grandchild with ASD out in public. They often feel unsafe doing so alone and worry about societal judgment. Many grandparents feel deep sympathy for their own children, who are frequently subjected to harsh judgment from strangers when their child has a public meltdown. These public reactions are particularly painful when they come from professionals, as grandparents expect more understanding and support from them. The general public’s reactions, ranging from laughter to indifference, leave grandparents feeling hurt and frustrated.

Grandparents of children with ASD often face significant social isolation, which is exacerbated by their own health and mobility issues. Many grandparents, while helping to care for their grandchildren, may choose to avoid public places to minimise societal judgment. Boyd (2002) suggested that establishing support groups for parents and families of children with ASD can offer essential social and emotional support. These groups create a safe space for individuals to share experiences, resources, and coping strategies. Enhancing public awareness, developing support networks, and promoting inclusive practices can significantly improve the quality of life for these families.

To manage these situations better, many participants have developed strategies to prepare their grandchildren for outings. They take time to explain in advance where they are going and what activities will take place. This preparation aims to reduce the likelihood of verbal outbursts, which are a major source of anxiety for the grandparents. By preparing the child, the grandparents hope to create a more predictable and calming experience, which in turn allows them to feel more relaxed and confident when going out.

The study highlighted how these grandparents not only have to navigate the complexities of their grandchild's condition but also contend with the lack of empathy and support from society. Despite these challenges, they demonstrate resilience and proactive approaches to make public outings less stressful. Their dedication to preparing their grandchildren underscores their commitment to providing the best possible care and support, even in the face of societal misunderstanding and prejudice.

Moreover, these experiences emphasise the need for greater public awareness and education about autism. Increased understanding and acceptance from the public could significantly alleviate the stress and emotional burden on families of children with ASD. By fostering a more supportive community, families would feel more comfortable and less judged when navigating public spaces with their children.

Support groups and NGOs in Malta, like the Autism Parents Association, are designed to assist and facilitate the lives of families who have a child on the spectrum. The association's goals are to raise awareness in our local community, as autism is a hidden condition, and the number of children diagnosed with autism is increasing year after year. Unfortunately, parents have several challenges in obtaining a diagnosis, identifying their children’s needs, and finding the necessary help. As an association, they communicate opportunities, information seminars and social activities held locally and internationally either by us or by other entities (APA, 2024).

The sentiment of immense gratitude and happiness expressed by participants when their grandchildren with ASD are included in societal activities aligns with existing literature. Studies consistently highlight the emotional uplift and sense of satisfaction that grandparents feel when their grandchildren are accepted and integrated into various social settings. For instance, Prendeville and Kinsella (2018) found that grandparents of children with ASD often report increased levels of joy and fulfilment when their grandchildren are included in school and community activities.

The specific mention of joy from seeing grandchildren involved in school activities, particularly through shared photos on social media, adds a nuanced dimension to this general sentiment. Social media can serve as a powerful tool for showcasing inclusion, providing visual evidence of participation and engagement that can have a profound emotional impact on grandparents. This aspect is less emphasised in the broader literature but is touched upon by Huws et al. (2016), who discuss the role of digital platforms in enhancing the visibility of children with ASD in inclusive settings, thus providing reassurance and pride to family members.

The visual confirmation of a child’s involvement, such as through photos of them engaging with peers, contrasts with the distress grandparents feel when their grandchildren are isolated or marginalised. This point is supported by Mitchell et al. (2019), who noted that the visual representation of inclusion is crucial for grandparents. It serves as a tangible sign that their grandchildren are not being excluded or sidelined, which is a common fear among families of children with ASD.

The literature widely supports the notion that inclusive practices significantly enhance the emotional well-being of grandparents. Studies by Margetts et al (2020) echo this by showing that inclusive education and social practices lead to a reduction in stigma and an increase in family cohesion and happiness. In contrast, when children with ASD are isolated or excluded, it can lead to feelings of helplessness and frustration among grandparents, as noted by Hock et al. (2012). This dichotomy between inclusion and isolation is a recurring theme in the literature, underscoring the importance of societal acceptance and integration for the well-being of both children with ASD and their families.

The participants also reported a deep sense of satisfaction when their grandchild takes part in school concerts or Christmas processions with friends. For these grandparents, seeing the child included in such events is a significant and positive contrast to the isolation that children with disabilities often faced in previous generations. The inclusion of their grandchild in these social and educational settings is seen as a significant achievement and a source of pride.

This sense of inclusion and acceptance is incredibly meaningful to the participating grandparents. It reassures them that their grandchildren are being treated with the respect and dignity they deserve while also reflecting progress in societal attitudes towards children with autism. The joy they feel when their grandchildren are included in group activities underscores the importance of inclusive practices in schools and other social environments. It highlights the value of creating supportive, inclusive communities where all children, regardless of their abilities, can participate fully and equally.

Fear for the Future

Grandparents of children on the autism spectrum often harbour a range of fears about the future. One significant fear is about the child's ability to live independently and safely as an adult. Grandparents worry that their grandchildren might not develop the necessary life skills to take care of themselves. This fear is particularly pronounced for children who struggle with understanding the consequences of their actions (Rodrigue et al., 1990; as cited in Dunn et al., 2001).

Chambers et al (2008) mentioned that communication is another major concern. Grandparents fear that their grandchildren will not be able to effectively communicate their needs, thoughts, and feelings, which can lead to misunderstandings and neglect (Chambres et al., 2008).

Participants in the study expressed significant concerns about the future of their grandchildren with ASD. They worry about what will become of them, fearing negative outcomes. One major concern is that children on the spectrum often do not consider the consequences of their actions, which could lead to problematic situations.

The anxiety grandparents experience regarding the safety of their grandchildren with ASD when in public aligns with existing literature, which frequently documents the stress and fear caregivers feel in managing children with ASD in potentially hazardous environments. For instance, Hock et al. (2012) noted that caregivers often experience heightened stress due to safety concerns, such as a child's tendency to run into dangerous situations, a sentiment echoed by grandparents in the study.

The physical inadequacy grandparents feel when responding to emergencies is also documented in the literature. According to Prendeville and Kinsella (2018), many grandparents express a lack of confidence in their ability to manage sudden, risky behaviours exhibited by their grandchildren with ASD. This fear leads to a preference for indoor activities, which, while protective, can contribute to social isolation and limit the child's experiences, mirroring findings by Mitchell et al. (2019).

To address these concerns, involving grandparents in the development of the child's care plans is a recommended strategy. This approach is supported by Huws et al. (2016), who found that empowering grandparents through education and involvement in care planning can reduce anxiety and improve their ability to manage their grandchildren's behaviour safely. This involvement helps grandparents feel more competent and less isolated, aligning with broader calls for increased family support and inclusion in care strategies.

Collaborative care planning can also help ensure that everyone is on the same page regarding the child's needs and necessary interventions (Guralnick, 2017). Training sessions that focus on practical skills for managing specific challenges associated with autism, such as handling meltdowns, communication strategies, and sensory issues, can increase grandparents' confidence in their ability to care for their grandchildren with autism (Autism Society, 2023). Family therapy sessions can help improve communication and understanding between grandparents, parents, and grandchildren, addressing any underlying tensions and fostering a supportive family environment (Goodman & Silverstein, 2002). Grandparents can seek counselling or join support groups. Counselling can help them process their emotions and develop coping strategies, while support groups, provide a community where they can share experiences and gain support from others in similar situations (Hastings, 2016).

Recommendations

I would recommend a comparative study to compare the experiences of grandparents of children with ASD to grandparents of children with other developmental disorders. This could highlight specific challenges and needs. This research could provide a deeper understanding of how these experiences differ. By identifying these differences, the study could help create targeted support systems and interventions tailored to the specific needs of grandparents, improving their ability to provide care. Additionally, such a study could raise societal awareness and improve advocacy strategies for families affected by ASD and other developmental disorders.

It is recommended to enhance support for those grandparents who are heavily involved in caring for their grandchildren with ASD. Providing opportunities for these grandparents to participate in group sessions with others who share similar experiences could be highly beneficial. These sessions would allow grandparents to openly discuss their feelings, share their unique challenges, and learn from each other's experiences. This kind of support network can alleviate feelings of isolation and provide mutual encouragement and solidarity among grandparents facing similar circumstances. Building such a community can foster a sense of belonging and empowerment, enhancing their resilience and ability to navigate the complexities of caregiving for grandchildren with ASD effectively.

Limitations of the Study

One of the limitations of the study was the challenge to recruit participants. Despite reaching out to an NGO for assistance, I did not receive any response. Consequently, I had to rely on my personal network of family and friends to find participants for the study.

Additionally, coordinating schedules to conduct interviews proved to be quite challenging. Finding a mutually convenient time slot was difficult, and as a result, I had to reschedule several interviews to accommodate both my availability and that of the participants. Additionally, one participant withdrew before the interview could take place, necessitating a quick search for a replacement within a short timeframe.

All of the grandparents interviewed were from Gozo, and only one participant was male. Additionally, all the children with ASD were boys. So, this study was not able to detect any potential gender differences.

I was particularly mindful of how to approach the participants, as I wanted to avoid asking questions that might make them feel uncomfortable, and I was uncertain about how to handle such situations. Additionally, I found that my profession as an LSE interfered with my study, as my thoughts often shifted focus to the child with ASD rather than the grandparents. This presented a significant challenge for me.

Chapter Six: Conclusion

Throughout the study, I explored the experiences of grandparents of children with ASD. I examined the dynamics between the grandparents and the parents of the child on the spectrum, as well as their relationship with the grandchild and their interactions with society. Using IPA, I analysed the results in the context of existing literature. I also questioned my own assumptions about the grandparents' knowledge and awareness of autism and gained a deeper understanding of how participants experience the same occurrence in various ways.

Furthermore, I examined the various roles I fulfil, including my profession as an LSE and my role as a researcher. This exploration involved reflecting on the responsibilities, challenges, and contributions associated with each role. As an LSE, I engage directly with students, providing support and guidance to enhance their learning experiences. Meanwhile, as a researcher, I delve into academic inquiry, conducting investigations and contributing to the body of knowledge in my field. Balancing these dual roles requires effective time management, flexibility, and a commitment to professional growth. Each role offers unique opportunities for personal and professional development, enriching my understanding of education and research practices while shaping my overall career path.

The research illuminated the experiences of grandparents as they navigated the initial reaction to their grandchildren's autism diagnoses. Initially, they often experienced shock, which gradually transformed into acceptance over time. Many grandparents found themselves comparing the child to themselves, which sometimes led to self-blame and concerns about genetic responsibility. This introspective process was compounded by the misinformation they received from non-professionals and the general public, further complicating their understanding and coping mechanisms. Additionally, the grandparents often felt judged by society, not only towards themselves but also towards their child and grandchild.

Before the diagnosis, there was a noticeable lack of knowledge and awareness about autism among the grandparents. It became clear that their interest in the condition only heightened following their grandchildren's diagnoses. This newfound interest was driven by a need to better understand autism to support their grandchildren effectively while also assisting their own children in managing the condition. This learning curve was steep but necessary, as it enabled the grandparents to play a more active and informed role in their grandchildren's life.

From the results, it is apparent that many grandparents refrain from taking their grandchildren with ASD out in public. They fear that something adverse might happen under their care, such as the child getting hurt. This fear is exacerbated by their anxiety over potential tantrums, as they often feel unequipped to manage such situations appropriately. Although some grandparents develop strategies, like preparing the grandchild in advance, they still prefer to avoid public outings when possible, to mitigate potential challenges and stress.

The study also highlights how these dynamics impact the overall family relationship, often fostering a stronger sense of unity among family members. Despite some disagreements between grandparents, these conflicts generally stem from a shared desire to do what is best for the grandchild. The diagnosis often prompts a collective family effort, with siblings, cousins, aunts, and uncles all rallying to provide support. This sense of unity and shared responsibility is pivotal in creating a supportive environment for both the child with ASD and the immediate family.

In conclusion, I am struck by the intricate emotional landscape that grandparents navigate following their grandchildren's autism diagnosis. The study illuminates the profound initial shock they experience, which gradually transforms into a journey of acceptance. This path to acceptance is often marked by a proactive commitment to educating themselves about autism, underscoring their dedication to better support their grandchildren.

The research also brings to light the societal judgements grandparents face, which often lead to hesitations about taking their grandchildren out in public. These external pressures can exacerbate their fears and anxieties, adding another layer of complexity to their experience. Despite these challenges, the diagnosis of autism often serves as a unifying force within the broader family unit. It fosters a collective effort to support the grandchild and each other, highlighting the strength and resilience of familial bonds.

This study has provided valuable insights into the multifaceted experiences of grandparents. It underscores the critical role of support and education in managing autism within the family, emphasising that, while the journey is fraught with challenges, it is also filled with opportunities for growth, unity, and deeper understanding. The findings remind us of the importance of compassion, both within families and from society at large, in creating an environment where every member feels supported and empowered.

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Appendix 1: Participants' Information Sheet and Consent Form

Dear,

Thank you for taking the time to read this information sheet.

I am Miriana Portelli, I am currently reading for a bachelor's degree in Psychotherapy, with the Institute of Family Therapy, Malta. I am currently working on my thesis which will focus on "*The unique experiences encountered by grandparents who have grandchildren with Autism Spectrum Disorder (ASD) and the ongoing journey of navigating this situation."*

Objective of the research

The objective of this research project is to contribute valuable insights to the existing literature by examining the experiences and reactions of grandparents who have a grandchild diagnosed with Autism Spectrum Disorder (ASD). While extensive research has been conducted on the impact of autism on parents, the specific topic of grand parenting a child with ASD remains understudied. Therefore, I am interested in exploring this area further.

Aims of the research

This study aims to investigate the reactions and coping strategies of grandparents who have a grandchild with Autism Spectrum Disorder.
By conducting this research, I hope to shed light on the experiences of grandparents and their unique perspectives regarding autism. This knowledge will not only expand our understanding of how grandparents cope with such situations but also offer valuable insights for families and professionals supporting individuals with ASD.

Interview information

I would like to invite you to participate in the research process through an interview. The interview is approximately 45 to 60 minutes long with grandparents of grandchildren on the Autism Spectrum. The interview will focus on the lived experience and when they are given the news of their grandchild's ASD diagnosis by professionals and how they cope and co-construct meaning in the period following the news.

The interviews will take place at a location chosen together and the language used will be Maltese or English, as preferred. The interviews need to be recorded for the purpose of transcription. All information given during the interviews will remain confidential. Your responses will not be linked to your names in any written or verbal report of this research project and your name will never be revealed to third parties. A fictitious name will be used instead. Information will only be handled by myself and my tutor, Fr Eric Cachia.

All the data obtained during the interviews will be destroyed on completion of the study. I will provide the participants with a copy of the findings after the finalization of the work, upon request. A copy of this thesis will also be available at the Institute for Family Therapy – Malta (IFT).

What if any aspect of the research makes you feel uncomfortable?

If I observe or you feel that the interview is causing you any difficulty or distress, please feel free to discuss or withdraw from the study at any moment and I will refer you to support services like private practice or the Institute for Family Therapy Malta services if necessary. You can withdraw from the study at any time without having to justify your choice up to 4 weeks after the interview has been held.

Before deciding whether to participate in the study and throughout the research, you will have the opportunity to express any issues or questions you may have. After the interview, you will be offered the opportunity to reflect on your research experience.

This research proposal has been evaluated and approved by the IFT Research Ethics committee, which their task is to make sure that the individuals participating are safe from any harm.

Participating in this research is entirely voluntary. If you want to participate in the study or have any additional questions or concerns regarding it, please let me know by email on miriana.portelli@gmail.com.

Thank you for taking the time to read all this information. If you feel confident about completing the form on the next page, I would really like it back at soon as possible. Please retain these four pages for your own information.

Researcher Miriana Portelli:

Bachelor’s degree in Psychotherapy; Institute for Family Therapy- Malta (IFT)

Research title: “*The unique experiences encountered by grandparents who have grandchildren with Autism Spectrum Disorder (ASD) and the ongoing journey of navigating this situation.”*

Consent form for Participants

Please
Initial

	By accepting to take part in this research project, I understand that the personal data collected from and about me during the duration of the project will be used for the purposes of the Bachelor Degree in Psychotherapy.
	I understand that data collection shall involve individual research interviews.
	I understand that Miriana Portelli will take all the possible measures to safeguard anonymity such as using pseudonyms and eliminating identifiable information.
	I agree that my data shall be kept in an encrypted data vault. Any files that are shared with you or with my supervisors will be zipped and encrypted and a password will be supplied to secure channels.
	Research records will be retained for a period of time after the completion of the research. However, any identifying information and linking files will be destroyed securely on successful completion of the Bachelor Degree. Your data can never be shared with third parties
	I understand that if I choose to not participate in the research project no information about me will not appear in Miriana Portelli’s thesis.
	I understand that I am free to withdraw my participation at any point without giving a reason by contacting Miriana Portelli. Data collected about me will only be used up to the point of my withdrawal.
	I understand that if participation in the study has a negative impact on my mental health, I need to inform IFT-Malta and/or Miriana Portelli with immediate effect for my well-being to be safeguarded.
	I have read and understood the terms of this consent form, have been given the opportunity to ask any questions, and agree to take part in this research project.

Participant’s Name: ____________________________________

Signed: ________________________ Date: ________________________

Appendix 2: Interview Questions

Interview Questions

Mistoqsijiet tal- Intervista.

1. How old are you?
2. How many children and grandchildren do you have?
3. Are you retired or still working?
4. What was/is your job?

1) Kemm għandek żmien?
2) Kemm għandek tfal u neputijiet?
3) Inti rtirat jew għadek taħdem?
4) X'kien/x'inhu x-xogħol tiegħek?

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1. Reflect back to the moment when you received the news about your grandchild being on the Autism Spectrum/ having Autism. What remains vivid or memorable for you from that particular day?

1.Irrifletti lura għall-mument meta rċevejt l-aħbar dwar in-neputi/ja tiegħek li qiegħed/qiegħda fuq l-Ispektrum tal-Awtiżmu. X'jibqa' ħaj jew memorabbli għalik minn dak il-jum partikolari?

2.Before hearing the news, what was your understanding of autism? What differences have you noticed in your perception since then? How did you address this newfound, lived awareness?

2.Qabel ma rċevejt l-aħbar, x'kien il-livell ta' għarfien tiegħek dwar tal-Ispettru tal-Awtiżmu? Liema differenzi innotajt fil-perċezzjoni tiegħek minn dak iż-żmien 'l hawn?

3.Before you were informed of the autism diagnosis, what indications did you notice, if any, in the child's development or behaviour that led you to suspect something might be amiss?

3. Qabel ma ġejt infurmat bid-dijanjosi tal-awtiżmu, liema indikazzjonijiet rajt jew innutajt, jekk kien hemm, fl-iżvilupp jew l-imġieba tat-tifel/tifla li wassluk biex tissuspetta li xi ħaġa tista' tkun ħażina?

4.How did the dynamic between you and your child who parents a child on the autism spectrum change?

4. Kif inbidlet id-dinamika bejnek u bejn it-tifel/tifla tiegħek li huma ġenituri ta’ tifel/tifla fuq l-ispettru tal-awtiżmu?

5.How is your relationship with the other grandchildren different? And then in relation to society and thinking about it how do you deal with it?

5. Kif inhi differenti r-relazzjoni tiegħek man-neputijiet l-oħra? U mbagħad fir-rigward tas-soċjetà u taħseb dwarha kif tittrattaha?

6. How would you describe your relationship as a couple? What sorts of conflicts or difficulties have you encountered in your relationship that you believe stem from the presence of autism?

6. Kif tiddeskrivi r-relazzjoni tiegħek bħala koppja? X’tipi ta’ kunflitti jew diffikultajiet iltqajt magħhom fir-relazzjoni tiegħek li temmen li joħorġu mill-preżenza tal-awtiżmu?