



GRANDPARENTS' SENSE OF RESILIENCE SPENDING TIME WITH AUTISM SPECTRUM DISORDER GRANDCHILDREN (RESILIENCY AND ASD)

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ABSTRACT

Autism Spectrum Disorder (ASD) includes various types of disorders encompasses varying verbal, mental and behavioural severities that affects the functioning of an individual throughout their life. Resilience is perceived as a structure consisting of several defence mechanisms. Resources of resilience stem from personal, biological and environmental mechanisms, or a combination of some or all of these. The objective of this study is to examine the perceptions of grandparents of children on the autism spectrum on the concept of these children's wellbeing experience. By opting for a qualitative method using the narrative approach, we conducted in-depth interviews with 30 grandparents. The interviewees were asked to address the notion of leisure time and to provide examples from their own experiences. Researchers analysed data using inductive content analysis to generate results. The resilience of grandparents is an important resource that must be recognised and harnessed. They have to bounce back to a state of normality following disruptive and often unexpected events or crises. The responses of the grandparents indicate that they need guidance on the subject regarding both the knowledge on the specific subject of autism and the tools that can help foster relationships with the children, parents of the children and the vicinity. There is place to provide tools for grandparents to build their resilience so they can function in the complicated family framework imposed on them. We found that there is a lack of training programs for grandparents and they would have appreciated to get formal education about how to deal or to get along with their ASD grandchildren.

KEY WORDS : Autism Spectrum Disorder, Resiliency, Grandparents, Grandchildren.

INTRODUCTION

While interest in the concept of resilience is growing within the field of gerontology, there is little agreement on how the concept should be used or defined (Wild, Wiles, & Allen, 2013). Nevertheless, one thing can be distinguished: the connection between the personal resilience of grandparents and their grandchildren on the autistic continuum is a special one. Since they do not choose to be in a given situation, they find an inherent strength in themselves in order to be part of the special world of their grandchildren and serve as partners. Indeed, resilience is perceived as a structure consisting of several defence mechanisms. Resources of resilience stem from personal, biological and environmental mechanisms, or a combination of some or all of these, but beyond any doubt, grandparents who have a grandchild with ASD possess an unconditional love for their grandchild.

Grandfathers And Grandmothers

Families are important for the overall growth and development of children. The health of a family is foundational to the everyday life in which a child and family can blossom (Smith & McQuad, 2021), especially in a system where grandchildren are seen as continuity and even as a symbolic sense of eternity (Findller, 2009). Grandparents are often close and loving persons who are sometimes more comfortable near their grandchildren than within the framework of parental authority. A grandparent's relationship with their grandchild is not just a relationship of giving, but also one shared insights and life experiences, intergenerational connection, presence and emotional commitment. In many cases, the care of grandparents acts as a substitute for parenting or motherhood. Novak-Pavlic et al. (2020) demonstrated that these grandparents play an active role in families by providing emotional, financial and instrumental support to their adult children and grandchild with a disability Weinstein and Neugarten (1964) mention roles that grandparents may play for their grandchildren: as a source of continuity and biological renewal (i.e. a link between the past and the future); as second parents, trying to achieve self-realisation and a sense of satisfaction, especially in areas they may have failed in the past; as guides and teachers in the transmission of the family heritage; as emotional support that manifests through their warmth and love (Crettenden, Lam, Denson, 2018); and simply as

grandparents, where their relationship with their grandchildren is loose and the meaning given to the grandparents' lives by their grandchildren is not very significant. Grandparents played an important role in strengthening the family system by providing respite care for their grandchildren (Prendeville & Kinsella, 2019)

Berkovitch and Manor (2015) emphasised that despite the changes that have taken place in the family institution in the contemporary era, grandmothers still have a central role in raising their grandchildren, and young adults have expectations that their mothers will help care for their children. Grandparents play a fundamental role in family life and can be a significant source of social support for parents, including those caring for children with disabilities (Baxter & Warren, 2015; Findler, 2000).

Grandparents are usually the first people parents turn to for help or advice on parenting and other issues, as well as financial support in difficult times (Winefield & Air, 2010). Additionally, they are the ones who express joy in watching their grandchildren achieve their goals, and they feel proud when their grandchildren garner achievements (Mansson, 2016).

Grandparents Having A Grandchild With Autism Spectrum Disorder (ASD)

Caring for a child with autism can be a unique and challenging experience. However, little is known about the relationship between these children and their grandparents (Zakirova - Engstrand, 2020). Grandparents can play critical roles in the lives of children with intellectual and developmental disabilities, and grandparents can become key support resources in these families (Yang et al., 2018). For families raising a child with autism, the chronic, intense nature of everyday life affects family health, partly due to increased parental stress and the potential centralisation of the child with autism in family functioning (Smith & McQuad, 2021). Intergenerational relationships, i.e., the interactions that occur between grandparents, parents and children, affect a family (Seligman & Darling, 2007). The quality of relationships that exist between parents and grandparents may be a source of support or stress that can impact the family system (Cox & Paley, 1997). Hastings (1997) suggested that grandparents of children with

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disabilities act as important sources of practical and emotional support. However, grandparent involvement in the families of children with disabilities can also be complex (Sullivan et al., 2012).

Sherman et al. (1995) documented a process of mourning and adaptation when a child with ASD is brought into the family. Grandparents described the experience of having a grandchild on the continuum as an 'emotional roller coaster' but felt proud of their family's ability to adapt to the challenging situation (Woodbridge et al., 2009).

In a study by Baxter and Warren (2015), grandparents described the impact that having a child with special needs had on their family quality of life and detailed how it delayed life goals: grandparents rejected travel and retirement plans, parents rejected career opportunities, and a dimension of jealousy in relationships with family members was introduced. Grandparents had a role to play in strengthening the family system. The ability of a family to adjust its equilibrium or homeostasis when a child in the family has ASD was supported by grandparents. This theme included the planning required to meet the needs of a child, the way a family is strengthened by prior experiences of special education needs and the variations in roles played by paternal and maternal grandparents. The role of the grandfather was also significant. The subthemes that emerged from the analysis included the following: the 'active role of grandparents' and the 'calming role of grandfathers' (Prendeville & Kinsella, 2019).

Others (Margetts et al., 2006) noted that grandparents who have a disabled grandchild see a strong need to keep their family nuclei together. They also feel a sense of happiness and self-fulfilment when they manage to maintain their quality of life. Grandparents experience frustration at not being able to identify the specific cause of the disorder (Margetts et al., 2006), as well as shock and grief for the child, the parents and themselves (Katz & Kessel, 2002). Grandparents may be concerned not only about how the family will adapt to the present situation, but also about the future and whether diagnosis and treatment decisions will serve the needs of the child (Katz & Kessel, 2002).

Grandparents who want to help children and their parents feel unsure how to do so because they lack comprehensive or accurate knowledge on the specific disability of their grandchildren and are afraid to interfere in family matters (Mirfin-Veitch et al., 1996; Trute, 2003). Therefore, ineffective communication can cause grandparents to withdraw from helping and getting involved (Katz & Kessel, 2002; Lee & Gardner, 2010).

It was further noticed that grandparents who had different views on disabilities or on how to deal with behavioural problems related to disabilities did not cooperate with parents, because they were dissatisfied with parents' attitudes (Harris et al., 1985; Katz & Kessel, 2002). On the other hand, acceptance and adjustment by grandparents may contribute to improved parental coping (Mirfin-Veitch et al., 1996), as well as psychological wellbeing and a sense of optimism (Halstead et al., 2018). Grandparents of children with disabilities can help families interact well in the family circle (Mirfin-Veitch et al., 1996).

Their support and involvement can reduce parents' feelings of isolation and serve as a model for a positive approach to the growth potential of children with disabilities (Lee & Gardner, 2010). Some grandparents pushed for the diagnosis of their grandchild and, as a result, found themselves doubly concerned: first, for their adult children and second, for their grandchild (D'Astous et al., 2013; Hillman et al., 2017; Margetts et al., 2006; Wright et al., 2012; Hillman & Anderson, 2019).

ASD is a lifelong neurodevelopment condition characterised by core features in two domains: impairments in social communication

and the presence of restricted, repetitive behaviours and interests across multiple contexts (Huang et al., 2020).

Autism was first defined in 1943 by psychiatrist Leo Kanner as an innate inability to relate to people and situations. This is a large-scale disability whose most prominent and central component is defined by a basic disability in the socioemotional field. It is also characterised by heterogeneity, which implies that individuals diagnosed with ASD can demonstrate a wide variation in behavioural representation and differences in cognitive and language developmental profiles, in addition to the presence or absence of coexisting conditions.

The most up-to-date definition can be found in the psychiatric diagnosis book DSM-V (2013), which chose the term ASD as a comprehensive term for spectrum disorders. By definition, ASD is a major sub-disorder in the category of large-scale developmental disorders (CDC, 2020). The disorder includes various types of disorders of varying verbal, mental and behavioural severities and affects the functioning of an individual throughout their life. To define a person on the autism spectrum, it is expected that there will be widespread deficiencies in communication and social relations that are not characterised by other developmental delays. Another criterion that falls under the realm of stereotypical and repetitive behaviours is the incidence of hypersensitivity and sensory under-reactivity, which are significant factors in stress and impaired functioning. Consequently, children with ASD experience significant difficulties in both the field of sensory processing and regulation and in the motor field. These extensive difficulties create a burden and stress on the child's daily functioning. They prevent the evolution of diverse developmental abilities and create a lack of success in broad areas of functioning. Social disabilities in autism change slightly over time but continue to be a significant disability, even in high-functioning autistic adults (True & Debt, 2012). Children with ASD are rigid in their behaviour and routine, and regularity is very important to them. Any change in routine causes unexpected transitions and triggers rage attacks and aggression (Sivberg, 2002; Beebe & Risi, 2003). Thus, children with ASD tend to have extensive therapeutic needs that require high levels of energy and attention from caregivers and family members (Hillman, 2007).

Parents of children with ASD report more stress, depression, anxiety, social isolation, financial burden, and family conflicts than parents of children who develop in a normative way (Katz & Kessel, 2002; Hillman, 2007). It has also been suggested that families' cultural characteristics can influence their access to various educational and health care services within a certain cultural context (Yang et al., 2018).

Given the complexity of the disorders listed, autism treatment is long-term and includes various areas, such as educational interventions, group situation engagement, community programmes, and parent mentoring. Significant efficacy was found in psychoeducational interventions, which enhanced social, communicative and cognitive abilities. These interventions improve long-term outcomes, especially when they are given continuously and intensively in conjunction with support and guidance provided to parents and other relatives.

Resilience

Although there is no conceptual consensus regarding a definition of resilience (Halstead et al., 2018), resilience has been defined by some authors as adapting positively in the face of adversity (Al-Jadiri et al., 2021). Resilience refers to the adaptive capacity, coping mechanisms refer to cognitive and behavioral efforts or strategies to manage taxing and stressful events (Dachez & Ndobu, 2018).

Two commonly accepted definitions of resilience are 'the ability to cope successfully with difficult situations including traumatic situations' (Hazel, 2018). Resilience is dynamic and modifiable, and

characterized by two criteria including, risks (adverse biological or environmental circumstances) and positive adaptations (competence and successful adjustment to life events) (Kaboski et al., 2017), and to withstand and overcome adverse experiences/situations to rebound and become more adept and self-confident when faced with future challenges (Milstein & Henry, 2000; Waxman, Pardon, & Grey, 2004).

Resilience is typically defined as the capacity to adapt successfully despite experiencing adversity (Masten, 2014). In the sciences, this definition emphasises the speed with which a material or system returns to a state of balance. Several coping mechanisms have been already identified including problem-focused coping (where an individual aims to solve the problem that is causing stress) and emotion-focused coping (where an individual attempts to manage the negative emotions caused by the stressor and the search for new meaning to a stressful situation) (Dachez & Ndobu, 2018).

According to the American Psychological Association (APA, 2013), resilience is not a characteristic with which one is born, but rather a combination of thoughts, behaviours and activities that can be learned by an individual. The APA (2009) notes several factors that contribute to mental resilience. In addition, APA (2009) proposes ten strategies for building mental resilience: developing positive relationships, taking a different view of unsolved problems, accepting change as part of life, setting goals and pursuing them, acting with determination, seeking opportunities for self-discovery, believing in one's abilities, viewing things in perspective, maintaining hope, practicing self-preservation and seeking additional ways to build personal resilience. Mental resilience is defined as one's ability to cope with difficulty, such as a period of continuous stress, and emerge strengthened and with new insights, as well as the ability to return to the previous condition (Killian, 2004), recover and adjust to change. Resilience can also refer to one's capacity to persistently work towards a previously plotted idea, even after crisis. Adults have an important role in the process of building children's resilience. A person with mental resilience is said to be able to adjust to the circumstances of life, even if these include hardship, and to succeed in the long term (Berggren, 2006).

Research on resilience generally treats coping skills and social support as protective factors or moderating processes that exert greater influence at higher levels of adversity (Masten, 2014). However, stress process models applied to grandparent caregivers variously treat coping as a mediating variable (Hayslip et al., 2013), as a moderator or buffer (Choi et al., 2016), or as a promotive factor that has direct effects on wellbeing regardless of the degree of adversity (Hayes & Watson, 2013). Thus, primitive factors are compensatory in that they counteract risk exposure (Masten, 2014). Kaplan (1996) noted two fundamental factors that affect the process of building resilience: the personal characteristics of the individual, which are determined by both the environment and the individual's genetic makeup, and the combination of all the protective elements in the individual's life that provide support and enable them to cope with the stresses of life. Taplin (2011) suggested and demonstrated four main components that constitute mental resilience, the most prominent of which is based on organic components, such as beliefs, values and skills, which are derived from the individual's personality and manifested in the individual's thoughts and behaviours. The next most important component, according to Taplin, is the factor that combines family, school and the surrounding community, followed by society in general.

The process of resilience building is an individual matter that combines elements derived from biology, the environment and learning (Taplin, 2011), resilient child uses mental activity and effective methods to cope with stress. Resilience includes developing coping processes that create confidence and reduce anxiety, constructing social patterns that include support and

intervention, and using prevention tools (Rose & Fiitout, 2003). According to Kobasa (1979), three personality components affect hardiness and create resilience: commitment, challenge and control. The concept encompasses not only the ability to regain health and functioning but also the notion of continuous personal growth. For example, Nolan et al. (2014) demonstrated that resilience can affect learning and development on both the individual and the group levels. Notwithstanding the numerous definitions, the concept cannot be easily translated into efficient educational strategies (Srikandarajah et al., 2010), because it represents a complex set of constructs (Masten & Obradovic, 2006) and is discernible in multidimensional contexts (Gu & Day, 2013) concerning skills, processes and outcomes (Miller & Daniel, 2007). Parents with resilient potential are capable of overcoming the difficulties stemming from raising their children in trying situations and, therefore, achieve positive functioning in the family core (Hayes & Watson, 2013).

Schaefer & Moose (1992) listed four resources that interact with each other and can cause change and positive outcomes as a result of a crisis.

The first resource is the characteristics of the crisis, such as its severity, its suddenness of the crisis, the person's ability to predict the outcome of the event, the person's sense of control over the event and the number of people who experienced it. The second resource is personal variables, which includes demographic variables, such as age, gender, socioeconomic status; human temperament; self-confidence; philosophical or religious approach; and attempts to deal with previous crises. These resources can help a person evaluate how to use existing coping resources to deal with a crisis. The third resource is surrounding's variables, which includes various support systems that are related to and affect the person. Some examples of these are family members, co-workers, friends and the culture from which the person comes. The surroundings resource may help a person redefine the event and focus on positive outcomes. The fourth and final resource is the assessment of the crisis and coping responses; the cognitive assessment refers to the person's perception and interpretation of the state of stress and the action that needs to be taken. This cognitive coping process may help a person find the positive aspects of the crisis and thus reduce the trauma in trying to find meaning, which will allow the assimilation of the loss into the existing world of concepts.

Methodology

The study aims to illuminate the leisure experience of children with ASD and their grandparents. The research will focus on the significant experience of leisure, because leisure is a focused time in which there is an interaction between the grandparents and the child. Through this point in time or shared experience between the grandparents and the grandchild on the autistic continuum, it is possible to illuminate intergenerational relationships.

Research Questions

What characterises the leisure experience of grandparents while spending time with grandchildren? How does the leisure experience contribute to illuminating the quality of their resilience?

Research Method

A qualitative narrative-type research method was employed. The research method relies on a focused approach using content analysis, deals with detecting recurring patterns within the data collected (Shaked, 2011), and seeks to examine the reality under investigation and understand the phenomenon responsible for its complexity (Stake, 1995). The study examined the personal perceptions and experiences of grandparents of children on the autistic continuum.

Through an open-narrative interview, grandparents were asked to describe a shared time experience with their grandchild on the

continuum, such as a story that they think has a meaningful experience that illuminates their existing relationship.

The personal interpretive perspective allows for the retrospective observation of the reality of life and the values that emerge from the story (Strauss, & Corbin, 1990).

In addition, a resultant perspective examined the following components of the experience: emotional mechanisms; self-discovery mechanism; and the practical, personal, behavioural and value-based impacts of the experience over time.

The Population

The study population consisted of 30 individuals who had grandchildren with ASD, with 10 male participants and 20 female participants from Israel. The participants were recruited through the Facebook social media platform, a closed group intended solely for grandparents of children with ASD. The researcher requested for the group manager's permission to join the group for this research. After being accepted, the researcher uploaded a post explaining that the author sought to interview the grandparents of children with ASD for research purposes. All participants responded voluntarily and received an explanation regarding the ethical constraints that would be upheld during the course of the study.

Data Processing

For the analysis of the interviews, all the materials were read in sequence to obtain a comprehensive orientation (Charmaz, 2014) and to ensure that the context of the data was not lost (Shaked, 2010).

The analysis of the content of the texts was done in three stages: revealing reading, decomposition and concluding (Weber, 1985). In the first stage, notes were written in the margins of the text, and these dealt with everything relevant that 'stood out'. In the second stage, the text is 'disassembled' into relevant words, sentences and sayings. In the third stage, the inference stage: the set of meanings was rebuilt by creating links between the text meaning units. Repetitions of the same statement in the texts of several writers made the private statement a common statement, revealing the existence of fixed patterns and characteristics common to quite a few people.

The findings provided relevant quotations from interviewees.

RESULTS

A number of themes were extracted from the interviews. These are listed and detailed in the following section

Crisis Events

A crisis event forces grandparents to face worldviews about themselves and their unstable ground while they identify a crisis when meeting their grandchild. When meeting their grandchild, grandparents need to equip themselves with the appropriate tools to face the new situation and quickly exercise informed thought to prevent the situation from deteriorating.

Crisis While Getting Information About Autism

Crises presented: crisis while obtaining information about autism, inability to share information about the grandchild, crises while staying with the grandchild outside the home.

The discovery of my grandson's autism pretty much broke me. I took it very hard. I keep walking around with the questions of what lies ahead and what will happen in a few years when he will have to be independent? He does not know how to deal with people. I'm losing my mind thinking of how he will behave in front of the world. (M)

The discovery of autism in my eldest grandson was accompanied by a lot of crying by my daughter and me, the crisis experienced by my daughter was very difficult. She cried not about dealing with the daily

difficulties but about the difficulty of standing up again in front of all the authorities providing assistance: social security, the school principal, and the repulsive attitude of the other parents. (J)

I fell apart... I screamed... I did not want to get out of bed... I don't want to make this public for all the world to know, because then, you know... [there's no telling] how our neighbours and friends might react. (T)

Those grandparents describe their experience after the first recognition as a deep emotional break. None of them described a mediator in the process of notifying the grandson's ASD diagnosis.

Inability To Share Information About The Grandchild

The difficulty of dealing with the diagnosis and the word Autism. The need to keep it as a secret from the surrounding society.

Once, I was unable to tell anyone; I was unable to say the word autistic. I was looking for bypass words... slowly, I realised I could not run away. (I) I felt like I was walking around with a huge secret. It added a weight to me that I could barely bear; I only realised the price of concealment in retrospect. (G)

I find it difficult to come out and say, 'This is my grandchild'; that is my weakness, so I'm constantly covering it up. I'm still in the stage of feeling ashamed. I never expected such a grandchild and I still can't come to terms with the fact that this is what I've got. It means constantly coping. When I consider whether I should take him with me, I have to consider every aspect: where I'm going, whether he'll have bursts of rage, the length of the trip or whether he'll be able to cope with the people around. I can't just take him with me anywhere. I find it difficult because I'm left with a secret. I have to cover it up or justify it. There's something easy about just saying 'okay, he has autism' without trying to explain or conceal it. She [the character in the story] is courageous and she also believes that it would be good for the child to find a friend. (D)

Denial the definition of the grandchild's status ostensibly gives the impression that the situation does not really exist.

Crises While Staying With The Grandchild In Public Areas

Kind of afraid of the people out there and showing up with him in public.

We sat in the restaurant with our grandson. We requested that the items not touch each other. The dish served to him was not arranged as we requested, which resulted in our grandson throwing a tantrum. The restaurant owner approached and said, 'Take the child away from here and do not come to the restaurant'. I do not want to tell how we felt. (M) I was sitting with my grandson in the theatre, and the show had not yet begun. My grandson was drumming his hands on his knees... The one sitting next to him reacted angrily, 'Enough!' I told him, 'I am his grandmother; you could ask nicely'. The man responded and said, 'Why did you come with him?' Sometimes, my grandson makes vague imaginary movements (as if playing with swords), and it is quite frightening to the society that does not know how to interpret his strange movements. (L)

The feelings following crises lead to feelings of frustration alongside feelings of empowerment. Tedeschi and Calhoun (1996) indicate that the experience of crisis and feelings of urgency may cause reactions such as depression, helplessness and distress, but can also become a challenge that can lead to positive change, different priorities and a reassessment of life (Schaefer & Moos, 1992).

The Feeling Of Frustration While Staying With The Grandchild

Frustration is an emotion created due to the non-fulfilment of a desire, need or urge. Frustration can arise when the individual is faced with a challenge that is, or perceived to be, at a level of difficulty that is too high in relation to their ability (Messiah, Spector, & Ronen, 2004). Frustrating situations can turn into worry, which can intensify into feelings of anxiety, especially when needs are not met

or when there is a realistic deprived view that this viewing will materialise.

Frustration Resulting From Expectations

I help my daughter as much as possible, supporting her financially, taking care of the girl's needs, and helping find solutions to any problems that arise, but the hardest part for me is that she thinks the situation can improve and is unable to see the real situation. (O)

I try to convince the parents to take the girl (my grandchild) to a "Hyperbaric Oxygen Therapy". I read that treatment helps alleviate the symptoms of autism. It may not eliminate it, but at least, it may improve functioning. I want the partners will be part of the process. It costs a lot of money, but I am willing to fund it. (H)

The above quote represents observation of a grandmother who wants to help the parents and be involved. She is hopeful regarding the process Hyperbaric Oxygen Therapy and the possibility that the parents will cooperate but it had never occurred.

Frustration At The Grandchild's Lack Of Cooperation

He is not ready to stay asleep, and when he stays over, he asks to call home to talk to his mother every 10 minutes. (k)

When he stays, I expect to get a hug, but they (the grandchildren) are unable to hug. My grandson is afraid to hug; he shivers and does not want to be touched. He is willing to sit down and talk to me, but not hug! (J)

It cannot be called a story. He lives in his bubble, not communicating and not available for games. It dictates everyone's agenda: no eating in restaurants, no going to crowded places, and mostly going on nature trips. (t)

I tried to challenge him to speak but never did. Now, for the first time, he says 'I saw' and does not stop saying it; he repeats it all the time. I tried building a tower of cubes with him and it was not that simple. (E)

The grandparents expect simple and "normal" communication with the grandchild. Instead, they find themselves confronted with repetitiveness, compulsiveness and a lack of affection on the part of the grandchild.

Frustration From Society-related Situations

Grandparents hesitate in choosing a term with which they felt comfortable to describe their grandchild's condition, as they did not wish to label their grandchild. They mentioned personal issues related to shame, concern and discomfort; hence, they elected to use expressions such as 'the child has a communication disorder', 'communication difficulties' or 'a deficiency'. Occasionally, no definition was used at all. The attempt to avoid a definition is an attempt to escape and pretend that the problem does not exist; however, reliance on buzzwords reflects a situation in which the parents use softened or refined language to describe a phenomenon that is difficult and painful for them to avoid calling it by its proper name.

I'm angry at the in-laws who said they could not contain my grandson's behaviour. I cannot forgive them. He does not go to them and all the burden is on us. (C) (a statement said angrily).

Anger At The System

The expectation is that state institutions will assist in the formal proceedings. While in practice they pile up difficulties.

I have anger towards the education system: when the child-assistant does not show up, they always call his mother asking her to pick her up. The mother, of course, ask me to do it and be responsible, because she thinks I'm not busy. (O)

The health care system is the one to blame because the treatment is

always be delayed. Until you get an appointment, then it takes time to fill out the forms. Not everything can be bought with money. We feel that every passing day hurts our grandson. (M)

The grandparents want to be partners but to be asked what part they want to take and not as a duty. They see the difficulty in dealing with the authorities and they are frustrated by it because they think it hurts the child.

Quality Time That Becomes A Punishment

When he spends time at my place, I constantly have to keep an eye on him because he's running away. Although we had made a gate and a wall, he found ways to escape. He sometimes acts like a nightmare, then everything can be right, and then suddenly commits a burst of violence. (I)

The place of expecting to spend quality time with the grandson becomes a challenge due to objective difficulties

Acceptance of the grandchild despite the physical or mental difficulties involved in meeting

Meeting with the grandchild sometimes requires physical exertion into activities that involve caring for them.

It's tiring to stay with him all day: to feed, to play, and to chase after him, but on the other hand I love him so much. (I)

I like meeting him, but every meeting breaks my heart. (Looking very sad) I want to hug and kiss him, but it's impossible; it involves a physical effort to hunt down this moment. Lately, he's kind of allowed me to hug and kiss his back. I try to play with him. ©

'We joined a community that I would not choose to be a member of, but since our creator or fate has other rules of the game, I have no choice but to learn the rules of the community of Autism' (C).

This statement is an expression of resilience expressed through humour that relies on optimism as a directed tool (Sigelman, 2000). The psychological component allows people to maintain their mental health and wellbeing when they are in a state of coping with distress, while the behavioural component allows them to remain effective, focus on tasks and perform them (Gibbs & Miller, 2013).

The news made me slack. I took it hard, but on the other hand, it built us a brave relationship. (M)

We try to be strong so we can give our daughter the strength so she can promote him. I have a sense of consolation, knowing that it could be worse and harder... and I thank God that I have the financial means and mental resilience to face challenges and be there for the children. (G)

Formal and informal sources of social support are known to be of great importance in reducing stress and increasing mental wellbeing in times of crisis and distress (Sarason, Pierce, & Sarason, 1990), particularly when coping with raising a child with a disability (Smith, Oliver, & Innocenti, 2001). Grandmothers are one of the main sources of support for the family and often experience stress and distress themselves.

Empowerment

Empowerment, some grandparents face coping with significant and dramatic changes, mobilising their inner strengths and tackling the processes they are faced with as opportunities for personal growth. This is true in the case of those who are in this situation and can accept the mental difficulty and physical difficulty involved in what should be quality time with their grandchild. This serves as a process of personal growth through which their ability to observe is sharpened. The ability to look inward involved in this process has in it the construction of resilience (Kobasa, 1979), as well as the foundation of being able to look at the 'other' differently (Finkler,

2009).

He comes to me a lot, and here, he gets all the love he can. During the meeting, he does crossword puzzles and logic games. We signed up for a pool because he likes water. Every weekend, he comes to me, and my life is dedicated to him. (M)

My grandson allowed us to explore the limits of our ability, the limits of love, and the limits of patience. With all the pain, he made us more understanding people. (L)

Giving up is the easiest thing, but we do not have that luxury; breaking up is an escape, but we are sober and know that it is impossible to escape. You can call this process exactly by its name, empowerment! In this process, our power helps and empowers the family. The fact that we are great grandmothers stems from our ability not to break down. (L)

I push away what makes me depressed, and what encourages I put in. I define myself as Grandma who struggles. (A)

We try to be strong so that we can give our daughter the strength to promote him. (I)

The encounter with my grandson contributed to the redesigning of my point of view.

Due to my grandson condition, I look at the 'other' differently. My level of compassion has risen, and the level of inclusion or acceptance of the disabled no longer distances me. (M)

Although all the difficulties, I discovered the inner strength inherent in me. I am indeed heartbroken, but stand as a 'solid rock' in front of the troubles of existence. (J)

I understand that despite my comprehensive knowledge, education and professional position of strength, in this situation, I am a novice. In addition, the situation taught me to listen to the real needs of life and to see moments of joy. (H)

The grandparents try to mobilize all the forces they have. Despite the difficulties they understand that they must be in this place.

Another approach was also introduced.

The encounter taught me that even if my grandchildren with ASD need me, I must put my 'I' first and foremost! The other thing is that, following the meeting with my granddaughter, I finally let go and learned to understand that my son was also on the continuum; we just never dared to say it out loud and certainly never dared to deal with it. The meeting with this painful situation of dealing with autism helped me release barriers... I started taking spiritual courses that will, first of all, strengthen my 'I', in hopes that I can also be a better mother and a more efficient grandmother. (H)

The grandmother is looking for ways to deal with the situation personally. She tries through the intellect to deal with emotion.

Practical Conduct Following The Situation

In this theme, the interviewees noted that the source of their insights into ways of conduct rests on intuition and the need for outside help. The ability to observe their inner world through the leisure experience has created a window of opportunity to explore the world around them in different ways. The personal coping of each of the grandparents taught them in a subjective and personal way to deal with the phenomenon.

The ability to mobilise intuition

No one guides me except for my inner intuition. (J)

We act according to intuition. In the beginning, it was hard for me to see the difficulty I was in conversations with a psychologist, why did it

happen to me? The psychologist advised me not to respond to my daughter complains, just to listen when she calls for help. There were creaks and anger in her attitude. Today, I do not have the privilege to simply rebel or run away. I agree with myself that I am doing the right thing. (A)

What guided me in how to deal with it? Inner insights, common sense! (H)

The encounter with my grandchildren forced me to learn 'how to build change' and how to bring myself to clear blocked places in the mind to alter my coping. (H)

The ability to ask for help

Grandparents have no support. Although I was happy to receive advice, tools and information, I was always brought back to my box of insights. I took it extremely emotionally, and I was constantly anxious. I kept thinking about what would happen in a few more years. To this day, I have not been freed from these feelings. In general, everything related to my child is precious to me, which is why I collect every bit of information that can help me decipher the riddle and give me tools. (M)

We try to learn everything possible that can promote us as moneylenders, go to courses to obtain tools, listen to others and look for things that will help us and possibly solve our problems, despite the recognition that our situation will probably not change. ©

We go to a psychologist for help and for recommendations how to act while meeting our grandchild. (I)

My daughter, who is a teacher, learns the material and then explains to me what I need to do. She also signed me up for a group where grandparents of those on the spectrum meet. There, I heard a lot of things, which I then tried to do with my granddaughters. (G)

Lack of professional help and explanations of what to do is a recurring theme in grandparents' interviews.

DISCUSSION

This study shed light on the components of resilience as perceived by grandmothers and grandfathers who have to deal with repeated statements about situations where? Love creates resilience, which may result in interesting situations. Resilience in this case can prevent psychopathological crises (Seligman & Csikszentmihalyi, 2014) and provides a measure of optimism (Seligman, 2002). The interdisciplinary stay experience of grandparents seeking to create quality time and an empowering experience often depends on two factors: the grandchild's level of functioning and the grandchild's emotional state at the given moment of the meeting, a moment that can change due to the grandchild's sensitivity to society conditions. The feelings of the speakers in describing the experience of time together with their grandchildren ranged from a sense of acceptance of the situation to frustration, as one of the grandmothers said: 'My grandson came without a replacement note'. The grandparents emphasised the love dimension that covers every situation. In order to increase the grandparent's resilience, we should understand their mourning process and provide them social support.

Despite being in a 'crisis world', some felt that they experienced a process of empowerment that stems from the dimension of mental-personal resilience. Resilience requires the individual to rely on all acquired sources, as well as on those imprinted within, in order to cope with the risk of an impending crisis. Resilience allows individuals to emerge from crises strengthened and with new insights. In the process of resilience, they recognise the ability to function in a crisis and understand that their predicament is not a transient crisis but an ongoing situation. Even if the process is difficult, in the end, grandparents feel that they are successful. This is mainly reflected in the long-term view of the situation. Indeed, most

interviewees noted this state of recovery and sustained growth (Reich, Zautra, & Hall, 2010). Standing in the face of difficulties has shown them that mental resilience is not an innate trait, but a mixture of thoughts, behaviours and actions, and its essence depends on supportive and caring relationships within and outside the family during the crisis or coping process.

trainers' professional background, competences, and experience in evaluations and support of child with autism are important prerequisites for successful implementation and delivery of psychoeducational programs for families of children with ASD specially for grandmothers (Dolbin-MacNab et al. 2019)

Given grandparents' wish for a follow-up course, professionals at the outpatient habitation services may want to consider planning and designing a follow-up course for grandparents as part of a more comprehensive intervention program for grandparents with children with ASD to meet grandparents' needs over time, i.e., at grandchildren's school entry with recognizable changes in needs among children with ASD, their parents and extended family members (Zakirova-Engstrand et. Al., 2021).

In addition, the ability of grandparents to point out the change in perspective at different points in time indicates personal growth. In this process, they give empowering meaning in the face of crisis or existential distress (Calhoun & Tedeschi, 1996). On the contrary, a sense of frustration and distress manifested in multiple cases at the root of a crisis. The crisis accompanies the grandparents from the moment the grandchild is born and throughout the various stages in the process of raising them, which made them understand that a grandchild on the spectrum necessitates a new set of tools. Additionally, some of the interviewees presented a feeling of frustration that accompanies leisure. Within this frustration, the respondents expressed a sense of personal ability, even if they did not do so intentionally. Specifically, they demonstrated the ability to organise and perform the behaviours necessary to achieve the desired results in their eyes (Bandura, 1997). Regarding the question of where grandparents gain insights regarding how to work with their grandchildren, the answers indicate that there is no person responsible for assisting them in learning the subject in an orderly manner or a body that provides tools for dealing with the subject. Professionals rarely made contact with grandparents, and this too comes mainly through the initiative of the middle generation (Finkler, 2009). The following topics were also addressed: how to get out of public places; how to get out of the circle of loneliness they got into because of their grandchildren; and how to help the nuclear family in various ways, ranging from emotional support to financial aid (2018). Grandparents have reported that they need a variety of guidelines; they need help with educational matters, such as how to communicate verbally with their grandchild to create a more effective connection. Grandparents need guidance on behaviours, especially those that are unpredictable (outbursts of anger or continuous crying). On this side, they are worried because they did not know how to make their grandchild feel "better" or less anxious, or how to treat them in public (Sullivan et al., 2012). Grandparents of children with ASD provide supports, not only to the children themselves, but also to their son or daughter whose child has autism. To reduce the burden families can experience, they would benefit from a family systems approach to empower grandparents to respond proactively to the needs of the family. It is incumbent upon professionals to devise supports to meet this need and to give recognition to grandparents of the valuable role they play (Prendeville, & Kinse, 2019; Lindsey & Barry, 2018; Lu et al., 2018; Pozo et al., 2014). Raising awareness in society of the place of grandparents in the family process of raising children with ASD, will enable to manage of a holistic plan for the entire family circle.

CONCLUSIONS AND RECOMMENDATIONS

There is a call to recommend and increase the appropriate funding

for ASD-related services on local, state, and federal levels (Ghanouni, & Quirke, 2022). The resilience of grandparents is an important resource in the overall fight against ASD that should be recognised and harnessed. Given the role of grandparents, the online programmes for improving communication (Minjarez et al., 2011) and the action plans for parents (Southern, 2018), there is place to provide tools for grandparents to build their resilience so they can function in the complicated family framework imposed on them. We found that there is a lack of training programs for grandparents and they would have appreciated to get formal education about how to deal or to get along with their ASD grandchildren.

Limitations Of The Study

The self-report of grandparents limits the perspective on the subject, which can be expanded through observational research of professionals and further enlightenment on the part of family members. It is important to note that bias is present because the interviews only reflect the experiences of those who agreed to be interviewed. The experience of those who refused to be interviewed is missing.

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