

Support Program to Reduce Anxiety in Grandparents of Children with Autism Spectrum Disorder

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Received: January 03, 2021

Abstract

Introduction: The grandparents of children with autism spectrum disorders show a double concern; because his grandson “will not be like the others” and because of the impact of diagnosis in their children, the children’s parents. This situation generates anxiety and changes in daily life.

Objective: Anxiety is evaluated before and after attendance at a family school, and the quality of life in grandparents.

Method: The State-Trait Anxiety Questionnaire is administered at the beginning and end of the period - families, and the Family Quality of Life Scale at the end. The school consists of five sessions of two hours each. Anxiety results are analyzed before and after the intervention as well as the quality of life.

Results: There is a decrease in state anxiety after school. The quality of life of participating grandparents is good.

Conclusions: family schools are an effective tool to reduce anxiety. Offer grandparents a place to share experiences and receive real information about disorders of the Autistic spectrum.

Keywords: *Autism Spectrum Disorder; School of Families; Anxiety; Quality of Life; Family Impact*

Introduction

The struggle for survival that forces parents to dedicate themselves to work, a fact that impairs the fulfillment of the affective and cultural functions of the family and leaves the issue of children’s education in the hands of other relatives (siblings, grandparents), nurseries or, in the worst case, the influence of the street [1]. The role of grandparents in society is so important that, sometimes, having their help is a decisive factor when families consider having more children, since having the support of an informal caregiver is prolonging the quantity and quality of life of many dependent people [2].

Currently, Spain is among the four countries with the highest life expectancy in the world, with an average of 82.9 years, surpassed only by Japan, Switzerland and Singapore, and could be the country with the highest life expectancy for the year 2040 if current health trends continue, reaching 85.8 years [3]. This would place Spain as the oldest country in the world.

In view of these data, grandparents should play an important role in society, and actions such as taking care of their grandchildren should even be considered within “active aging” programs [4], a task that They have been doing it for a long time and it has experienced

an increase in recent years. Along these lines, Miralles [5] reflects on “productive aging”, emphasizing the productive potential of the elderly as an influencing factor in the quality of life and an essential resource for the development of society, among other issues, playing the role of caregiver for their grandchildren. Similarly, Badenes and López [6] analyze the role that grandparents should play in the educational process and the variables that define caregiver grandparents, as well as the principles that should govern public policies to support this group to improve their quality of life. We are before grandparents convinced of belonging to an isolated generation: they took care of their children and now they take care of their grandchildren, and they are part of a generation of elderly people whose family dedication contributes to the balance and economic support of society. According to Megías and Ballesteros [7], they are grandparents and grandmothers “for everything” who, in general, spend a lot of time with their grandchildren, have a greater presence in their daily care and take on greater responsibilities in certain areas of their education. The grandparent-grandchild relationship is maintained with the traditional roles (unconditional love and spoiling), and also expands its functions with that of grandparent caregiver and substitute for parents, which has begun to gain positions [8]. According to Martínez [9], if the grandchildren have a disability, the grandparents act as a protection system and offer their care to satisfy the physical, psychosocial, emotional and economic needs of the dependent person, whether it be a specific or permanent help. Pereyra [10] already pointed out that when there is a case of disability in the family, the grandparents participate in the family tension, providing serenity and tranquility, taking care of the child, and helping out in the treatment and rehabilitation, establishing those deep ties that create a strong affective current in solidarity and intergenerational affection.

The functions performed by grandparents of grandchildren with disabilities remain unconditional love, empathy, emotional support, giving advice, caring for their grandchildren and sharing activities with them, but they lament the lack of resources and information directed at grandparents with grandchildren with disabilities [11]. Faced with this situation, Merrick, *et al.* [12] give a voice to grandparents and put on the table the need to review working life policies due to their involvement in the families of children with disabilities.

On the other hand, since 2013, autism¹, considered as an autism spectrum disorder, is classified within the group of neurodevelopmental disorders [13]. Autism is characterized by alterations in the development of social communication, and by a restricted repertoire of interests and behaviors. The clinical expression can vary greatly from one person to another, and also in the same person in the course of their development. The manifestation of autism has an impact on the family that, in many cases, will cause serious and profound changes in the mood of its members, and each of them will be affected to different degrees. Hence, psychological support is necessary. Thus, Heller, *et al.* [14] demonstrated the importance of emotional support and the acquisition of practical tools to care for the child, not only from their mothers, but also from her grandparents. This support is associated with the frequency of contact and, to a lesser extent, with residential proximity. For their part, Margetts, *et al.* [15] state that the grandparents of children with autism should be considered an important support for the parents in crucial moments such as the evaluation and intervention processes, moments that suppose a lot of stress for the family. This support is associated with an improvement in the well-being of the parents [14]. That is why grandparents are key candidates to receive information about the child and autism, since they often assume additional roles [16].

Traditionally, interventions designed for children with autism tend to focus on their social, cognitive, and behavioral deficits. However, approaches based on understanding the strengths of an individual with autism are just as important as understanding their limitations. The grandparents perceived that communication and relationships with their grandchildren with autism improved after participating in workshops designed under this approach [17]. Davison, *et al.* [18] found that people seeking support felt social anxiety and alienation from their usual support network, a fact that in grandparents translates into isolation and stigmatization. Although the grandparents had not actively sought this peer support, they seemed to enjoy the opportunity to discuss their experiences, fears, concerns, and concerns for the future. They recognized and valued the challenges of others and also celebrated and enjoyed the achievements of their grandchildren. Woodbridge, *et al.* [19] state that both grandparents and parents of children with Autism Spectrum Disorders (ASD) need support to help them process their emotions and to develop effective strategies to cope with their situation. The support of grandparents is crucial

to reduce parental stress, and this is not sufficiently covered in support programs. Several authors [20-22] emphasize the importance of developing support programs for grandparents with the aim of equipping them with skills to care for their grandchildren with the condition of autism, on all with a view to improving communication and relationships between them. There are few studies that address the impact of parent-grandparent relationships on parental stress when there are children with severe developmental disorders, however, many studies report that grandparents are a source of support for the family in these cases and should also be taken into account when designing support programs for autism [23].

There are some experiences to involve grandparents in support programs for their grandchildren with autism. Most of them stem from initiatives of family associations and foundations. Among them, in the United States, the Autism Speaks Guide for Grandparents [24] stand out. In Spain, the FEAPS Good Practices Notebooks for Grandparents [25] and the guide from the Nexxe Foundation [26]. Lozano and Valero [27] carry out a systematic review of the effectiveness of training programs for parents of children with autism, and only found three, which focus on teaching and training parent so that they are the ones who carry much of the treatment in their daily context, in addition to reducing the stressful effects of managing their children. The study carried out in Navarra by Ayuda, *et al.* [28] that observe improvement trends in the reduction of parental stress, in the perception they have of the response they give to the behaviors of their children and, significantly, in the assessment of the quality of the shared time of the children. Parents and siblings with typical development. These authors conclude that it is necessary to expand the studies with larger samples to determine the effectiveness of training programs for families of children with ASD as a way to reduce stress.

Objective of the Study

The objective of this study is to determine what effects a family support program has on reducing anxiety and on the quality of life of participants, in this case grandparents of children with autism.

Methods

Participants

The study initially involved 24 people (19 women and 5 men) from Gran Canaria who attend a family school in a health center. Eight cases were lost for not delivering the questionnaire after finishing school, or because of another family link (mothers, aunts). The remaining 16 completed the Family Quality of Life Scale. They are 10 grandmothers and 6 grandfathers, aged between 62 and 70 years. All are married and live with a partner, except for two women, who are widows, these being the only ones who live in the same home with their grandchildren with autism (Table 1). All the participants are retired and collaborate in the daily care of the children, accompanying them to the health center when the parents cannot do so due to their working hours, or because they have to attend to other family matters. All the children are diagnosed with autism, they are minors of school age, enrolled in Infant and Primary Education schools, and receive psychoeducational treatment at the health center where the family school is held, with a frequency of 3 - 5 weekly sessions.

		N	Age	Marital status Married	Marital status: widowhood
Sex	Women	10	62 - 70 years	8	2
	Men	6		6	0

Table 1: Participant data

Source: Self made.

Process

Data collection is carried out in workshops called “family schools”. These are workshops aimed at family members of users of the Child Psychology Health Center², carried out since 2008, and which are positively valued by the participants through evaluation sheets of the center itself. The participants are the families, who, while waiting for the minors who are in psychoeducational treatment sessions, demand from the center’s management the need to build new schools, and when there are an adequate number of families a new school is organized. On this occasion, the lawsuit came from some grandparents who looked after their grandchildren while their parents were in one of the schools. This proposal is accepted by the center and it is proposed to other grandparents if they want to participate. When you have 15 grandparents, the dates of completion are planned. All those who agreed to participate gave their consent to carry out this study.

The design of this school follows the same program as in those previously carried out with parents. They consist of five sessions of 2 hours each, with a weekly frequency. The objectives that the school intends are the following:

- Encourage the creation and maintenance of a balanced family climate.
- Involve all members of the family in the situation created by the presence of a member with autism.
- Offer the grandmothers a meeting place to share ideas and feelings.
- Offer simple and real information about autism.
- Improve life quality.

The phases through which this school develops are the following:

- a) Presentation of the participants.
- b) Description of the objectives of the family school:
 1. Make all members of the family participate in the situation created by the appearance of a member with autism.
 2. Encourage the creation and maintenance of a balanced family climate.
 3. Offer a meeting place to share ideas and feelings.
 4. Offer simple, accessible, real and effective information about the TEA.
 5. Obtain before-after measures of anxiety and quality of life of the participants.
- c) The participants share what they want to achieve. Objectives such as helping their children, being able to play with their grandchildren, acquiring strategies to “reach out to them”, knowing what autism is, is it cured?
- d) Breaking myths: it is false that... They hear many things and do not know what to keep.
- e) What is the reality of autism in your family?
- f) Treatment involvement: what can they do?
- g) Strategies to improve communication (augmentative communication), ways of relating through play, acquisition of daily routines and daily habits, what they should allow or not, how to manage the behavior of others (comments, attitudes, looks...).

Instruments

The following instruments have been used for data collection.

State-trait anxiety questionnaire: The Spanish adaptation [29] of the “State-Trait Anxiety Inventory, STAI” [30] was used. The STAI is a self-report composed of 40 items organized into two subscales. The first one assesses anxiety as a state (A-E), understood as the transi-

tory emotional state, which occurs at the current moment, characterized by subjective, consciously perceived feelings of attention and apprehension and by hyperactivity of the autonomic nervous system. The second evaluates anxiety as a trait, the relatively stable anxious propensity that characterizes individuals with a tendency to perceive situations as threatening. Each subscale consists of 20 items with a 4-point Likert response system according to intensity (0 = almost never/not at all, 1 = somewhat/sometimes, 2 = quite/often, 3 = a lot/almost always). The total score in each of the subscales varies between 0 and 60 points. In samples of the Spanish population, levels of internal consistency have been found that range between 0.84 and 0.93 [31].

Family quality of life scale: The adaptation to the Spanish context of the Family Quality of Life Survey developed at the Beach Center on Disability [32] of the University of Kansas (USA) was used. The adaptation [33] has been carried out at the University Institute for Integration in the Community (INICO) of the University of Salamanca, with the experience of several years of use in professional and research contexts. This scale assesses, using a 5-point Likert scale, the importance and level of satisfaction of the family in the five dimensions taken from the quality of family life model proposed by the Beach Center: Family interaction, Role of parents, Emotional well-being, Physical and material well-being, Supports. The indicators for each dimension appear in table 2.

Dimension	Indicators
Family interaction	Family members enjoy spending time together, express themselves openly to each other, solve problems together, support each other to achieve goals, love and care for one another, and cope with problems.
Parents' role	Family members help the family member with a disability to be independent, to carry out their activities and tasks, to get along with others, to make decisions appropriate, to take care of individual needs, and are concerned with knowing the people who relate to him.
Emotional well-being	Family members have supports to release stress, they have friends who support them, they have time for themselves, and they have outside help.
Physical and material well-being	The family has means of transportation to go where they need it, with medical and oral assistance, they can take care of financial expenses, and they feel safe at work, at home and in the neighborhood.
Supports	Family members with disabilities have support at school, at home, making friends, and with the service providers they need.

Table 2: Indicators of the dimensions of the quality of life scale.

Source: Selfmade.

Data analysis and design

It is a quasi-experimental design with measures of anxiety before and after the completion of school for families, and measures of quality of life of grandparents and grandmothers of children with autism. The workshop was held in a privately run health center in Gran Canaria, where psychoeducational interventions are carried out, mostly aimed at children with autism, as well as support and guidance for their families.

The STAI, used as an instrument to measure anxiety, was administered for the first time at the beginning of the first session of the family school, and for the second time at the end of the last session. The Family Quality of Life Scale was completed at the end of school, either at the family home or in the waiting room of the health center. An analysis of frequencies and correlations of the items in each of the STAI categories was carried out, and the Wilcoxon Test was used to determine the changes in the anxiety questionnaire before participating in the family school, and afterwards. The results of the Quality-of-Life Scale were used to analyze the frequencies and correlations between importance and satisfaction, as well as to establish possible correlations between anxiety and quality of life.

Results

In general terms, the data show that trait anxiety is lower than state anxiety, in the two moments evaluated, and that there is a decrease in both, more marked in state anxiety, after school (Table 3).

		Media	N	Dt.	Typ. of the average
Par 1	A-And-Before	65,31	16	24,464	6,116
	A-E-After	60,69	16	27,813	6,953
Par 2	A-R-Before	48,19	16	32,094	8,024
	A-R-After	46,13	16	32,292	8,073

Table 3: Comparison of anxiety scores before and after the support program.

Source: Self-made.

Table 4 shows the results that show that state anxiety is lower after participation in school in 8 grandparents, higher in 4 and the same in another 4, which reports that state anxiety is reduced in half of the participants. Regarding trait anxiety, it was reduced in 8 participants, increased in 5 and maintained in 3 of them. As a result, half of the participants improve their trait anxiety, as is the case with state anxiety.

		N	Average range	Sum of ranges
A-E-After - A-E-Before	Negative ranges	8(a)	6,94	55,50
	Positive ranges	4(b)	5,63	22,50
	Ties	4(c)		
	Total	16		
A-R-After - A-R-Before	Negative ranges	8(d)	6,19	49,50
	Positive ranges	5(e)	8,30	41,50
	Ties	3(f)		
	Total	16		

Table 4: Wilcoxon signed rank test.

Source: Self-made.

In general, the quality of life is good, ranking above the 92nd percentile in all dimensions except the Parental Role, which is at the 85th percentile. With the exception of Supports and Emotional Well-being, in the rest of the dimensions is greater the importance that is given than the satisfaction shown. The role of parents is considered the least important, and the satisfaction experienced in this dimension is also the lowest of all, standing at a 76th percentile (Table 5).

	Importance	Satisfaction
Family interaction	93	91
Parents' role	85	76
Emotional well-being	92	94
Physical and material well-being	93	80
Supports	92	94

Table 5: Frequency analysis between importance and satisfaction.

Source: Self-made.

The analysis of correlations between the importance and satisfaction between the five dimensions of the Quality-of-Life Scale shows a relationship between several dimensions in terms of the importance given to it. Thus, the importance given to supports is closely related to the importance given to family interaction, emotional well-being and the role of parents, and in turn, these two dimensions are also closely related to each other. In addition, the importance given to family interaction is related to physical and material well-being. Some of these relationships also occur in terms of the satisfaction they show in them. Thus, satisfaction in the dimension of the role of parents is related to the satisfaction obtained in emotional well-being and supports, and satisfaction with family interactions with it in physical and material well-being.

The importance given to each dimension is positively and significantly correlated with satisfaction in the same dimension, with the exception of material and physical well-being, whose relationship between the importance given and the satisfaction one has is not significant. The importance given to Family Interaction is related to high satisfaction in the Supports received, and the importance given to these, is related in turn to satisfaction with the Role of the parents, whose importance is also related to satisfaction in Emotional Well-being.

Regarding the results of the analysis of correlations between anxiety and quality of life, they show relationships between anxiety and satisfaction in three items (Table 6). Thus, the fact of not having the necessary supports to relieve stress (item 3), leads to high trait anxiety, regardless of whether it is before or after attending school, that is, support to relieve stress does not change from attending school. If family members do not have support from friends or other people (item 4), state anxiety is high. Anxiety in general (state and trait) is related to the fact that the family can take care of the expenses generated (item 16) by the new situation of a member with ASD in the family, that is, if it is not counted with sufficient support to face the economic costs that a person with autism implies in the family, anxiety is high, regardless of whether they attend school.

Item (Dimension satisfaction)		A-And-Before	A-R-Before	A-E-After	A-R-After
Item 3 (Emotional well-being)	Pearson's correlation		-,714(**)		-,737(*)
	Sig. (bilateral)	,240	,004	,118	,024
Item 4 (Emotional well-being)	Pearson's correlation	-,592(*)			
	Sig. (bilateral)	,026	,203	,133	,110
Item 16 (Physical and material well-being)	Pearson's correlation	-,577(*)	-,634(*)	-,761(*)	-,879(**)
	Sig. (bilateral)	,031	,015	,017	,002

Table 6: Analysis of correlations between anxiety and quality of life.

*: The correlation is significant at the 0.05 level (bilateral).

**: The correlation is significant at the 0.01 level (bilateral).

Source: Self made.

The quality-of-life scale ends with open-ended questions about supports and concerns. Regarding support, they consider that they, grandparents and grandmothers, provide support at home to help in learning, health and provide security. They are willing to give all the supports they need, especially emotional, social, and financial. They would like to learn and receive more training to be able to help more and better in learning, and to know augmentative communication techniques. Their concerns revolve around the future of their grandchildren, their autonomy, doubts about whether they can receive an inclusive quality education, and social integration. All agree on the economic concern due to the high costs of the services that their grandchildren need and that are not covered by the public administration. Finally, they suggest creating more spaces to better understand autism, improvements in health and educational services, and sensitize society about autism.

Discussion

Participating grandparents are often in charge of taking their grandchildren to the clinic where they receive psychoeducational treatment, in the same terms as Lee and Gardner [16] and as part of family support, which is in line with what is provided by others. Authors [5,7,8], are a resource that affects the quality of family life, and that families need, without this role being contemplated in public support policies disability [6]. On the other hand, seeing the positive side, it could be considered as one more action of the “active aging” programs [4] and thus would be considered within the disability support programs.

Grandparents often comment that they are very happy to help their children with their child with autism, but they observe two limitations: their free time is reduced, and they do not feel with enough information to be able to serve you as it would be desirable, as previous studies pointed out [11,14]. In relation to that provided by Margetts., *et al.* [15] during in family schools, grandparents reported that they need to feel useful to become that important support for their children (parents of the grandchild with autism) during the crucial periods of diagnosis and decision-making about which intervention to choose as the best for these people, reconciling with family life. In addition, this support is associated with better well-being of the parents [14] and in their role as caregivers, they relieve the stress of the parents [20-22].

Everything discussed so far makes them give importance to aspects that were not given before, thus seeing their level of satisfaction reduced and, as a consequence, with negative repercussions on their stability and even their quality of life. However, grandparents are a very important family support, which affects well-being, not only emotional but also physical and material.

When grandparents (and parents) describe the emotional impact of the presence of a child with autism in the family, it is inevitable to see it from the psychoeducational field as a need, on the one hand, to receive emotional support and, on the other, to acquire adequate tools for the proper development of the person with disabilities, as described by Heller., *et al.* [14] and Woodbridge., *et al* [19]. Thus, the reduction of anxiety has direct consequences in the improvement of the emotional state, and for this reason the family schools are postulated as an element to take into account in the design and continuity of new actions of this type. The increase in state anxiety could be a consequence of the recent appearance of autism in the family, since in some cases, the diagnosis had occurred in recent months. The increase in trait anxiety in some participants could be interpreted as the awareness that autism persists throughout life, and perhaps the fear that at some point they will not have the necessary help.

The quality-of-life scores are high, both in importance and satisfaction in the five dimensions. It is taken for granted that these are upper-middle class families that have sufficient financial resources to pay for psychoeducational treatments in private centers, where the family school is held. This could explain that anxiety may increase in some cases with the possibility of not having family supports and with sufficient financial resources to pay for expenses.

Grandparents came to the family school with traditional ideas such as that the interventions designed for children with ASD should focus on their deficits (communicative, social, cognitive, behavioral...) to overcome them; The school tried to change their vision, and thus they began to see that their grandchildren have many strengths that are as important or more important than their limitations, and that by relying on them the grandchildren will overcome many barriers; This is related to the decrease in state anxiety once school has finished, in half of the cases, a fact that coincides with that reported by Davison., *et al* [18].

Grandparents reported that they had acquired effective coping strategies, improving communication and general interaction with their grandchildren since they began participating in school, as previously noted by some authors [17,19]. They all agree that actions such as the school in which they have participated should be repeated periodically and as part of the support program that the family needs.

There are few experiences with grandparents, somewhat more frequent with parents and siblings, but the results of the few examples found [28] can be compared to those obtained in this experience presented here. The participating grandparents, like those in the cited study, had never attended.

To any workshop or school for relatives of people with autism and although they had not actively sought this support, they seemed to enjoy the opportunity to discuss their experiences, fears, concerns, and future concerns with other grandparents. They recognized and valued the challenges of others and also celebrated and enjoyed the achievements of their grandchildren. Thus, by participating in these actions, they were able to feel better emotionally, more useful for their children and better able to understand the situation they are going through by incorporating a new condition such as autism into their lives. This is reflected in the results of this study with the reduction of anxiety in half of the participants, once they finished school.

Conclusion

Despite being a small sample, the family school project initiated should continue to confirm the results, increasing the number of participants and expanding to other relatives who were discarded (mothers, aunts), and new ones such as siblings and parents.

In the sample we can observe a bias that may be affecting the quality-of-life data. The scores for this are high, both in importance and satisfaction in the different dimensions. These are upper-middle-class families that have sufficient resources to pay for psychoeducational treatments in private centers, where the family school is held. For this reason, it would be interesting to expand the sample to families that do not have sufficient financial resources to pay for the treatments that autism requires. Perhaps the data were not so positive.

Furthermore, it is observed that family anxiety and stress are highly dependent on supports, both personal (family, friends) and material (expenses generated by the needs of the person with autism). Perhaps this serves as an approach to further study the need to continue to create public resources to meet all the needs of people with autism throughout the life cycle.

Grandparents demand information about the difficulties their grandchildren have and ways to help them. Receive current and complete information on autism [13], eliminate disability myths associated with autism, and provide them with effective strategies to improve communication and interaction with their grandchildren, as well as teach them ways to control crisis, it is necessary and It makes them feel more useful and effective in the relationship, not only with their grandchildren, but also with their children.

Another line of research may be to demonstrate that the proposed family school format favors the creation and maintenance of a balanced family climate, as verbalized by some participants, reducing anxiety in the different members and maintaining the previously existing good quality of life- mind, despite the emotional impact that the appearance of a member with autism in the family can have.

The school offers grandparents a meeting place to share ideas and feelings, in addition to providing them with simple and real information about the condition of autism.

For all this, and following the considerations raised by the authors cited previously, we conclude with the need to consider the role of grandparents within support programs for autism [23] and for disability in general, as well as reviewing work-related policies for their impact on the working and economic life of affected families [12].

Finally, and considering the increase in the life expectancy of the population [3] and the good health conditions in many of them, one should start to think about the possibility of considering these programs of support within the framework of productive aging in the terms proposed by Miralles [5].

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Volume 12 Issue 3 March 2021

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