

Impact of the Grandchild's Autism Diagnosis on the Grandparent: A Case Study

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Abstract

A grandparent can give unconditional love and companionship to a grandchild with disability(s) as the relationship develops over the years and help provide balance within the entire family system. Autism is a complex and often devastating disorder for both the individual affected and his or her family. The emotional, functional, and financial support that a grandparent could provide may help buffer the increased stress having a child with ASD places on the family system. In this case study in-person interviews were conducted with grandparents of children newly diagnosed with autism, participating in the parent training program for the first time. This investigation shows that most grandparents are

willing to change their mindsets and help their grandchild with autism as best as possible.

Keywords: Grandparent, autism, intervention, mindset.

1. Background and Objective

With longer human life expectancy in industrialized societies, the opportunity for grandparents to play a significant role in the lives of their grandchildren has also expanded. Not only are more people living to experience the role of grandparent, but the length of time that they spend in this role is also extended. For the family of a child with disabilities, the grandparent's role and relationship with different members may adapt in response to varying levels of stress and coping ability. With the diagnosis of ASD the grandparents may provide emotional support and nurturance for the parents and extend functional and financial support as well.

Literature review states that a grandparent has a 1 in 166 chance of becoming a grandparent to a child with an autism spectrum disorder¹. The grandparents' reaction and interactions with their child, their son or daughter-in-law, their healthy grandchildren, and their grandchild with the disability impacts the family dynamics and the family's adaptation².

2. Impact of autism diagnosis

The impact of the autism diagnosis reverberates through the child, parents, family, community, and society. For the grandparent, who anticipated hugs and kisses, disappointment and worry for both their child and grandchild becomes a reality³. The experience of being a grandparent to a grandchild with ASD, is often described by researchers as the "double burden of caring for two younger generations" by some researchers⁴. The parents of the child with ASD and the parents' relationship with the grandparents have a direct effect on the grandparent-grandchild relationship.

2.1 Autism in brief:

Autism Spectrum Disorder (ASD) happens when the brain develops differently. Autism spectrum disorder (ASD) is a lifelong developmental disability. Autism is a complex and

often devastating disorder for both the individual affected and his or her family. Because of the complexity of the disorder, it is critically important to help families understand the disorder, manage stress, and sift through information that frequently includes erroneous media views and unsubstantiated claims of treatment efficacy⁵.

Autism, like many mental disorders, carries with it a stigma across cultures and generations. In India, the stigma associated with autism can be especially heavy because the individual with the disorder is not the only one who carries the burden of diagnosis –the family does, too. This can be understood by considering that there is a great emphasis on social relationships in India, particularly among family members. Accordingly, there is pressure to adhere to social norms and expectations of behavior⁶.

2.2 Role of grandparents of a child with autism:

Grandparents may provide adaptive resources for parents of a child with Autism Spectrum Disorder, ensuring the integrity of the family⁷. The emotional, functional, and financial support that a grandparent could provide may help buffer the increased stress having a child with ASD places on the family system.

1. Significance of the study

Family members affect one another's thoughts, feelings, and actions. It is both the connectedness and reactivity that make the functioning of family members interdependent. A change in one person's functioning is predictably followed by reciprocal changes in the functioning of others.

Given the family's interconnected relationships outlined in the 'family systems theory', it is likely that grandparents may recalibrate family contributions to enhance the social, emotional and developmental requirements of grandchildren with greater needs⁸.

With the diagnosis of ASD the grandparents may provide emotional support and nurturance for the parents and extend functional and financial support as well. A grandparent can give unconditional love and companionship to a grandchild with disabilities as the relationship develops over the years and help provide balance within the entire family system^{9, 10}. However research on the mindset or expectations of grandparents of a child with autism in India is scanty. This provided the impetus on this investigation.

This project was conducted in conjunction with Autism Society West Bengal (ASWB), Kolkata, India, a not for profit organization, that seeks to spread awareness about autism, advocate for the rights of individuals with autism and their families, and support these individuals and families by providing various services such as consultations and training programs. ASWB conducts both short parents training for 10 days and advanced Parents Training for 3 months. Both our parents training program at school and ASPIRES (Autism SPectrum Intervention Research Education and Support) uses research based teaching methods known to address the areas of impairments in Autism. These include ABA/VBA and TEACCH methods. Till date it has trained numerous parents from different urban and rural parts of Bengal. There had also been parent form Hyderabad and Bangladesh. Grandparents are encouraged to attend the program. This investigation was carried out over a period of ten weeks from June, 2013 to August 2013.

As often grandparents' of grandchildren with ASD are often overlooked in research, the qualitative design of this investigation will provide a glimpse of the lived experience of this small group of grandparent participants.

2. Methods

2.1 Research Instruments

In-person interviews were conducted with grandparents of children newly diagnosed with autism, participating in the parent training program for the first time. The interviews were structured and guided by a list of qualitative questions created beforehand. Sometimes the grandparents' responses themselves—their “stories,” were much more revealing than the aggregated data.

2.2 Sample size

There were eight participants, grandparents to eight children with autism.

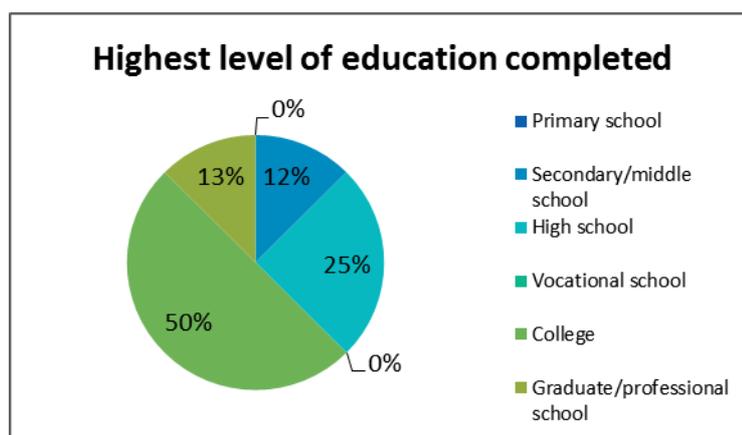
2.3 Demographic Information

Demographic information on subjects' educational attainment and place of primary residence while growing up was collected to provide a context for understanding their interview responses. These two categories were selected because it was determined that the level of education of the grandparent and

the environment in which he/she grew up are two factors which may influence his or her knowledge, attitude, and behaviors regarding autism.

Education: Five of eight grandparents interviewed (62%) completed higher education (college and/or graduate/professional school) as depicted in Table I.

Table I. Level of education among the grandparents



3. Result and Discussion

3.1 Understanding of Mental Disorders among the grandparents

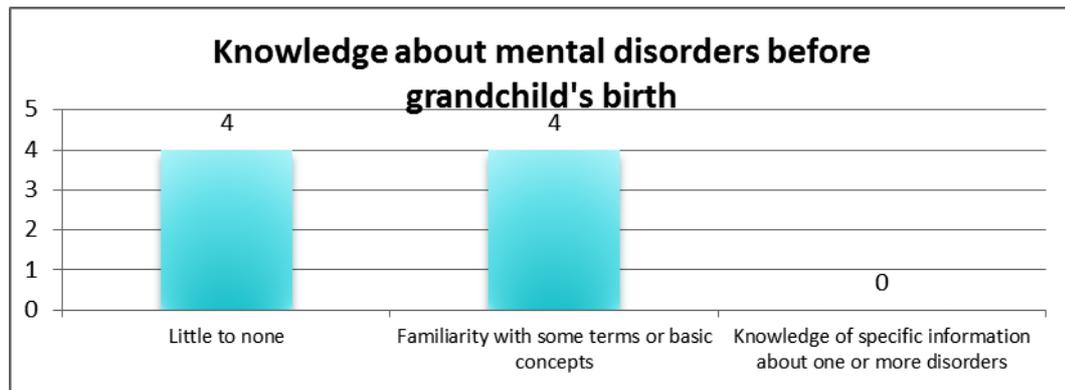
We obtained information about grandparents' knowledge of mental disorders at two time points:

- 1) Before the grandchild was born
- 2) Since the grandchild's autism diagnosis.

Knowledge. The eight grandparents interviewed were split equally between those who had no knowledge about mental disorders before the grandchild's birth and those who were aware of other disorders like Down syndrome or cerebral palsy or had heard of terms like "mental

retardation.” These responses did not change at all when the grandparents were asked about what they had learned about mental disorders post-diagnosis as shown in Table II.

Table II. Knowledge about mental disorders prior to their grandchild’s diagnosis

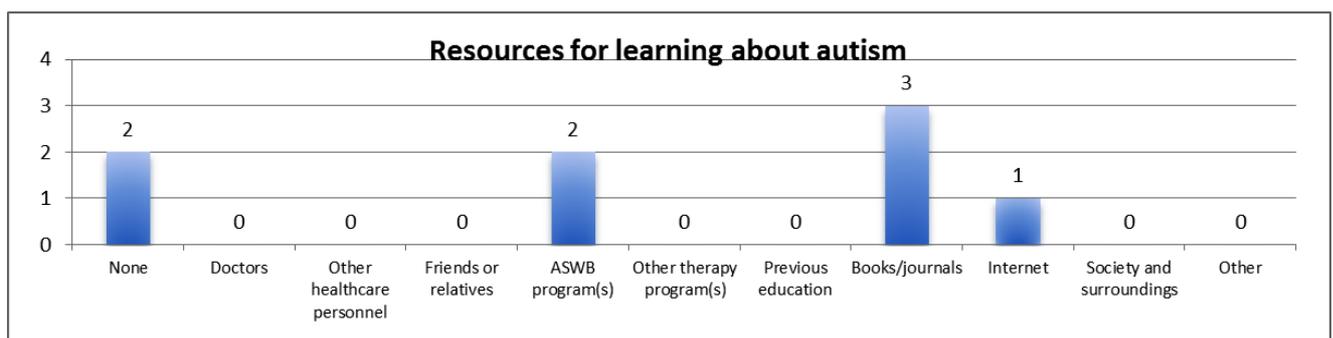


3.2 Understanding and learning about of Autism among the grandparents

As with the parents, each grandparent was asked about his or her knowledge of and experience with autism. Grandparents were additionally asked about their beliefs regarding the cause(s) of autism as another measure of their understanding of the disorder.

Knowledge: None of the grandparents knew about or had experience with autism before their grandchild was born. After the child was diagnosed, many had learned a considerable amount about autism, primarily by reading books and journals (38%) as shown in Table III.

Table III. Means of learning about autism by Grandparents



3.3 Grandparent's Mindset

To supplement the information from the parents in ASPIRES about their family members' reactions to an autism diagnosis, the grandparents were asked how they personally felt about their grandchild's condition and how these reactions changed over time.

Upon child's diagnosis. As expected, all of the grandparents reported various degrees of shock, disappointment, and heartbreak upon hearing that their grandchild had autism. Because each response was unique and vivid, a summary of the actual responses is included below.

One question viz. *"How did you feel when you found out the child had autism?"* was asked to very grandparent. The response was noted down in isolation and shown in Table IV.

Table IV: Summary of the responses among grandparents following the diagnosis of autism in their grandchild.

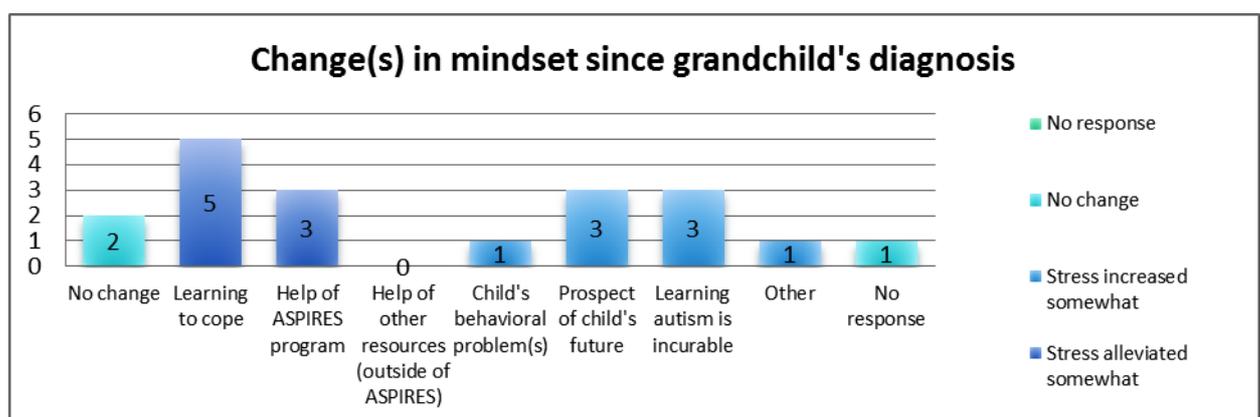
Subject	Response
M (maternal grandmother)	-Felt bad, but did not think autism was incurable. Now knows otherwise.
N (paternal grandmother)	-Was prepared for diagnosis but was still very heartbroken. -At one point, "wanted to leave this world" because did not want to see child's future -Told herself she could not do so because it would not help if she didn't accept the situation and take responsibility
O (paternal grandfather and grandmother)	-Felt bad, but most of the decisions regarding the child's care are made by the child's parents -Worried b/c autism is not something that can just go away (transliteration: "be disposed of")
P (maternal grandfather)	-Felt bad, "of course," upon realizing something "was wrong" with the child
Q (maternal grandfather)	-"What can I say? Such a beautiful child...why has

	God given me a child...who cannot be cured?"
R (maternal grandfather)	-Shocked
S (maternal grandmother)	-Devastated and shocked when told by professionals at Manovikas Kendra that grandchild would not lead a normal life
T (maternal grandmother)	-Very hurt at first because did not know anything about autism, but is staying strong

4. Changes in the mindset since diagnosis

5 (Five) grandparents reported a reduction in their stress at the time of interview. Five grandparents also reported an increase in their stress since the time of interview, two of these also having reported some things that contributed to a reduction in stress. The particular factors cited by grandparents that contributed to either an increase or decrease in their stress levels are given in the graph. Two grandparents (P, Q) did not experience a change in their stress levels from the time of their grandchild’s autism diagnosis to the time of interview. The results shown in Table V.

Table V. Changes in the mindset of the grandparents after diagnosis.



5. Conclusion

Research has demonstrated that the grandparent-grandchild relationship is valuable for the grandparent¹¹ and for the grandchild¹². The unique bond formed through the grandparent-grandchild relationship can function as a family resource for the entire family system. For a grandchild with Autism Spectrum Disorder this relationship may be even more critical.

Family involvement is the one invariable factor and an integral part of the success of early intervention programs for children with autism spectrum disorder (ASD). The collaboration between the parent and the professional working with the child in the program is critical to the effectiveness of programs¹³. Empowering family members with knowledge about autism; child management methods leads to better outcomes for the families, their loved one with ASD, and the professionals who serve them¹⁴. This investigation shows that most grandparents are willing to change their mindsets and help their grandchild with autism as best as possible.

Grandparents are often excluded from the normal information networks available to parents. Programmes and curriculums should be designed to help grandparents to define their role as grandparents of a child with autism and give concrete skills to help them to communicate with their children (the parents of a child with autism), connect with support groups and help with advocacy for their grandchild. Grandparents, as well as parents, need support to help them process their emotions and to develop ongoing strategies to cope with the situation of grandchild's autism diagnosis¹⁵.

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