

Grandparenting an autistic child: Challenges and rewards

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Summary

This study explores grandparents' involvement in the upbringing of their autistic spectrum grandchild and the quality of their relationship. Twenty-five grandparents with their autistic spectrum grandchild attending nursery or primary school took part in the study. They filled a questionnaire assessing their understanding of the child's difficulties, their involvement in his/her care and treatment, their access to support services, the acceptance of the grandchild and the quality of their relationship. The findings suggest that grandparents are more involved in the care than in the treatment of their grandchild. They claimed a good understanding of the child's difficulties but they rarely refer to specialists. They reported enjoying a satisfactory relationship with their grandchild.

Introduction

Autism Spectrum Disorders (ASD), characterized by impairments in social interaction and communication, restricted interests and repetitive behaviours, pose a challenge to the families of children with ASD including their grandparents (GPs). It is well documented that grandparents play a vital role on their grandchildren's upbringing, care and development (Luo, Lapierre, Hughes, & Waite, 2012; Tan, Buchanan, Flouri, Attar-Schwartz, & Griggs, 2010). However, most studies on the effect of ASD on family's life are restricted on its effect on parents' and siblings' well-being (Margetts, Le Couteur, & Croom, 2006; Orsmond & Seltzer, 2007). Little is known about the GPs of children with special educational needs and even less about the GPs of children with ASD. Margetts et al. (2006) found that GPs care for their ASD grandchild, search for professional advice and try to keep the family united. Sullivan, Winograd, Verkuilen and Fish (2012) found that ASD was associated with more flexible family functioning, but less family satisfaction and greater grandmother difficulties.

This is an exploratory study that aims to examine GPs: a) emotional reaction upon the diagnosis of their ASD grandchild, b) the acceptance of their grandchild, c) the understanding of the child's difficulties, d) their access to specialists and support services, e) their involvement in his/her care and in the treatment of the disability, and f) the quality of their relationship. Moreover, the study examines which of the above parameters affect the quality of their in-between relationship.

Methods

Participants

Twenty-five GPs (16 female), with a mean age of 68 years (age-range: 61-74 years) living in Crete, Greece participated in the study. The majority of GPs were retired (74%). Their ASD grandchild was attending either nursery (44%) or primary school (56%).

Measures

GPs were asked to complete a structured questionnaire at home. Apart from demographic items and information regarding the GP, the ASD grandchild and the frequency of their contact, the questionnaire examined the following parameters: a) *feelings* upon the child's diagnosis, b) *understanding of the difficulties* experienced by their grandchild, c) *access to information and support services*, d) *involvement in his/her daily care* and in the *treatment of disability*, e) grandchild's *acceptance*, and f) the *quality of their relationship*. The questionnaire had the form of a 5-point rating scale (0= not at all, 4= very much).

Results

GPs were in frequent contact with their grandchildren: 82% of them met more than twice a week. Despite their initial feelings of sadness and frustration (96%) upon the child's diagnosis, most GPs had accepted their grandchild's condition ($M = 2.24$, $SD = .76$). They were quite involved in his/her care ($M = 1.94$, $SD = .99$) by preparing meals, observing hygiene, etc. but had less involvement in the treatment of disability ($M = 1.3$, $SD = .97$). GPs reported a good understanding of the child's difficulties ($M = 3.08$, $SD = .81$). However, they reported a limited access to information and support services ($M = .38$, $SD = .73$); the majority (76%) had never consulted an ASD specialist. GPs stated the need for receiving guidance and support from specialists ($M = 1.72$, $SD = .76$) and participating in self-support groups ($M = 1.68$, $SD = .74$). Overall GPs enjoyed a good and close relationship with their grandchild ($M = 3.05$, $SD = .78$).

A series of Pearson's correlations revealed interesting associations between the explored parameters (Table 1). The understanding of the disability was correlated to GPs involvement in the daily care ($r = .60$), the treatment of disability ($r = .56$), the acceptance ($r = .48$) and the overall quality of their relationship with their grandchild ($r = .62$). Acceptance of the disability was highly correlated with the quality of the relationship ($r = .62$). There was also a correlation between GPs access to services and their involvement in the treatment of the disability ($r = .60$).

To examine which parameters affect the quality of the relationship, stepwise regression was performed with daily care, treatment involvement, understanding of the disability and acceptance as independent variables. Only acceptance ($\beta = .42$) and daily care ($\beta = .41$) entered the model ($F(2, 18) = 8.96$, $p = .002$, $R^2 = .49$).

Table 1. Correlations between the explored parameters

| | 1 | 2 | 3 | 4 | 5 | 6 |
|--------------------------------|-------|-------|------|-------|------|---|
| 1. Daily Care | | | | | | |
| 2. Treatment Involvement | .49* | | | | | |
| 3. Access to services | .14 | .60** | | | | |
| 4. Understanding of disability | .60** | .56** | .17 | | | |
| 5. Acceptance | .48* | .29 | -.22 | .48* | | |
| 6. Quality of the relationship | .61** | .34 | -.14 | .62** | .63* | |

* Correlations are significant at the .05 level

** Correlations are significant at the .01 level

Discussion

Despite the feelings of sadness and frustration upon the child's diagnosis most GPs had accepted their grandchild's difficulties. Moreover, they were involved in his/her daily care, a finding consistent with research of children with disabilities, but had less involvement in his/her treatment and education. This finding contradicts previous research showing that GPs are actively involved in the education and treatment of their special-needs grandchildren (Gardner & Scherman, Mobley, Brown, & Schutter, 1994).

GPs reported a good understanding of the child's disability but stated a limited access to information services. Surprisingly, most of them had never consulted an ASD specialist. This finding might explain why GPs were not particularly involved in their education and treatment. The majority of GPs stated the need for receiving support from specialists, a need also reported in research about the GPs of children with special educational needs. GPs claimed that participation in self-support groups would be of a help. These findings have implications in designing intervention and support programmes that would target not only the parents/siblings but also the GPs of children with ASD.

Overall GPs enjoyed a close relationship with their grandchild. Acceptance of the disability and involvement in his/her daily care were found to be correlated with the quality of this relationship.

This study was exploratory and descriptive. Future studies should examine how GPs interact and communicate with their ASD grandchild in a natural setting. Parents' perspective about the role and the contribution of GPs would also be of an interest.

GPs are a source of stability for the family, but they also need the help and support of professionals to understand their ASD grandchild and face the everyday challenges. Educators and policy makers should invest on their motivation to be involved in the upbringing of their ASD grandchild and get the best out of it.

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