

Social support and grand parenting in autistic children families

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Abstract

About 1 in 68 children has been identified with autism spectrum disorder among children aged 8 years according to estimates from Autism and Developmental Disabilities Monitoring (ADDM) (Baio, 2014). Not only undiscovered cause of autism is a source of stress for parents of autistic children, but the stress of raising a child with autism can lead to depression (Morgan, 1988, 263-280). In order to cope with this stressful situation, it is very important for parents of autistic children to find some explanation for their child's developmental disorder, and even to be supported by their family, institutions and society. Even though the pace of research has increased dramatically in recent years, a majority of studies on families with a child with autism collect information from the parents, but not from the other members of the family. This study examined the involvement of grandparents of autistic children. The study is based on a sample of 40 mothers of autistic children from Albania who completed a structured questionnaire. It was hypothesized that mothers of autistic children who live with other members of the family such as grandparents, perceive more social support compared to families of autistic children that consist only by the natural parents.

Keywords: autism, child, grandparents, mothers, social support.

Introduction

Autism is a pervasive development disorder. The diagnosis of autism indicates qualitative impairments in communication, social skills, and range of interests and activities (Saqellari, 2011, 113). To live with an autistic child is a very demanding and stressful situation (Tupja, 2009, 29). Caring for a child with autism can be a twenty-four hour job throughout the child's entire lifetime. A child with autism is a large stressor on the family because of the ambiguity of diagnosis, the severity and duration of the disorder, and problems with the child's lack of adherence to social norms (Bristol, 1984, 289-310). A mother of an autistic child (Lala 2014, 17) explains the way she felt at the beginning:

"The next day it was the same ritual ...stress, boredom, pain and tears..."

Fathers and mothers blame each-other for their child condition and sometime they blame their child for the disorder. Mothers get depressed and do not follow their careers anymore. Mothers of autistic children need professional help, but especially they need their close people to help them physically and psychologically. Because of this stressful situation some couples get divorced. In USA 4 in 5 families that have autistic children get divorced (Kurti, 2013, 302).

ABCX-Family crisis model

Having a child with special needs does not always mean a crisis/stress in the family

if we take into consideration the ABCX model. The ABCX family crisis model can be used to describe the stress that can attack the family after the recognition of autism in a child. "A" stands for the stressor event (child with autism), "B" is the family's crisis-meeting resources, "C" is the way the family defines the event, and "X" is the crisis/stress. The "A" factor is a significant transition in the family's life that can produce a change in the family system. The family may need to activate its existing resources to prevent the stressor from becoming a crisis. The "B" factor is related with the use of the family resources, by utilizing community services, social support. The "C" factor is the way the family defines the event of having a child with autism. This factor is a product of the family's values and its previous experience in dealing with crises. Functioning on all three factors together represents the family's ability to prevent the stressor from creating a crisis/stress ("X" factor).

Related to "B" factor concerning the stressful situation, there are some internal and external coping strategies. Internal coping strategies are when an individual changes one's view of the situation. The external coping strategies include social support, spiritual support, and formal support (community resources such as doctors and teachers). To fulfill the physical and psychological needs of the child, parents acquire formal social support such as medical doctors, psychologists, social workers, and special education teachers. (Boyd, 2002, 208-215) argues that low levels of social support are strong predictor of maternal depression in families with children with autism. Konstantareas & Homatidis (1989) found that the stress level of mothers of children with autism was negatively related to perceived level of social support.

The main source of informal support is the partner or the spouse of the caregiver, family members outside of home, friends, and support groups (Raif & Rimmerman 1993, 97-103) found a strong informal support system to be significantly associated with parent feelings able to continue caring for a child with developmental disabilities. Even though some researchers are taking in consideration the size (number of available supports), they are focused on the importance of the perceived quality and helpfulness of parents' social network.

Children and environment

Psychologists today are interested in the role the context plays in the development of a child. The children are part of different communities. They go to school, play in teams, learn with friends, live, give and take within different contexts (Woolfolk, 2011, 66-68). An interesting explanation about child-context connection is given by the social ecological system theory. Social ecological context was pioneered by Bronfenbrenner in 1979, who suggests that the ecological system comprises a number of subsystems: the microsystem, mesosystem, exosystem and macrosystem. Every person lives in a microsystem (family, friends, teachers, etc) that is inside a mesosystem (interactions between all the factors) which is inside exosystem (social environment that influence on the child). These three systems form a macrosystem (law, society, values, etc) (Woolfolk, 2010, 66).

The microsystem is the nearest environment where a child can experience different emotion in interaction with his parents, other children or teachers. This relation is

two directional. What happens to the child has impact on the parents and what happens to the parents is felt even by the child. Mesosystem has to do with interaction of all the actors of microsystem. Exosystem includes interaction between two or more environments such as friends and neighbors, medical care, extended family, peers outside the school, other parents, support groups, and local community. Even psychologists or experts of the field are an important part of this system. The child is not directly connected with this system but it has an impact upon the child, for example the mass media can describe disabled people as people in need or undesirable. Based on child's disorder neighbors can be humanist and friendly or stigmatizing. The impact that economic and political factors have on the child has to do with macrosystem. Macrosystem is the society expressed in values, laws, conventions, traditions and has an impact upon families. The bioecologic system of a child can be expressed as: the child is influenced by a microsystem of his mother, father, brother, friends, teacher, by mesosystem of interaction between these people and by exosystem of governmental policies. (Woolfolk, 2010, 67).

Parents and grandparents as part of microsystem

The role of a mother is irreplaceable in a child's life, especially when there is a child with autistic disorder. Compared to fathers the role of mothers is much more important. As a father of an autistic boy Tupja (2009) wishes his child survives after his death, but especially after his wife's death (Tupja, 2009, 29). Gjika (2009) explains that a child feels protected when he is in contact with his mother's body. A baby discovers "the others" through his mother. A child feels his mother even when she is not with him, because his mother is like the air to him. It is the mother's duty to sustain and protect her child during a lifetime. Later as a grandmother she should give protection, peace, security and advice not only to the grandchildren, but even to her own children.

"The best doctor, psychologist and therapist of an autistic child... is his mother"(Kurti, 2013,303).

The specialist (Kurti, 2013, 367) in her last book dedicated to autism, explains:

"Dear parents...autism of your child has involved all the family, even all the relatives."

When we talk about our family, grandparents are the closest context. Living with grandparents is an essential part of Albanian family. Even though there are no statistics on extended families in Albania, there is a tendency for the couples with children to live with their parents. This is related with many factors such as the culture, tradition, economic reasons or even strong bounds between generations. (Lussier et al., 2002, 363-376) found that involvement of grandparents in grandchildren life is associated with lower difficulties in their life. In USA today there are a lot of facilities for grandparents of autistic children. One of them is grandparents' network where they can share opinions and help each other, not only for their autistic grandchildren, but mainly to help their own children (parents of the autistic child). (Attar-Schwartz et al., 2009, 74) admits the influence of grandparents on the well-being of their grandchildren in different family types:

"Public institutions ...need to recognize grandparents as a potentially important role source for support in adolescents' lives in general, but in particular, for those increasing numbers of adolescents going through a family transition."

Even though there are not a lot of studies concerning the influence of grandparents in their autistic grandchildren and family, their role is indispensable.

Method

The sample for the current study include 40 mothers of children that are diagnosed with Autism Spectrum Disorder (Asperger's Disorder, Autistic Disorder, Rett's syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Disorder, not otherwise specified) based on DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disabilities). Mothers are members of MEDPAK (Protect the Rights of Persons with Disabilities), a non-governmental organization in Albania. 20 mothers live with other members of the family such as grandparents. Information was collected from mothers by an anonymous structured questionnaire. Letters were sent to the sampled families detailing the purpose of the study. Mothers were told they could withdraw if they did not want to take part. They were made aware they were free to withdraw from the study at any time for any reason. Confidentiality was ensured to all participants. All the mothers measures used in this analysis were self report measures. Parental social support was measured by an adaptation of the Parent Support Scale. This scale lists 17 potential sources of support (e.g., family, friends, community agencies, other parents of children with special needs) that are rated on 5-point Likert scale to indicate the degree of helpfulness of each source to the parent. Higher scores signify greater levels of helpfulness.

Result

A paired samples t-test was conducted to determine if there are any significant differences within mothers' perceived social support. The t-test assesses whether the means of two groups are *statistically* different from each other. This analysis is appropriate whenever we want to compare the means of two groups. A two-tailed test, also known as a non directional hypothesis, is the standard test of significance to determine if there is a relationship between variables in either direction. Two-tailed tests do this by dividing the .05 in two and putting half on each side of the bell curve. The t statistic is a measure of how extreme a statistical estimate is. We compute this statistic by subtracting the hypothesized value from the statistical estimate and then dividing by the estimated standard error. The traditionally accepted P-value (probability) for something to be significant is $P < 0.05$. It was hypothesized that mothers of autistic children who live with other members of the families perceive more social support compared to families that are compound just by parents and the child. Based on the result $P > 0.05$, we can say that there is no significant difference between the two groups of mothers. In this way our hypothesis was not supported.

Discussion

The purpose of this study was to find any difference between extended families and non extended families of autistic children concerning the social helpfulness from

formal and informal support. This research differs from previous researches, because it includes not only the mothers of autistic children, but even grandparents. Mothers' self reports of social helpfulness were collected and compared. Even though it was not found any significant difference, this research serves as a platform for other investigation in the future. The influence of grandparents in their children's families is undisputable. Living within the family, or not, grandparents are a guarantee of family well-being in different family types, especially in families with autistic children.

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