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Self-reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups

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ABSTRACT

Many parents of children with autism spectrum disorders (ASD) participate in support groups, but very few studies have explored their motives to do so. The present study aims to explore the self-reported needs and expectations that parents express according to their gender and education and according to the age and gender of their child with ASD. The 299 parents (72 fathers and 227 mothers) of children who were diagnosed with ASD were aged from 27 to 60 years old (with mean age = 46 years and 8 months). They were asked to complete an anonymous open-ended questionnaire during one of their support group's meetings. The self-reported needs and expectations that parents expressed differed significantly according to their gender and education, as well as the age and gender of their child with ASD. These findings should be taken into consideration when organising and running support groups for parents of children with ASD.

Autism is a pervasive developmental disorder characterized by restricted and repetitive interests and activities, communication impairments, and atypical social interaction skills (American Psychiatric Association, 2000), which often result to challenging or undesirable behaviours (Randall & Parker, 1999). Therefore, parents of children with autism spectrum disorders (ASD) exhibit more stress than parents of typically developing children (Hoppes & Harris, 1990; Konstantareas & Papageorgiou, 2006; Rodrigue, Morgan, & Geffken, 1990; Sharpley & Bitsika, 1997) or children with other developmental disorders, such as Down Syndrome (Sanders & Morgan, 1997).

The levels of stress that parents of children with autism experience may be affected by the resources available to them (White & Hastings, 2004), such as social support (Beresford, 1994; Freedman & Boyer, 2000). Parents who receive adequate social support can adapt more successfully to the difficulties associated with raising a child with autism (Fisman & Wolf, 1991; Henderson & Vandenberg, 1992; Konstantareas & Homatidis, 1989; Sanders & Morgan, 1997; Siklos & Kerns, 2006). Social support has been defined by Cobb (1976) as information that makes the individual believe that he/she receives care and love and that he/she is valued and esteemed; social support plays an important role in a network of mutual obligation and communication.

Social support entails both functional aspects of social interaction and structural characteristics of social interaction (Huws, Jones, & Ingledew, 2001). Social support may be available through: (a) spousal support or satisfaction with the marital relationships (Herman & Thompson, 1995; Konstantareas & Homatidis, 1989; Sloper, Knussen, Turner, & Cunningham, 1991; (b) support from extended family members, such as grandparents (Hastings, 1997); (c) support from available respite care services (Chan & Sigafoos, 2001); and (d) support through informal sources, such as friends and

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religious groups (Hastings & Johnson, 2001; Salovita, Italinna, & Leinonen, 2003) or parents of children with disabilities who form support groups (Huws et al., 2001; Smith, Gabard, Dale, & Drucker, 1994).

Parent support groups are designed to provide mutual support and friendship and to gather and distribute information regarding the prevalent disability (Rawlins & Horner, 1988); they do not usually train parents to act as therapists of their children with developmental disabilities (Smith et al., 1994; Tellen, Herzog, & Kilbane, 1989). Many support groups provide emotional support in combination with educational information regarding the shared disability (Betz, Unger, Frager, Test, & Smith, 1990), while others may provide group-therapy type support (Weissbourd & Kagan, 1989). Parents who participate in support groups experience less child-related stress and reduced feelings of social isolation (Bennett & De Luca, 1996; Tellen et al., 1989), which in turn foster more positive mother–child interactions, as explained also by the double ABCX model (McCubbin & Patterson, 1983).

Although several studies have researched the types of social supports that are effective in parenting a child with ASD (Fisman & Wolf, 1991; Konstantareas, 1991; Konstantareas & Homatidis, 1989; Sanders and Kerns, 1997; Siklos & Kerns, 2006), they have largely overlooked the influence of important variables, such as the severity of the child's disability and the child's age, that can moderate the effectiveness of social support (White et al., 2004). Moreover, very few studies have examined the self-reported needs of parents who take part in support groups (Siklos & Kerns, 2006), as well as the reasons and expectations from their participation (Bennett & De Luca, 1996). Indeed, most knowledge about parent support groups derives from "conventional wisdom" (Koroloff & Friesen, 1991). Therefore, the aim of the present study was to explore the self-reported needs of parents who participate in support groups and the expectations that parents have from support groups according to their gender and education and according to the age and gender of their child with ASD.

1. Method

1.1. Participants

The participants of the present study were 299 parents of children who were diagnosed with autism spectrum disorders. There were 72 fathers and 227 mothers with their age ranging from 27 to 60 years old (with mean age = 46 years and 8 months). More than half of the parents (58.9%) were graduates of secondary education and the rest (41.1%) held a university degree. Most of the parents were not employed (35.1%), almost one third (30.1%) were public employees, 19.7% were private employees, and 15.1% were self-employed. The majority of the parents (80.6%) had a boy who was diagnosed with ASD either by the local educational authority or by another public service (e.g., hospital), while the rest 19.4% had a girl diagnosed with autism by the same agencies. Almost 3/4 of the children (73.6%) attended special schools, 15.4% attended inclusion classes, and only 11% were in mainstream schooling. More than half of the parents (57.2%) had children attending primary school and the remaining 42.8% attended nurseries or other preschool settings. Only 70 parents (23.4%) reported that they did not provide any extra support for their child with ASD outside school, while the remaining 76.6% said that they took their children to speech therapists, occupational therapists, and psychologists or that they had some help for their child at home. All the parents who participated in this study were members of parent support groups from every prefecture of Greece—so, the sample was representative of the entire Greek population of parents of children diagnosed with ASD who are members of support groups.

1.2. Material

The parents were asked to complete a questionnaire that included some questions regarding demographic data: their gender, age, education, and profession, as well as the gender, age, type of education and extra support for their child with ASD. Then they were asked to answer some open-ended questions regarding the main problem that was faced by the child with ASD and the family as a whole, the perceived reaction of the family, social, and work environment towards the child with ASD, the reason why the parents participated in support groups, and the expectation that they had of these groups. As far as the coding system of the open-ended questions was concerned, each question was coded independently. The codes for these questions were identified from a preliminary analysis of 70 questionnaires, and their key categories were extracted and examined for common themes before they were classified into categories. The resulting categories were mutually exclusive and ambiguous answers were discussed between the researchers in order to decide on the allocation to a category. Forty questionnaires were randomly selected and coded independently by the authors and the mean Cohen's K reliability was satisfactory (90%).

1.3. Procedure

The parents of children with ASD who formed the sample of the present study were contacted through the parent support groups to which they belonged. They were given a letter during one of their meetings that explained the purpose of this study together with the questionnaire that they were asked to complete and return to the researchers using the self-addressed envelope that was enclosed. Out of the 340 parents who were contacted initially, 299 returned completed questionnaires; the return rate (87.9%) was considered very satisfactory.