PERCEPTIVE SOCIAL SUPPORT AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

Ana Rita Curval [1,a], **Ana Isabel Igreja** [b], **Victor Viana** [a] **and Micaela Guardiano** [a]
[a] Centro Hospitalar Universitário de São João , [b] Centro Hospitalar de Trás-os-Montes e Alto Douro.

ABSTRACT Introduction: Social support, especially provided by close family and friends, has been consistently identified as one of the most powerful predictors of psychological adjustment among parents raising children with ASD. **Material and methods:** A cross-sectional study including 51 parents of children with ASD was carried out in our pediatric development department. The study's objective was to verify the degree of satisfaction of the participants regarding their family, friends, intimacy, and social activities. **Results:** There was a negative correlation between the children's age and the degree of parental satisfaction. However, there was a statistically significant association between the parent's educational level and the degree of satisfaction they reported in all domains except the family domain. **Conclusion:** Based on study findings regarding the importance of help from parents' informal social network, special attention should be focused on developing services that assist parents in making more effective use of existing sources of support from family members, friends, and other parents of children with ASD.

KEYWORDS Autism spectrum disorder; Parents; Social support; Family; Friends

Introduction

Autism Spectrum Disorders (ASD) include a variety of conditions characterized by difficulties in social communication and behaviour, including problems interpreting non-verbal gestures, developing age-appropriate friendships and adapting to environmental change and rigid routines[1,2]. The symptoms and subsequent challenging behaviours associated with ASD present parents and children with many undesirable consequences, including (but not limited to) higher parental stress levels, poor sibling adjustment, family dysfunction, and disruptive behaviour, which tends to lead to social isolation[1−5].

Research has shown that non-normative family stressors, such as the disability of a child, can result in acute pressure on parents, placing them at risk for various mental health problems. One of the most serious disabilities affecting young children is autism, which affects nearly every aspect of the child's development. Compared to other childhood disorders, autism's impact on the family appears to be particularly severe, with parents of such children frequently reporting high levels of stress, typically due to their child's social and communicative deficits, problematic behaviours, and level of dependency[2−,6].

Studies also suggest that, for many parents, taking care of a child with ASD becomes a full-time commitment, overriding other life priorities. For these parents, life tends to revolve around the disabled child, with interactions inside and outside the home constantly altering to accommodate their needs. Particularly mothers may find it necessary to reduce working hours or quit their jobs to provide care. In addition, due to the child's odd and sometimes unpredictable behaviour, normal family activities may also be affected. Family members may find it difficult to bring outsiders into the home, increasing the family's social isolation[3,4,6].

Among the various protective factors studied by investigators, social support has been consistently identified as one of the most powerful helpers of psychological adjustment among parents raising children with ASD and other disabilities. In particular, the support provided by close family and friends has been frequently linked to a reduction in their levels of stress[7−10]. Additionally, some studies suggest that it is primarily the existence of strong and intimate ties, not ties in general, that contribute to high levels of support and positive adjustment[4,11−14].

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[1]Corresponding author: Ana Rita Curval (rita_cur@hotmail.com)

Table 1 Demographics characteristics of the parents.

Parents	N = 51
Gender	
Female	30 (59%)
Male	21 (41%)
Mean age (SD)	39,2 (5,7)
Education	
Level 1	16 (31%)
Level 2	8 (16%)
Level 3	24 (47%)
Level 5	2 (4%)
Level 3	1 (2%)

Table 2 Demographic characteristics of the child.

Child	N = 51
Gender	
Female	6 (12%)
Male	45 (88%)
Mean age (SD)	6,4 (3,0)
Education	
Level 1	28 (54%)
Level 2	14 (28%)
Level 3	9 (18%)
Communication skills	
Verbal	38 (75%)
Non-verbal	13 (25%)
School	
Yes	44 (86%)
No	7 (14%)

Table 3 Kruskal-Wallis Test between the level of ASD and parental satisfaction.

	Satisfaction with friends	Intimacy	Satisfaction with family	Social activities
Chi-Square	1.912	4.316	2.139	3.972
df	2	2	2	2
Asymp. Sig.	0.384	0.116	0.343	0.137

Table 4 Pearson correlation coefficient between children's age and the degree of parental satisfaction.

	Satisfaction with friends	Intimacy	Satisfaction with family	Social activities
Pearson Correlation	-0.450	-0.309	-0.366	-0.258
Sig. (2-tailed)	0.001	0.029	0.009	0.021
N	51	51	51	51

Table 5 Pearson correlation coefficient the parents' educational level and the degree of satisfaction.

	Satisfaction with friends	Intimacy	Satisfaction with family	Social activities
Pearson Correlation	0.442	0.688	0.240	0.468
Sig. (2-tailed)	0.001	<0.001	0.090	<0.001
N	51	51	51	51

Material and Methods

A cross-sectional study including 51 parents of children with ASD was carried out in our pediatric development department. The study's objective was to verify the degree of satisfaction of the participants regarding their family, friends, intimacy, and social activities. Parents of children with ASD who agreed to participate were included. Exclusion criteria were refusal and/or incapacity to answer the questionnaire and the presence of other comorbidities which may interfere with results. No patient or parent refused to participate.

Data were gathered from participating parents using questionnaires and interviews. Study questionnaires included items on child and family characteristics and social support. The analysis also included several parent and child sociodemographic characteristics as control variables. Parent demographics included gender, age, residence (rural or urban), and years of education. Child demographics included gender, age and school attendance.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), ASD has been classified into three levels of severity: LEVEL 1 – "Requiring support" (Social communication: Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions; Restricted, repetitive behaviours: Inflexibility of behaviour causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence); LEVEL 2 – "requiring substantial support" (Social communication: Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others; Restricted, repetitive behaviours: Inflexibility of behaviour, difficulty coping with change, or other restricted/repetitive behaviours frequently appear enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action); LEVEL 3 – "requiring very substantial support" (Social communication: Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others; Restricted, repetitive behaviours: Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action).

The instrument used to assess the social support given by parents was the "Social Support Satisfaction Scale", developed by Pais-Ribeiro[15], whose main purpose is to verify the level of satisfaction of its participants, considering four factors. The first factor - satisfaction with friends - includes five items (3, 12, 13, 14, 15), the second factor is related to intimacy and includes four items (1, 4, 5, 6), the third factor - satisfaction with family - includes three items (9, 10, 11) and the last factor - social activities - includes three items (2, 7, 8). This is a multidimensional scale with 15 items, whose answers are Likert-like: 1 - Agree, 2 - Mostly Agree, 3 - Nor Agree nor Disagree, 4 - Mostly Disagree and 5 - Disagree. In order to access the total score, one must add the items that constitute each factor. Once the number of questions is different to each factor/dimension, their minimum and maximum score are also different (satisfaction with friends – high test score= 25, intimacy - highest score=20, satisfaction with family - highest score=15, social activities - highest score=15). The final score can range from 15 (15×1) to 75 (15×5), and the higher the score, the better perception of social support. It is then advisable to convert these scores to a scale between 0 and 100, 0 being the lowest possible score and 100 the highest. In order to achieve this, it is necessary to use a simple rule of three[15].

Results

The final parent sample consisted of 30 mothers and 21 fathers. Parent age ranged from 28 to 53 years, with a mean of 39,2 (SD = 5,7). Most (70%) were married at the time of the study, and 80% were employed, at least on a part-time basis, outside the home. In terms of education, 16 parents had concluded level 1 (middle school), 8 had concluded level 2 (high school), 24 graduated from college (level 3), 2 had a bachelor's degree (level 4), and one had a master's (level 5). In addition, parents included in the present study had at least one child younger than 18 who had been diagnosed with ASD. Table 1 presents the demographic characteristics of the parents included in the study.

Regarding child characteristics, 88% were male, and 12% were female, with a mean age of 6,4 years (SD = 3,0). According to DSM-5, 54% of children were classified as level 1, 28% as level 2 and 18% as level 3. Regarding communication skills, the parents reported 25% of the children as primarily nonverbal (the primary mode of communication was signing and picture icons). In addition, 86% of the children included in the study attended school. Six families had at least one other child also diagnosed with ASD. Table 2 presents the demographic characteristics of the child included in the study.

Data analysis by the Kruskal-Wallis Test showed that the relationship between ASD and parental satisfaction reported in each domain was not associated with statistically significant differences. However, it was found that there is an association between the different domains. That is, the level of satisfaction mentioned is, in most cases, in agreement with the different domains (Table 3).

The individualized analysis of the 4 dimensions that the study included showed that the degree of satisfaction of the parents with children with ASD is higher regarding family, followed in descending order by friends, intimacy, and social activities. However, there were no statistically significant differences.

There was a negative correlation between the children's age and the degree of parental satisfaction; therefore, the older the child, the lower degree of satisfaction shown by the parents (Table 4).

There was a statistically significant association between the parent's educational level and the degree of satisfaction they reported in all domains except the family domain (Table 5).

There were no statistically significant differences between the degree of satisfaction reported and the gender or age of the parents.

There was no statistically significant correlation between the degree of parental satisfaction and the existence of one or more siblings with ASD.

Discussion

Parents raising children with ASD often deal not only with their child's communicative, social, and behavioural deficits, but also with various additional stressful factors related to their child's

disorder. Because many of these factors tend to influence other life domains, such as marriage, family, and work, they are likely to interfere with the parents´ well-being[17].

Previous studies have found that parents of children with ASD show higher levels of stress, anxiety, depression, social isolation, and poorer physical health compared to the general population and even to parents of children with other chronic health conditions, such as Down syndrome or cerebral palsy[22].

Gentles et al. reported that the stress experienced by caregivers of children with ASD often resulted in depression, anxiety, and marital breakdown[22,23]. Indeed, along with other coping mechanisms, parents often use social withdrawal to avoid judgmental comments from the public and close relatives[6].

Given this impact on family and intimate relationships, it is not surprising that social support has been indicated as an important tool in dealing with the stress associated with caring for a child with ASD. Parents with strong social and emotional support systems, both inside and outside the family, report higher levels of happiness and well-being. However, research suggests that social isolation can intensify over time, as parents attend to the daily demands of their child and connect less with their close community[13,14,24].

Multiple studies have also found that formal and informal social support contributes to the mental health of caregivers of children with ASD. Since formal social support provided by healthcare professionals is generally paid for, it is important to establish a network of informal social support, such as peer support groups, religious groups, friends, and family members, which will act as a stress buffer from the daily challenges of caring for a child with ASD[22].

A review by Lai and Oei (2014) reported parent gender and age, child age, the changing nature of their child's challenging behaviours, time since diagnosis and cultural effects as the most important factors influencing how parents cope with ASD[7,20,25].

Although there were no statistically significant differences between the degree of satisfaction reported in our studies and the gender or age of the parents, in previous studies, however, mothers of children with ASD have reported employing more social support, problem-focused coping, and spiritual coping strategies than fathers of the same children. In contrast, fathers reported more emotional coping (e.g., suppressing frustrations and avoiding family problems by going to work) than mothers in the same family. Additionally, other studies comparing parenting stress and parenting responsibility between mothers and fathers of children with ASD reveal that mothers show higher levels of parenting responsibility than fathers and are significantly less likely to be employed full-time than fathers[26,27]. On the other hand, considering parents' age, younger parents of children with ASD have been reported to employ more problem-focused coping than older parents, while older parents of children with ASD engaged in more emotion-focused coping than young parents[20].

In our review, there was also a negative correlation between the children´s age and the degree of parental satisfaction. This was also verified in previous studies, where the effects of child´s age on parental and caregiver satisfaction were frequently reported[20,26]. One of the explanations presented by previous research was that parents of young children with autism often had expectations that their child would make substantial progress towards normality as they aged[20]. However, in most cases, the medical evolution of autism does not support this optimism, which translates into anxiety, frustration, social isolation and dissatisfaction in all key domains of the parents' life.

In our studies, there was also a statistically significant association between the parents' educational level and the degree of satisfaction reported by them in all domains except for the family domain. Previous studies showed that education is related to the well-being of parents of children with and without disabilities since higher education is positively related to parents' positive affect and negatively related to parents' negative affect. Moreover, education levels relate to family support and family resources[26]. Research conducted by Sharabi et al. found positive relations between mothers' and fathers' education and their social support and social involvement. Mothers and fathers with more than a high school education reported receiving more general support, formal support (specialized services), and informal support (informal kinship) than those with only an elementary or high school education. Both mothers and fathers with higher education reported greater social involvement than those with a lower level of education. In addition, the differences between mothers and fathers in collaboration and social involvement were found only in those with lower education, in favour of mothers.

In comparison, no differences were found between mothers and fathers with higher education. Beyond the differences between mothers' and fathers' involvement, differences within the group of fathers were revealed. Fathers with higher levels of education collaborated more and were more socially involved than those with lower levels of education. Among mothers, those with higher education levels were more socially involved than those with lower degrees of education[26].

Our data analysis showed that the relationship between ASD and parental satisfaction reported in each domain was not associated with statistically significant differences. However, previous studies reported that parents of children with more severe levels of ASD are less likely to experience social support, which increases their risk of negative mental health outcomes. This difference in social support's real or perceived availability may be due to a few factors. For example, informal social support systems, such as family members and friends, may be less likely to offer support, or parents may be more reluctant to solicit support when the child is severely affected. Parents may also perceive support as less available when their child is impaired. It may also reflect a difference in the needs of families with children with more significant impairments (i.e., parents of more impaired children may require more respite than parents of less impaired children)[20−24].

Reconciling the position of family caregivers with maintaining various roles and social relationships becomes a challenge for parents and often leads to tension and conflict11. Given this, having support is essential when adapting to and exercising the role of caregiver to a child with ASD, especially because this is a very vulnerable period for these families. Being able to rely on someone to vent and to get validation for their care efforts from friends and family is described throughout the studies as one of the most valuable manifestations of support for caregivers. In addition, research results indicate that caregivers experience many challenges, such as maintaining long-term relationships and emotional support. Therefore, developing strategies to help family caregivers and care recipients must be a focus of attention within the community[11].

According to our studies, the individualized analysis of the 4 dimensions that the study included showed that the degree of satisfaction of the parents with children with ASD is higher

regarding family, followed in descending order by friends, intimacy, and social activities. In fact, as pointed out in previous studies, family members are described as essential when caregivers reflect on the support they need. In addition, family and closest friends are referred to as a major source of psychological and organizational support. Thus, caregivers often report feeling alone and abandoned when this support system disappears or fails, noting that it should be offered without asking for it[11].

Conclusion

In conclusion, the results of the study point to the utility of interventions aimed at improving parents' support networks. Unfortunately, although a big variety of parental and family support interventions are employed within the autism field, very little is known about how these various interventions affect participants' social networks, their real and perceived levels of social support, and their overall psychological health.

Based on the study's results regarding the importance of parents´ informal social network, there needs to be a special attention focused on developing services that help parents effectively use the existing sources of support from family, friends, and other parents of children with ASD. Furthermore, it seems important and advisable that the interventions focus on strengthening each of the informal social supports because each one is associated (directly or indirectly) with unique sources of benefits to parents.

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Conflict of interest

There are no conflicts of interest to declare by any of the authors of this study.

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