

Availability, Quality of Perceived Social Support and Quality of Life of Parents of Children with Autism Spectrum Disorder

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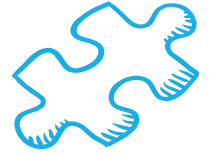
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Background



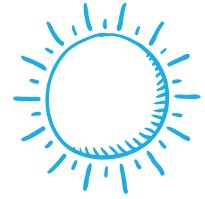
- The presence of an adequate and quality social support
 - Contributes to improve the parent's quality of life
 - Influences in a decisive way the well-being and health
 - Is associated to a better mental health and lower stress levels
- Studies done with parents with children with ASD show that they rarely receive the support level that they really need
 1. Daily care given to the child requires a lot of time and energy; therefore they need a high support level
 2. Appropriate resources are rare and often difficult to access

Social support

- Main forms of social support:
 1. Esteem support (ex., to encourage et reassure someone about his abilities)
 2. Informative support (ex., to offer information, advices or approbation)
 3. Emotional support (ex., to confess or talk about personal stuff)
 4. Material or financial support (ex., to offer material things, like money, rest, babysitting or help with domestic life)

- Different sources of social support (formal and informal):
 1. Colleagues
 2. Friends
 3. Family members
 4. Healthcare professionals





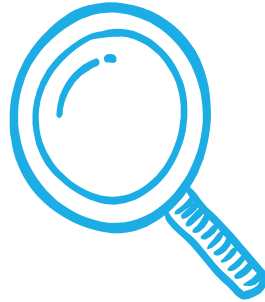
Quality of life

- Quality of life of parents of children with ASD is influenced
 1. By ASD characteristics and special needs of the child
 2. By transactional psychosocial variables like perceived social support, perceived stress, perceived control and coping strategies.

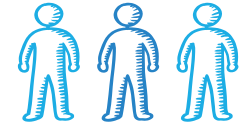
- Social support is an effective adaptation mechanism to face daily stress caused by the fact of being the parent of a child with special needs, such a child with ASD

Objectives

1. Describe the availability and the social support quality based on social support principal that forms (esteem, informative, emotional and material or financial)
1. Explore if there is associations between the availability, the social support quality, the scores obtained in the seven domains of the parent's quality of life and the global score of parent's quality of life



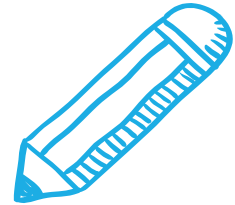
Participants



- 161 parents of children with ASD have participated in this study
 - 91.7 % are mothers
 - 8.3 % are fathers
- Average age of parents = 41 years old
- Parental situation
 - 81,6% live together (in a relationship or married)
 - 18,4% are single, separated, divorced, widowers or in another parental situation
- Time spent at work
 - 41,1% have a full-time job
 - 35,4% have a part-time job
 - 23,4% are at home, students, on welfare or retired
- Family income
 - 14,2% have an income lower than 35 000\$
 - 19,5% have an income between 35 000 and 50 000\$
 - 25,3% have an income between 50 000 and 80 000\$
 - 14,3% have an income between 80 000 and 100 000\$
 - 26,6% have an income higher than 100 000\$

Method

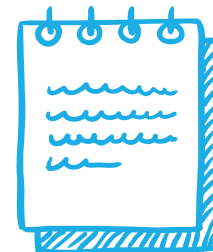
- Perceived Social Support Questionnaire (PSSQ)
 - Allows to evaluate perceived social support
 - Allows to establish two social support scores
 1. Availability (quantity) : Number of persons
 2. Quality : Level of satisfaction with the help obtained
- The higher the availability score is, the more the parents can count on an important number of persons to help them.
- The higher the satisfaction score is, the more the parents are satisfied of the help received from his surrounding (varies between 0 and 20)



Method

- Quality of life scale for parents with children with ASD
 - Allows to evaluate the consequences of an ASD diagnostic with 7 areas of parent's quality of life
 - Allows to establish a general score of quality of life and a score for each of the 7 areas of quality of life
 1. Daily activities
 2. Activities and professional relationships
 3. Activities and social relationships
 4. Activities, family and love relationships
 5. Activities and relations with the child with ASD
 6. Psychological well-being
 7. Self-fulfilment

- The higher the scores are, the more the child's difficulties have an impact on the daily life of his parent's



Results

- In average, parents have
 - 7 available people to offer esteem support
 - 4 available people to offer informative support
 - 5 available people to offer emotional support
 - 2 available people to offer material or financial support
- Thereby, the average number of available people varies between 2 for material support and 7 for esteem support
- Parents are usually satisfied of the support they received and that is true for the four principal forms of social support



Results

- Availability is significantly and positively associated to the quality of the social support
- Social support quality is significantly and negatively associated to
 - Daily activities
 - Activities and social relationships
 - Activities, family and love relationships
 - Activities and relations with the child with ASD
 - Global quality of life
- Thus, the more satisfied the parents are of the help they received from their surrounding, the less global quality of life they have

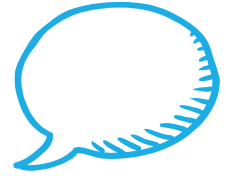


Discussion



- Important variation of the average number of available people according to the type of social support
 - Corroborates the results of Nader-Grosbois and Cappe (2015)
 - Average number of available people varies a lot
 - Availability changes according to the type of social support
 - 1,7 available persons for social support to 10 available persons for esteem support
- Family is the most important source for the three forms of social support, which are esteem support, emotional support and financial support
 - Supports the results of Poirier and des-Rivières-Pigeon (2013)
 - First place = common-law partner
 - Second place (at equal levels) = other children amongst the family and maternal grandparents

Discussion



- Healthcare professionals are the most important source of informative support
- The importance to evaluate the social support with quality over quantity
 - Corroborates the results of Siklos and Kerns (2006) and Cappe and Poirier (2014)
 - The most important element about mothers' well-being is their perception of the support given by the common-law partner, family and healthcare professionals
 - Importance of the satisfaction is about the received social support more than the availability of the social network

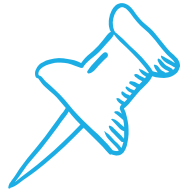
Discussion



- Significant and negative correlation between social support quality and-quality of life of parents
 - Supports the results of Belzil, Poirier and Cappe (2016)
 - The more satisfied the mothers are of the help they obtain from their social network, the less quality of life they have
 - This network doesn't count a lot of people
 - This network includes healthcare professionals
 - Opinions and recommendations from everyone around them negatively affect the parents' quality of life

Conclusion

- The help from the social network does not palliate the overload caused by having a child with ASD
- Parents don't have time for their daily activities and to maintain their social relationships (friendships, family and love relationships)
- Importance to bring support in the daily life of these parents, mostly for their child's cares (ex., an educator at home, respite services) to give them more social opportunities



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