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Assessing needs in parents of children with autism: a crucial preliminary step to target relevant issues for support programs

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Abstract

Background Raising a child with an autism spectrum disorder (ASD) implies significant stress levels and changes in family functioning. Most studies deal with parental difficulties whereas those focusing on parental self-reported support needs related to ASD are fewer, especially in France. Our objective is to explore in a French sample the needs of parents of children with ASD so as to provide recommendations for support.

Method Parents were interviewed (N=162 including 84 controls). A content analysis was performed.

Results Six dimensions of need emerged: material, information, guidance, daily management, relational support, and emotional support. Needs priorities are different for parents with ASD child involving the transmission of knowledge and skills as well as emotional and relational support. Our results should lead to recommendations for the selection of relevant topics to support parents of children with ASD.

Conclusions This study highlights the need to develop support programs focused on the needs of the parents that reflect educational, behavioural and psychological dimensions.

Keywords: Autism Spectrum Disorders (ASD); parenting needs; parents support; therapeutic education

Introduction

Autism Spectrum Disorders (ASD) are characterized by qualitative impairments in social interaction and in communication modalities, as well as restricted and repetitive activities and interests (American Psychiatric Association, 2013). These anomalies have a significant lifelong impact not only on the development of the individual but also on the family environment (Gau et al., 2012; Harper, Dyches, Harper, Roper, & South, 2013; N. Johnson, Frenn, Feetham, & Simpson, 2011). Parents often have to manage difficult symptoms such as sleeping and eating problems, behavioural disorders and stereotypies (Humphreys et al., 2014; K. P. Johnson, Giannotti, & Cortesi, 2009; Martins, Young, & Robson, 2008; Williams, Dalrymple, & Neal, 2000). In addition, they are faced with the child's lack of social reciprocity, which not only hinders learning but also limits emotional sharing. The impact of ASD is multidimensional as it relates not only to the financial, social, and professional spheres but also to the physical and mental health of parents (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Parents report significant stress levels (Eisenhower, Baker, & Blacher, 2005; Estes et al., 2009; Harper et al., 2013; N. Johnson et al., 2011) and are more likely to have anxiety and depressive disorders (Barker et al., 2011; Piven & Palmer, 1999). The whole family interaction and communication pattern are reshaped (Gau et al., 2012; Hahaut, Castagna, & Vervier, 2002; Hartley et al., 2010). The disorder also frequently leads to the social isolation of parents caused by the lack of time they can devote to activities outside the family but also by the avoidance strategies they may adopt to cope with the stigma (Divan et al., 2012; Gray, 2001).

In this context, a complex dynamic of self-maintenance of the disorder can set in which problems of parental adjustment and the clinical expression of the child's disorder influence each other (Burrell & Borrego, 2012). There is then a greater risk that the parent drops out of the care system and / or that the child derives less benefit from the care he/she is already

receiving (Llewellyn, 2005). Therefore, the best way to ensure a consistent course of care is to consider carefully the parental support once the diagnosis is made by accurately assessing the needs of fathers and mothers.

Studies to date have emphasized different needs areas for parents who have a child with developmental disability. Most of them have used Family Needs Survey questionnaire (Bailey & Simeonsson, 1988) which explores several categories of needs such as information, family and social support, financial, explaining to others, child care, professional support, and community services.

First, results of studies revealed the need for parents to be better informed by professionals about their children's disorder and to receive appropriate support (Brown, Ouellette-Kuntz, Hunter, Kelley, & Cobigo, 2012; Ellis et al., 2002; Hahaut et al., 2002; Papageorgiou & Kalyva, 2010; Siklos & Kerns, 2006; Whitaker, 2002). This seems especially important when the diagnosis is disclosed (Whitaker, 2002). In this regard, Hahaut et al. (2002) evaluated parental satisfaction about the information they received about the disease and the possibilities of receiving support. In most cases (87.5%, N=16), parents showed little or no satisfaction with the information provided about the disease and 62.5% were not satisfied by the opportunities for receiving support. The lack of information also concerned procedures for accessing services (Divan et al., 2012; F. K. Kohler, 1999; Siklos & Kerns, 2006) and the progress made by their children (Siklos & Kerns, 2006).

Parents also expressed a need to participate more actively in supporting their children (Siklos & Kerns, 2006). Some wished to be trained in techniques for managing the disorder, often in a context of poor collaboration and a lack of coordination between parents and professionals (Ahmadi, sharifi, Zalani, bolouk, & Amrai, 2011; Ellis et al., 2002; Granlund & Roll-Pettersson, 2001; Kohler, 1999; Papageorgiou & Kalyva, 2010; Safe, Joosten, & Molineux, 2012; Siklos & Kerns, 2006; Toomey, Chien, Elliott, Ratner, & Schuster, 2013; Volkmar,

Cook, Pomeroy, Realmuto, & Tanguay, 1999). In addition, parents expressed the wish to spend more time with their friends and communicate more effectively with their entourage (Ahmadi, sharifi, Zalani, bolouk, & Amrai, 2011; Bailey & Simeonsson, 1988; Papageorgiou & Kalyva, 2010).

Mothers and fathers reported the need to meet other parents of ASD children to share tips, experiences and restore parental confidence (Papageorgiou & Kalyva, 2010). Parents may also express a need to be helped to manage their fear about child's future (Ahmadi et al., 2011).

According to Papageorgiou and Kalyva (2010), the three main reasons why parents participate in support groups are: (1) need to be informed about ASD (64.5%), (2) need to receive practical help to develop the child's autonomy (19.5%), (3) need to meet and talk with other parents (8%) or benefit from counseling (3%).

Papageorgiou and Kalyva (2010) found that the types of needs reported by parents were influenced by their level of education, and sex and age of their children, while there were no differences in the type of occupation of the parents. Several studies also indicate that the health context and care available for children and parents could influence the expressed needs. The studies of Siklos and Kern (2006) conducted in Canada and those of Ahmadi et al. (2011) conducted in Iran showed differences in parenting needs, despite using the same research methodology. Thus, it seems that parents of children with ASD living in Canada have more needs associated with the management of their child while the Iranian parents were more concerned by needs related to social and family life. Kalyva and Papageorgiou (2010) emphasize the need to survey parents who participate in support groups and those receiving no support. Finally, Gau et al. (2012) note that the educational principles and requirements are not the same in different countries and cultures, and that this can certainly influence the difficulties experienced and reported by parents.

At present, knowledge of the needs faced by parents of children with ASD remains fragmented and is based on a few empirical studies, whose results are difficult to generalize to French context. Different parenting needs have been identified, mostly from questionnaires defined a priori by experts. To refine our understanding and obtain a more ecological assessment of their requirements, it seems essential to listen to what parents say. Then, according to Safe et al (2012), it is very important to consider parents' needs in different aspects of their lives, including those that were not directly related to their autistic child; this aspect is lacking in previous studies.

According to Albanese et al (1996), it is essential to develop this area of research so as to specify the provision of care and improve the quality of support for caregivers in France, in order to offer services in line with their expectations.

In addition, parents' support must aim for supporting the parenting process and to promote the commitment of parents. The challenge is also to prevent the emergence of a dysfunctional parent-child dynamic that would negatively impact the mental health of the parent and the clinical expression of the child's disorder. It is also important from a medico-economic perspective because the costs are mainly related to the impact on families and not to the management of patients. World Health Organisation guidelines states that "the repercussions faced by the families' emotional cost in care of disabled family members reduced quality of life, social exclusion, and stigmatization" (World Health Organisation, 2004, p.2).

Therefore, the main objective of this study was to explore the needs of parents of children with ASD in a French sample in order to identify areas of need and prioritize them. These results should lead to recommendations for the selection of relevant topics to support parents of children with ASD in practical way.

Method

Participants

This study concerned parents of children with ASD (clinical group) and parents of typically developing children (control group). All children were aged between 3 and 10 years. All participants were the biological parents, i.e. father and mother. The subjects included in the clinical group were parents of a child with ASD. The diagnosis was made by a professional using tools (The Autism Diagnostic Interview-Revised, Le Couteur et al., 1989; Autism Diagnostic Observation Schedule, Lord, Rutter, DiLavore, & Risi, 1999) recommended by the High Health Authority (Haute Autorité de Santé, 2005) and according to the criteria of international classifications (American Psychiatric Association, 2013). The presence of a neurological or genetic disease associated with the diagnosis of ASD was an exclusion criterion. The presence of a childhood psychiatric disorder and/or developmental disorder according to DSM-5 was an exclusion criterion for the control group. The clinical group was recruited in five centers specializing in the diagnosis of ASD, seven parents' associations, five centers providing care to children and in two schools. The control subjects were recruited from four schools at nursery and primary level, two of which were the same as for the clinical group. We recruited participants in different locations in order to have a representative sample of several socio-economic levels and cultural differences. There were a total of 21 recruiting centers over a period of one year from February 2012 to February 2013.

Study Design and ethical considerations

An explorative qualitative design was chosen for this study. An information letter and a consent form were sent out by education professionals and health. Each participant was

contacted for an interview. The research was prospectively approved by an independent protection committee.

Data Collection

Semi-structured interviews were conducted to collect qualitative data on parental needs. All interviews were performed by one psychologist and two psychology students (master degree) trained in this technique. Open questions were formulated to generate a conversation about the parents' needs. They were interviewed about three themes: (1) the child's profile; (2) everyday life with the child; (3) parental support.

For each theme, the interviewer had encouraged parents to speak about their experiences, the lacks identified and their needs and expectations in order to see intervention priorities and possible improvements.

Informants were asked to provide examples and elaborate or clarify their initial statements when appropriate (e.g. Do you have further examples of this? What do you mean by that?).

The investigator sought to develop what was said by asking other questions, if necessary.

The interview durations ranged from 15 to 60 minutes and formed the basis of a detailed report.

Data Analysis

A report of parents' responses for the three themes had been written after each interview based on the referential level of discourse (Blanchet, 1997), i.e. that what parents said about facts. Thus, some parents' sentences verbatim were put in reports. Content analysis was performed from these reports. All the interview reports were read several times, and analyzed by qualitative conventional content analysis according to Graneheim & Lundman (2004).

Qualitative data from the interviews were analyzed using the © Nvivo10 software.

The following steps were undertaken in the interviews data analysis.

- 1) Writing a report immediately after the interview. A data collection form was built for this purpose.
- 2) Preliminary reading of raw data, to go through the transcripts line by line and paragraph by paragraph, looking for significant statements and codes according to the topics addressed.
- 3) Identification of the relevant text segments related to the objectives of the research and labeling them to create categories.

The categories were created by consensus between 2 psychologists and 1 psychology student (master degree). Then, the reports were read and coded independently by 2 external researchers as well. A dual listing was carried out on twenty interviews in order to calculate inter-observer agreement with Cohen's kappa coefficient ($\kappa = .89$).

Furthermore, in order to increase transferability of the findings, the parents were recruited from several contexts (schools, parents' association, care center).

Three levels of coding selected as appropriate for coding the data.

Level 1 coding examined the data line by line and the key words and important phrases (Meaning units) in the text were noted.

Level 2 coding which was a comparing of meaning units and the creation of categories.

Categories were simply coded data that seem to cluster together and may result from condensing of level 1 code. Similar meaning units were put in one category with the same title, and formed subthemes.

Level 3 coding which concerned the title given to the central themes that emerge from the categories.

At the end, the main themes were emerged and finally 23 subthemes and 6 themes were created.

Descriptive Statistics

All statistical analyses were performed using SPSS 20 ©. Student's t tests of independent samples were used to compare the two groups on a set of socio-demographic variables. The homogeneity of variances was tested for each analysis (Levene test). In the event of non-homogeneous variances, a Welch test was performed in order to interpret the results. In addition, frequency comparisons on dimensions required were performed using the Pearson Chi Square test.

Cramer's V (for Chi square) and Cohen's d (for Student t test) were indicated for measure of strength of the relationship.

Results

Characteristics of sample

As presented in Table 1 our sample included 162 parents, 50 families of children with ASD and 56 control families. All participants were the biological parents. In most cases, the father and mother of the child participated in the study.

There were no significant group differences in parents' age, children's age, parents' gender, parents' occupational category and number of siblings. There was a higher percentage of boys in the ASD group than the controls; males were overrepresented in the ASD population owing to the sex ratio described in these pathologies (Investigators & Centers for Disease Control and Prevention, 2012). Unemployed parents were more in ASD group than in the control families. Finally, it is important to mention that no parent in ASD group went to parent training, family therapy or parent support group.

<Please insert Table 1 about here>

Domains identified

Analysis of the interviews identified the six areas of need shown in Figure 1. Examples of meaning units, categories and themes are presented in Table 2.

Material needs correspond to all concrete elements (objects, professionals, and institutions) necessary for parents to ensure a stable environment conducive to the healthy development of their child. This dimension has three sub-dimensions: financial need, the need for trained professionals, and the need for appropriate institutions.

Need for information refers to the body of knowledge necessary for parents to understand and adjust emotionally and behaviourally to their child. This dimension has six areas of information: the development and functioning of the child, education, administrative procedures, management of the child, diagnosis, and finally the need to be trained.

The need for parental guidance is the development of parenting skills to better fit the behaviour and emotions of the child at home while supporting the learning process. This dimension refers to three main areas: educational assistance (behaviour management and child anxiety, skills development, independence and social skills), management of relationships between siblings, and to be regularly reassured about one's parenting (need for feedback).

Daily management needs concern the logistical support required to harmoniously share out the temporal and emotional investment of parents in the various spheres of their life. This dimension is divided into four sub-dimensions: family life, married life, extra-family life (leisure, social life), working life.

The need for relational support reflects the parents' request for assistance so that they may develop more satisfying relationships with others. This refers to social and close relations, relationships in the couple (communication, emotional sharing), family relationships (siblings, parents and in-laws), and the relationship with the child, without there is necessarily being an educational learning objective involved.

Finally, the need for emotional support refers to the need to be accompanied and supported from an emotional point of view. This dimension include three forms of support: sharing experiences with others parents, support from family and friends, and finally the psychological support provided by a professional.

The results had shown the need for support on three levels: educational, behavioural, and psychological.

Main needs according to group

The parents of ASD children had reported significantly more needs than control parents in the following areas: material, information, parental guidance and emotional support. In contrast, there were no significant differences between the two groups for "daily management" and

"relational support" areas. Pearson Chi Square tests were performed for each needs areas and there were no differences according to the child's gender, in both groups. The main needs areas of the parents of ASD children were different from those reported by controls. The three priority areas identified by ASD children's parents were material need, the need of information and need of parental guidance. The three most important areas for controls were the need for assistance in daily management, material needs, and relational support.

Comparisons of frequencies per area per group are shown in Table 3.

<Please insert Figure 1 about here>

<Please insert Table 2 about here>

<Please insert Table 3 about here>

Discussion

We sought to explore the needs of French parents of children with ASD in order to identify relevant targets for supporting them. The thematic analysis of interviews that we used is an original methodology with the advantage of being closer to the needs of parents, allowing direct practical answers to be provided. Six areas of need were identified and included both the ASD and control children's parents. These categories each refer to five dimensions associated with parenting and involved in the parenting process: (1) knowledge (information need), (2) skills (parental guidance need - need for help in daily management), (3) trust (need for emotional support), (4) social network (need for relational support), and (5) material resources (material needs).

The results support the idea that being a parent means having knowledge about the child, being able to identify his physiological and emotional needs and to make sense of them. It also means being able to implement expertise and logistics, educational and interpersonal skills in order to best support his development. To do this, parents must feel a certain level of confidence in their parenting skills. The social and institutional network is an essential pillar that supports parenting by providing an educational and emotional framework. Finally, on a more concrete level, parents have a number of material resources available to ensure a secure and safe environment for their child.

Parents of ASD children have to try out all these dimensions associated with parenthood as much as any other type of parents. Nevertheless, the presence of ASD seems to accentuate certain needs in each of these areas. By highlighting these characteristics, this study has the potential to provide insights into support for parents. It points to needs and suggests concrete pathways in terms of format, objectives and themes that may be included in the support programs offered to parents of ASD children in France.

Framework and objectives of support

Parents of children with ASD reported mainly needing additional material resources, information and educational guidance. They found daily management difficult but this element did not distinguish them from control parents. They did not report the need for relational and emotional support to be a priority but it was specific to parents of ASD children.

The priorities they reported first underline their own need of support from professionals. It seems advisable that this support should be based on several methods of intervention to meet their diverse needs, while providing a holistic parent-centered approach. The aim is not only to make parents sufficiently competent so that they can play a satisfying role in the development of their child, but also to support the various aspects related to parenting. This is particularly important because it has been shown that parental stress could tend to increase in intensive psycho-educational programs where the parent acts alone as a co-therapist (Brookman-Frazer, 2004; Eiserman, 1995). Then, as mentioned by Safe (2012), parents could experiment difficulties to be a cotherapist for their children. So having knowledge and skills related to ASD does not seem to be enough for parents to feel sufficiently assured in their roles and decisions vis-à-vis their child.

Therefore, it is essential for the support of parents to cover all dimensions related to parenting (Safe, Joosten, & Molineux, 2012). In practice, it does not seem appropriate to provide emotional support before ensuring that parents have sufficient information and material support at their disposal. On the other hand, providing appropriate group support for the highest priority needs would promote relational and emotional support and the emergence of a group identity. Indeed, multifamily groups are conducive to the creation of a social network allowing the state of isolation to be broken down and leading to de-stigmatization (Asen, 2002).

Points discussed with parents

A single program to help parents is not sufficient to meet all the needs identified in this study. This is particularly the case for material needs, thus revealing gaps concerning the recognition and support of people with autism in France.

As pointed in previous study (Bailey & Simeonsson, 1988), the financial difficulties faced by parents concern the purchase of suitable equipment, the payment of specialized services and funding for leisure activities outside the family. In addition, French parents often complain about the non-funding of psycho-education by public authorities, which often is paid for entirely by the family. They also point to the lack of adequate facilities to cater for the specificities of their children, including relay institutions allowing them to get some respite at weekends. This point was highlighted in the studies by Siklos and Kern (2006), Ahmadi (2011), and Brown et al (2012) as being one of the most important needs for parents.

So, to assist parents, it is important to take into account physical constraints, allowing them to choose the right course of care for their child from among the different types of support available.

In addition, they need help to identify the right professionals for undertaking the administrative procedures for obtaining the financial support they deserve. The information provided to families should therefore focus on the procedures for accessing services (Divan et al., 2012; F. W. Kohler, 1999; Siklos & Kerns, 2006) as well as the pathology itself and how it can be managed (Auert, Trembath, Arciuli, & Thomas, 2012; Hahaut et al., 2002; F. W. Kohler, 1999; Mockett, Khan, & Theodosiou, 2011; Papageorgiou & Kalyva, 2010; Siklos & Kerns, 2006).

Parents say they are insufficiently informed about their child's condition and are insufficiency aware of the symptoms, causes, prognosis and management of the disorder. In addition to the information provided, it is important to offer parents scope to discuss their experiences and

emotions vis-à-vis the sacrifices and adjustments that they face daily. Communication within the family and with friends is a recurrent concern in a context of frequent social isolation (Bailey & Simeonsson, 1988; Divan et al., 2012; Safe et al., 2012). Similarly the issue of sharing emotions within couples is often cited by mothers and fathers. Finally, the way society looks upon the child and the parents is painful and could form the basis of constructive discussion between parents and professionals to prevent the risk of stigmatization.

From an educational point of view, the support given to parents should also include expertise to help them better manage their child's condition and help them identify their own resources. Whenever parents have the opportunity to learn and implement new educational skills, there is an increase in positive feelings (Koegel, Bimbela, & Schreibman, 1996; Solomon, Ozonoff, Carter, & Caplan, 2008), stress levels are reduced (Symon, 2001), and an improvement in self-efficacy (Feldman & Werner, 2002). Other specific themes that could benefit from specific help relate to the management of challenging behaviours such as anxiety, stereotypies, and hetero- and self-aggression. Another issue concerns the attitude to adopt towards the child with a behavioural disorder, what that form of behaviour means and how to prevent its occurrence.

Promoting child's autonomy and the development of social skills is also a common concern. In this regard, parental guidance is felt to be one of the most important needs in some countries (Ahmadi et al., 2011; Papageorgiou & Kalyva, 2010) but is not mentioned as a priority in others (Siklos & Kerns, 2006). This highlights how needs vary between different countries and cultures (Gau et al., 2012), which reflects not only the quality of the system of care for ASD children and their families but also social representations related to parenting. In this context, adapting support programs based on identified needs increases the likelihood of developing a positive therapeutic alliance and adherence on the part of parents.

Limitations of study

Limitations of the study include the representativeness of the sample and generalization of our results. In the future, the two groups should be matched on all socio-demographic data including working time and gender of the child. Indeed, the working time can potentially influence the needs reported by parents since it is associated with the economic status of the family which can hinder or facilitate access to information. In addition, by matching our two groups according to the gender of the child, there would be more control over the impact of this variable on the needs reported. This seems all the more important since differences have been identified in parents of children with ASD regarding their expectations of support if they have a son or a daughter (Papageorgiou & Kalyva, 2010). Control of the impact of the children chronological age distribution and ASD severity could be also a new direction of research with a larger sample. Indeed, these variables can imply changes in parental stress and needs as shown as previous studies (Brown, Ouellette-Kuntz, Hunter, Kelley, & Cobigo, 2012).

Also, some parents of the same child (mother and father) make up our sample. This item may be a bias in our results because some needs may be over-represented. However, the two groups are composed of the same proportion of such respondents, which leads us to believe that the bias is present for the 2 groups.

Despite the presence of bias due to the nature of our sample, it is important to note there was a large proportion of fathers among the respondents. This is very interesting because, as noted by Pelchat (2012) too many studies focus on the point of view of mothers whereas support is important for both parents.

To examine the real needs faced by parents, we adopted a qualitative approach by using semi-structured interviews. This methodology has the advantage of collecting the actual responses

of families without inducing categories of need defined a priori. However, it does not have the same psychometric qualities and a questionnaire may be biased both at the time the interviews are conducted and when the responses are encoded. We tried to circumvent these biases by defining a set of themes and by having several interviewers simultaneously conduct the interviews. In addition, a dual listing was conducted for twenty interviews with a good Kappa coefficient.

On the other hand, analyzes are based on reports which may be objectionable. The reports are written according the referential level of discourse (Blanchet, 1997), i.e. that what parents say about facts. When it was possible parents' sentences were noted instead of the word of the interviewers. That is why, we believe that this way of doing things has saved us time while not changing the meaning of the parent's word.

Concerning the analysis of the results, it would be interesting in the future to consider variables such as the time elapsed since the disclosure of the diagnosis or the presence of mental retardation associated with the primary diagnosis of ASD. Indeed, the needs might be different depending on whether the parent received the diagnosis a few months or several years beforehand. Furthermore, the presence of developmental delay is known to increase the risk that the child has behavioural problems (Medeiros, Kozlowski, Beighley, Rojahn, & Matson, 2012). This variable should be taken into account since the management of behavioural problems was one of the main requirements put forward by the parents.

This is the first study conducted in the French population, as far as we knew, regarding the needs of parents of children with ASD. We adopted a qualitative approach to gain an in-depth understanding of parental needs and support expectations to propose new elements and strategies for supporting them.

It demonstrates the range of needs experienced by parents and the fact that they should receive appropriate and multimodal support as soon as the diagnosis is disclosed. The findings throw light on how to prioritize support and can thus serve as a starting point to develop a support program taking into account the specificities of such parents. The themes and subthemes of needs highlighted in this study would help professionals to define specific and new targets for parents' support programs. First, we emphasize the importance of providing multimodal support by combining educational, psychological and behavioural approaches consistent with their range of needs. The priorities are to inform, guide, support and listen to parents with regard to educational, affective and relational dimensions.

The parent must be considered as a person with needs and expectations at the center of an ecosystem in which several contexts interact: walks of life (school, work, family, friends, etc.), the organisation of care and services (quality, availability, accessibility, continuity) and norms, values, and societal representations (Bronfenbrenner, 1979).

The objective of support is to combine these different aspects in order to allow the parent to play an active role in restoring a more harmonious family dynamic and preventing the risk of isolation and stigmatization. In this context, the contribution of therapeutic education and especially the model of multifamily psychoeducation offer interesting avenues for developing support for parents of children with ASD.

References

- Ahmadi, A., sharifi, E., Zalani, H. A., bolouk, S., & Amrai, K. (2011). The needs of iranian families of children with autism spectrum disorder, cross-cultural study. *Procedia - Social and Behavioral Sciences*, *15*, 321-326. doi:10.1016/j.sbspro.2011.03.094
- Albanese, A. L., San Miguel, S. K., & Koegel, R. L. (1996). Social support for families. In *Teaching Children With Autism: Strategies for Initiating Positive Interactions and Improving Learning Opportunities*.
- American Psychiatric Association (Éd.). (2013). *Diagnostic and statistical manual of mental disorders (5th ed)* (Washington, DC: Author.).
- Auert, E.-J., Trembath, D., Arciuli, J., & Thomas, D. (2012). Parents' expectations, awareness, and experiences of accessing evidence-based speech-language pathology services for their children with autism. *International journal of speech-language pathology*, *14*(2), 109-118. doi:10.3109/17549507.2011.652673
- Bailey, D. B., & Simeonsson, R. J. (1988). Assessing needs of families with handicapped infants. *The Journal of Special Education*, *22*(1), 117-127.
doi:10.1177/002246698802200113
- Barker, E. T., Hartley, S. L., Seltzer, M. M., Floyd, F. J., Greenberg, J. S., & Orsmond, G. I. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology*, *47*(2), 551-561. doi:10.1037/a0021268
- Blanchet, A. (1997). *Dire et faire dire: l'entretien* (Masson / Armand Colin.). Paris.
- Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design* (Cambridge, MA: Harvard University Press.).

- Brookman-Fraee, L. (2004). Using parent/clinician partnerships in parent education programs for children with autism. *Journal of Positive Behavior Interventions*, 6(4), 195-213.
- Brown, H. K., Ouellette-Kuntz, H., Hunter, D., Kelley, E., & Cobigo, V. (2012). Unmet needs of families of school-aged children with an autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities: JARID*, 25(6), 497-508.
doi:10.1111/j.1468-3148.2012.00692.x
- Burrell, T. L., & Borrego, J. J. (2012). Parents' Involvement in ASD Treatment: What Is Their Role? *Cognitive and Behavioral Practice*. doi:10.1016/j.cbpra.2011.04.003
- Divan, G., Vajaratkar, V., Desai, M. U., Strik-Lievers, L., & Patel, V. (2012). Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism research: official journal of the International Society for Autism Research*, 5(3), 190-200. doi:10.1002/aur.1225
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community mental health journal*, 37(1), 39-52.
- Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool Children with Intellectual Disability: Syndrome Specificity, Behaviour Problems, and Maternal Well-Being. *Journal of Intellectual Disability Research*, 49(9), 657-671.
- Eiserman, W. D. W., Claudia. (1995). Parent and professional roles in early intervention: A longitudinal comparison of the effects of... *Journal of Special Education*, 29(1), 20.
- Ellis, J. T., Luiselli, J. K., Amirault, D., Byrne, S., O'Malley-Cannon, B., Taras, M., ...
Sisson, R. W. (2002). Families of Children with Developmental Disabilities:
Assessment and Comparison of Self-Reported Needs in Relation to Situational

Variables. *Journal of Developmental and Physical Disabilities*, 14(2), 191-202.

doi:10.1023/A:1015223615529

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.-H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism: The International Journal of Research and Practice*, 13(4), 375-387. doi:10.1177/1362361309105658

Gau, S. S.-F., Chou, M.-C., Chiang, H.-L., Lee, J.-C., Wong, C.-C., Chou, W.-J., & Wu, Y.-Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6(1), 263-270.

doi:10.1016/j.rasd.2011.05.007

Graneheim, U. ., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112. doi:10.1016/j.nedt.2003.10.001

Gray, D. E. (2001). Accommodation, resistance and transcendence: three narratives of autism. *Social Science & Medicine*, 53(9), 1247-1257. doi:10.1016/S0277-9536(00)00424-X

Hahaut, V., Castagna, M., & Vervier, J. F. (2002). Autisme et qualité de vie des familles. *Louvain Med.*, 121, 20-30.

Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*. doi:10.1007/s10803-013-1812-0

Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449-457.

doi:10.1037/a0019847

Haute Autorité de Santé. (2005). *Recommandations pour la pratique professionnelle du diagnostic de l'autisme.*

Humphreys, J. S., Gringras, P., Blair, P. S., Scott, N., Henderson, J., Fleming, P. J., & Emond, A. M. (2014). Sleep patterns in children with autistic spectrum disorders: a prospective cohort study. *Archives of Disease in Childhood, 99*(2), 114-118.
doi:10.1136/archdischild-2013-304083

Investigators, A. and D. D. M. N. S. Y. 2008 P., & Centers for Disease Control and Prevention. (2012). *Prevalence of autism spectrum disorders - autism and developmental disabilities monitoring network, 14 sites, United States, 2008* (p. 1-19).
Consulté à l'adresse <http://www.ncbi.nlm.nih.gov/pubmed/22456193>

Johnson, K. P., Giannotti, F., & Cortesi, F. (2009). Sleep Patterns in Autism Spectrum Disorders. *Child and Adolescent Psychiatric Clinics of North America, 18*(4), 917-928. doi:10.1016/j.chc.2009.04.001

Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: Parenting stress, family functioning and health-related quality of life. *Families, Systems, & Health, 29*(3), 232-252. doi:10.1037/a0025341

Koegel, R. L., Bimbela, A., & Schreibman, L. (1996). Collateral effects of parent training on family interactions. *Journal of Autism and Developmental Disorders, 26*(3), 347-359.
doi:10.1007/bf02172479

Kohler, F. K. (1999). Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disabilities, 14*, 150-158.

Kohler, F. W. (1999). Examining the Services Received by Young Children with Autism and Their Families: A Survey of Parent Responses. *Focus on Autism & Other Developmental Disabilities, 14*(3), 150.

- Le Couteur, A., Rutter, M., Lord, C., Rios, P., Robertson, S., Holdgrafer, M., & McLennan, J. (1989). Autism diagnostic interview: a standardized investigator-based instrument. *Journal of Autism and Developmental Disorders, 19*(3), 363-387.
- Llewellyn, G. (2005). Out-of-home Placement of School-age Children with Disabilities and High Support Needs. *Journal of Applied Research in Intellectual Disabilities, 18*(1), 1-6. doi:10.1111/j.1468-3148.2004.00201.x
- Lord, C., Rutter, M., DiLavore, P. ., & Risi, S. (1999). *Autism Diagnostic Observation Schedule-WPS (ADOS-WPS)*, (CA: Western Psychological Services.). Los Angeles.
- Martins, Y., Young, R., & Robson, D. (2008). Feeding and Eating Behaviors in Children with Autism and Typically Developing Children. *Journal of Autism and Developmental Disorders, 38*(10), 1878-1887. doi:10.1007/s10803-008-0583-5
- Medeiros, K., Kozlowski, A. M., Beighley, J. S., Rojahn, J., & Matson, J. L. (2012). The effects of developmental quotient and diagnostic criteria on challenging behaviors in toddlers with developmental disabilities. *Research in Developmental Disabilities, 33*(4), 1110-1116. doi:10.1016/j.ridd.2012.02.005
- Mockett, M., Khan, J., & Theodosiou, L. (2011). Parental Perceptions of a Manchester Service for Autistic Spectrum Disorders. *International Journal of Family Medicine, 2011*. doi:10.1155/2011/601979
- Papageorgiou, V., & Kalyva, E. (2010). Self-reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups. *Research in Autism Spectrum Disorders, 4*(4), 653-660. doi:10.1016/j.rasd.2010.01.001
- Pelchat, D. (2012). *Reconstruire la vie: défi et espoir pour les pères et les mères d'un enfant ayant un problème de santé*. Guérin universitaire.

- Piven, J., & Palmer, P. (1999). Psychiatric disorder and the broad autism phenotype: evidence from a family study of multiple-incidence autism families. *The American Journal of Psychiatry*, *156*(4), 557-63.
- Safe, A., Joosten, A., & Molineux, M. (2012). The experiences of mothers of children with autism: managing multiple roles. *Journal of Intellectual & Developmental Disability*, *37*(4), 294-302. doi:10.3109/13668250.2012.736614
- Siklos, S., & Kerns, K. (2006). Assessing Need for Social Support in Parents of Children with Autism and Down Syndrome. *Journal of Autism and Developmental Disorders*, *36*(7), 921-933. doi:10.1007/s10803-006-0129-7
- Solomon, M., Ozonoff, S., Carter, C., & Caplan, R. (2008). Formal thought disorder and the autism spectrum: relationship with symptoms, executive control, and anxiety. *Journal of Autism and Developmental Disorders*, *38*(8), 1474-84. doi:10.1007/s10803-007-0526-6
- Symon, J. B. (2001). Parent Education for Autism Issues in Providing Services at a Distance. *Journal of Positive Behavior Interventions*, *3*(3), 160-174.
doi:10.1177/109830070100300304
- Whitaker, P. (2002). Supporting families of preschool children with autism: what parents want and what helps. *Autism: The International Journal of Research and Practice*, *6*(4), 411-426.
- Williams, P. G., Dalrymple, N., & Neal, J. (2000). Eating habits of children with autism. *Pediatric Nursing*, *26*(3), 259-64.

Table 1. Sample characteristics

Variables	Controls (N=84) Mean ± SD or %	ASD (N=78) Mean ± SD or %	Student t test or Chi-square statistics
Gender, n (%)			$\chi^2(1) = 1.063, p = .302, v = .081$
Female	53 (63.1)	43 (55.1)	
male	31 (36.9)	35 (44.9)	
Current age (in years) [min-max]	37.3 ± 4.4 [29-47]	38.5 ± 5.3 [29-60]	$t(160) = -1.660, p = .099, d = 0.25$
Respondents, n (%)			$\chi^2(2) = 3.88, p = .143, v = .155$
Mother and father	56 (66.8)	57 (73)	
Only mother response	24 (28.5)	14 (18)	
Only father response	4 (4.7)	7 (9)	
Household with two parents	79 (94)	73 (96)	$\chi^2(1) = .338, p = .561, v = .046$
Occupational category			$\chi^2(2) = 4.73, p < .094, v = .181$
Managers (self-employed)	11 (13.4)	15 (19)	
White-collar workers (executives)	33 (39)	17 (22.2)	
Blue-collar workers	40 (47.5)	46 (58.8)	
Working time (based on 35h per week)			$\chi^2(2) = 23.31, p < .001^{***}, v = .379$
unemployed	1 (1.2)	18 (23.1)	
Part-time	18 (21.5)	23 (29.5)	
Full-time	65 (77.3)	37 (47.4)	
ASD child's gender, n (%)			$\chi^2(1) = 9.974, p = .002^{**}, v = .307$
Girl	29 (51.7)	11 (22)	
Boy	27 (48.3)	39 (78)	
ASD child age (in years) [min-max]	6 ± 1.9 [3-10]	6.3 ± 2.4 [3-10]	$t(90.8) = -.977, p = .331, d = 0.14$
Child diagnosis			
Autism	-	18 (35.9)	
Asperger's syndrome	-	3 (6.4)	
PDD-nos	-	29 (57.7)	
Number of siblings	1 ± .661 [0-2]	1.04 ± .947 [0-4]	$t(104) = -.254, p = .800, d = 0.049$

Note. SD, standard deviation; v , Cramer's v ; d , Cohen's d ; PDD-nos: Pervasive Developmental Disorders-Not Otherwise Specified; ***: $p < .001$; **: $p < .01$

Table 2. Examples of three levels of coding

Level I: Meaning Unit	Level II: Categories	Level III: Theme
I would like to find psychologists specialized in ABA	Trained professionals	Material
Where to look for adapted leisure for my child?	Appropriate institutions	
What are the administrative procedures for financial aid?	Financial	
Can autism be cured?	Diagnosis	Information
I would like to find training for parents.	Parent Training	
What are the relevant therapies for children with ASD?	Health Care provider	
How to complete files for a teaching assistant?	Administrative procedures	
To know the different places where my child can be educated.	Child's education	
I'd like to understand the different stages of language development.	Child's development and functioning	Relational Support
Improve communication with my wife.	Relationships in the couple	
Help to share fun time with my child without educational objective.	Relationships with the child	
Improve the emotional sharing with my parents.	Family relationships	
Help to explain my child's disorder to my friends.	Social and close relations	
I would like to begin psychotherapy to cope with my child's disorder.	Psychological support	Emotional Support
I am very isolated, I would like to be understood by my friends and tell them about my problems.	Support from family and friends	
It would be nice to share tips with other parents who are experiencing the same problems as me.	Sharing experiences with others parents	
How to respond when my child has a seizure?	Educational assistance	Parental Guidance
Help to explain my son's disorder to his little brother.	Management of relationships between siblings	
Am I too overbearing or too lax parent?	To be reassured about one's parenting	
Help to have time to manage my career.	Working life	Daily Management
I'd like to be more organised to have time to see and share activities with my wife.	Marital life	
Find time together in our schedule to do things together as a family.	Family life	
Find motivation and time to enroll in a sports club to meet new people.	Social life	

Table 3. Frequency of areas of need based on group

Area of need	ASD <i>Frequency (%)</i>	Controls <i>Frequency (%)</i>	χ^2 Value	<i>p</i>	Cramers' V
Material	60.3 ^a	21.4	25.38	<.001***	.396
Information	52.6	10.7	33.19	<.001***	.453
Parental Guidance	43.6	13.1	18.74	<.001***	.340
Daily management	37.2	29.8	1.00	.317	.079
Relational support	33.3	20.2	3.55	.059	.148
Emotional support	32.1	10.7	11.10	.001**	.262

^a 60.3% of parents have a material need ; ***: $p < .001$; **: $p < .01$

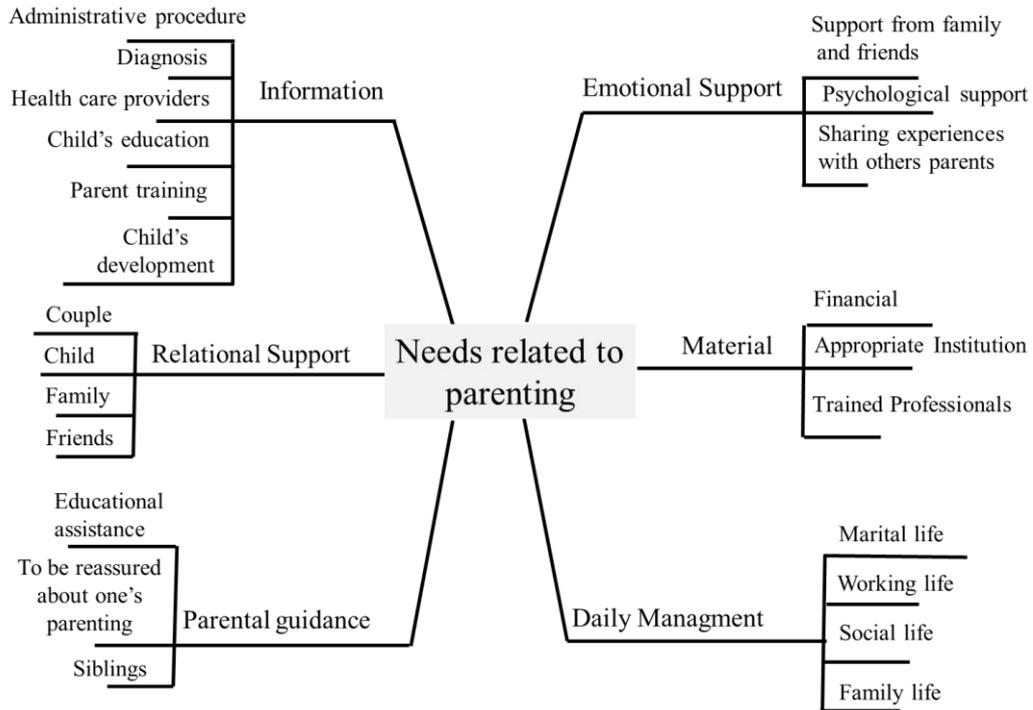


Figure 1. Areas of needs related to parenting