



Self-reported needs of caregivers of people with Autism Spectrum Disorder

Claire Colombet¹ · Céline Alcaraz¹ · Xavier de la Tribonnière^{2,3} · Maxime Morsa⁴ · Cécile Rattaz¹ · Amaria Baghdadi^{1,3,5} 

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Abstract

Objectives Autism spectrum disorder (ASD) has a major impact on caregivers. We aimed to describe caregivers' perceptions concerning their level of knowledge about ASD and their needs to better adapt education and training programs.

Methods This was a descriptive cross-sectional study conducted through a declarative and self-administered survey in France.

Results 1,013 individuals answered the questionnaire in 2020. If most caregivers felt they had sufficient knowledge about ASD, they still expressed a high level of needs regarding acquiring knowledge, identifying available resources, and finding social/emotional support.

Conclusions This study highlights the high level of needs of caregivers and their expectations of improving their knowledge and skills to help the person with ASD.

Keywords Autism spectrum disorder · Patient education · Caregivers · Needs · Self-care · Self-management

Introduction

Autism spectrum disorder (ASD) is an early onset lifelong neurodevelopmental disorder covering the association of disturbances in social communication with repetitive or stereotyped behaviors and restricted interests (APA, 2013). ASD characteristics have a major impact on caregivers. A family caregiver is someone who is informally responsible for the physical, emotional and often financial support of

another person who is unable to care for him/herself due to illness, injury or disability (Barello et al., 2019). Supporting the family caregivers has become an international public health priority given their essential role. Accurately assessing their needs is crucial in order to provide them adequate support and to ensure a consistent course of care once the diagnosis is made (Derguy et al., 2015).

In the case of ASD, caregivers, who are most of the time parents, experience greater levels of stress than parents of children with other neurodevelopmental disorders (Ingersoll & Hambrick, 2011; Schieve et al., 2007). ASD is also often combined with co-morbidities, including intellectual disabilities, learning disabilities, epilepsy, and attention deficit/hyperactivity disorder, which can increase its impact on caregivers (Kantzer et al., 2013; Kohane et al., 2012; Levy et al., 2010). Associated conditions can lead to deterioration of the health (anxiety, depression, etc.), lifestyle (for example, one of the two parents stopping working) and, ultimately, quality of life of caregivers (Hartley et al., 2014; Ingersoll & Hambrick, 2011).

Caregivers are subjected to repeated stressors and their abilities and resources to cope with them likely vary as a function of their status and the period of their lives. Several studies have identified differences between mothers and

✉ Claire Colombet
rech-clinique-autisme@chu-montpellier.fr

¹ Centre de Ressource Autisme Languedoc-Roussillon et Centre d'excellence sur l'autisme et les troubles neuro-développementaux, CHU Montpellier, Montpellier, France

² Unité transversale d'éducation du patient (UTEp), CHU Montpellier, Montpellier, France

³ Faculté de Médecine, Université de Montpellier, Montpellier, France

⁴ Laboratoire Education et Pratiques de Santé (UR3412), Université Paris Sorbonne Paris Nord, Bobigny, France

⁵ Université Paris-Saclay, UVSQ, Inserm, CESP, Team DevPsy, 94807 Villejuif, France

fathers, particularly in terms of stress levels and quality of life related to the role of mothers as the primary caregiver (Gau et al., 2012; Pastor-Cerezuela et al., 2016; Vernhet et al., 2019). Certain periods of life are particularly stressful for the caregivers of people with autism, notably the period following diagnosis. Indeed, the delivery of an ASD diagnosis is a major disruption for the parents, who are the primary caregivers (Chamak et al., 2011; Crane et al., 2016), and highlights the need for specific information, as well as the acquisition of the skills and support to cope with the daily difficulties they will encounter. Other periods, such as the transition from adolescence to adulthood, are also stressful times for caregivers, prompting requests for information and education (Baghdadli et al., 2014; McStay et al., 2014; Rattaz et al., 2014). Education and training programs for caregivers help them to meet such needs by focusing on their child with ASD and the family system.

Patient education (PE) programs were initially developed approximately 50 years ago for people with chronic diseases (Miller & Goldstein, 1972) and have since been adapted for many different health conditions (Hoving et al., 2010). In several French-speaking countries (France, Switzerland, etc.), such programs are described as “therapeutic patient education” (TPE) programs. The term “therapeutic” refers to the fact that they allow the individual to improve their confidence and self-sufficiency and to care for himself or herself and his or her family. Such programs have multiple goals that include both supporting the patient/caregiver and providing them education or skills (Dawson-Squibb et al., 2020). They aim to promote better knowledge about the disease and treatment, as well as to help the patient to acquire skills to manage their condition, with the goal of increasing independence and quality of life (Lagger et al., 2010). Numerous studies have demonstrated their efficiency based on highly diverse changes in outcome (Holman & Lorig, 2004; Lagger et al., 2010).

In the field of ASD, a large range of interventions and support programs targeting parents have been described in the literature (Bearss et al., 2015; Dawson-Squibb et al., 2020; Oosterling et al., 2010). However, few studies have examined parents’ needs and expectations in terms of support or education groups (Siklos & Kerns, 2006). In a qualitative study focusing on parental needs (Derguy et al., 2015), six dimensions were brought to light: material, information, guidance, daily management, relational support, and emotional support. The needs and priorities of parents of a child with ASD involved the transmission of knowledge and skills, as well as emotional and relational support. In one of the rare studies to investigate the needs of parents who participate in a support group through a questionnaire, conducted in Greece (Papageorgiou & Kalyva, 2010), important needs in terms of communication, social skills,

self-help skills, and behavioral problems were reported by the respondents. The self-reported needs of parents varied according to their gender and education but also according to the age and gender of their child with autism.

In France, parental programs in the field of ASD were developed a few years ago (Baghdadli et al., 2015; Derguy et al., 2018; Ilg et al., 2018; Rattaz et al., 2016) but they are not yet widely available and accessibility to such programs is still limited. The last five-year governmental plan for autism insisted on the importance of providing parents or caregivers appropriate support and training them to deal with their child’s disorder, through the promotion of TPE programs in the field of autism. The current study was motivated by the data collected to support this plan (Baghdadli et al., 2020).

If several studies focus on the stressful consequences of the caring experience, there is a dearth of data about the needs and expectations of the caregivers of people with ASD. Self-reported needs of caregivers need to be taken into consideration to ensure that the programs correctly address their information and support needs and to favor their participation. The goal of the present study was to first examine caregivers’ perceptions concerning their level of information about ASD and then describe caregivers’ needs as a function of the age of the individual with ASD to better adapt TPE programs to their expectations.

Method

Our study was a descriptive cross-sectional, declarative, and self-administered survey conducted in France between January and March 2020.

Participants

The participants were all caregivers of people with autism, regardless of their age or the clinical presentation of the person with ASD being helped. They were recruited through CRAs (Autism Resource Centers), GNCRA (National Group of Autism Resource Centers), and family and caregiver associations. They were asked to immediately complete an electronic version of a self-questionnaire using Sphinx, a survey software for quantitative and qualitative data analysis. All participants were volunteers. Participants responded over the period of January through March 2020.

Questionnaire

This was a self-administered questionnaire specifically designed to collect data on the educational needs (i.e., need of knowledge, skills, and social support) of the caregivers of

people with ASD. A brief explanation on the purpose of the questionnaire and the definition of the TPE were given to participants. Respondents were informed that their answers would be used to elaborate best practices and recommendations for the promotion of TPE programs in the field of autism, in the context of the last five-year governmental plan for autism. They were also informed that these recommendations would be available on-line on the website of the French HAS (“Haute Autorité de Santé”). The questionnaire consisted of the following sections: data on the respondent and socio-demographic data (age of the respondent, relationship with the person with ASD, marital status, study level, socio-professional category), data on the relative with ASD (age, age at time of diagnosis, benefiting or not from specialized support, i.e. from a service with health professionals who have training in the field of ASD), perceived level of information about ASD (“did you receive enough information regarding ASD”) and caregivers’ needs (“my needs are :...”). A list of needs was determined from the clinical experience of the authors of this study (AB, CA, and CR) from pre-existing programs and review of the literature (Table 1). Each need was rated on a 4-point scale (very interested, interested, not interested, not at all interested). The responses were grouped in two classes (interested vs. not interested) as there were very few responses in the “not at all interested” category. An initial pilot study was conducted on a sample of 10 volunteer caregivers from the Occitanie region to test the relevance and feasibility of the questionnaire.

Statistical analysis

Descriptive analysis of the data was carried out at regular intervals to verify homogeneity of the data collection. Descriptive statistics were computed using means and standard deviations (SD) for quantitative variables and proportions for categorical variables (%).

Associations between caregivers’ needs and the age of the individual with ASD / respondent’s status (mothers vs. fathers) were investigated using X^2 or Kruskal-Wallis non-parametric tests, as appropriate. Pairwise comparisons were made using the Bonferroni post-hoc test. The significance level was set to 5%. Statistical analyses were performed using SAS version 9.3 (SAS Institute, Cary, North Carolina).

Results

In total, 1,024 individuals answered the questionnaire. Respondents were from all French regions, including cities and rural territories. Eleven questionnaires were withdrawn because they were found to have been completed by health

Table 1 List of Needs

List of identified needs	Type of needs
Acquiring knowledge about ASD (diagnosis and clinical characteristics)	Acquisition of knowledge
Acquiring knowledge about specialized interventions for ASD	Acquisition of knowledge
Acquiring knowledge about sensory and cognitive functioning in ASD	Acquisition of knowledge
Acquiring skills to communicate with the person with ASD	Acquisition of skills
Acquiring skills to create a structured environment (visual schedules, timer, ...)	Acquisition of skills
Acquiring skills to manage challenging behaviors	Acquisition of skills
Acquiring skills to develop the self-help abilities of the person with ASD	Acquisition of skills
Acquiring skills to prepare the person with ASD for a medical examination	Acquisition of skills
Identifying available resources	Identifying resources
Finding psychological support	Social/emotional support
Finding social support / sharing my experience with other parents / caregivers	Social/emotional support
Finding support to manage sibling relationships	Social/emotional support

professionals and not by caregivers after reviewing them. The analysis therefore focused on 1,013 questionnaires completed by caregivers of people with ASD.

Socio-demographic data

The respondents’ characteristics are summarized in Table 2. Most respondents were parents (81.4% mother, 12% father) and they were married, in a civil union, or living together (74.8%). The questionnaire was filled by other respondents in 6.5% of cases (grand parent, sibling, partner, legal guardian). The respondents were distributed throughout all French regions. The average age of the caregivers was 46.1 years (SD=10.1). Most respondents had a level of education of two years post baccalaureate or more (65.5%) and the main socio-professional categories were employees or higher intellectual professions; 22.8% had no professional occupation.

Data on the relative with ASD

Based on the questionnaire, most of the people with ASD were children under 12 years of age (49.3%). Adolescents between 13 and 18 years of age made up 22.8% and adults over 18 years of age 27.9%. The average age at the time of diagnosis was 7.3 years (standard deviation 6.1), with a range from infancy to 43 years. Among them, 71.5% were receiving specialized support.

Caregivers' perceived level of information

Most caregivers (70.2%) felt they had sufficient information about ASD. There was a statistically significant relationship between the perceived level of information about ASD and specialized support. Among caregivers who felt they had a sufficient level of information, 76.1% received specialized support for their relative, whereas 62.6% among those who felt they had an insufficient level of information received specialized support ($p < 0.0001$). There was also a statistically insignificant relationship between the age of the person with ASD and the perceived level of information of the caregivers ($p = 0.06$), with a difference, in particular, between caregivers of adolescents and those of adults. Indeed, fewer caregivers of adolescents felt they had a sufficient level of information (66.2%) than caregivers of adults (75.3%), $p = 0.02$.

Caregivers' needs

The most frequently expressed needs were acquiring knowledge about sensory and cognitive functioning in ASD (93.7% of respondents), identifying available resources (89.1%), and acquiring knowledge about specialized interventions for ASD (88.7%) (Table 3).

Several caregivers' needs appeared to be significantly related to the age of the individual with ASD. Caregivers of children with ASD were more interested than caregivers of adolescents or adults in acquiring skills (create a structured environment, manage challenging behaviors, develop the self-help abilities of the person with ASD, prepare the person with ASD for a medical examination). We found significant differences between the three groups in terms of identifying available resources, more frequently expressed by caregivers of children than those of adolescents and more frequently by caregivers of adolescents than those of adults. Needs concerning support to manage sibling relationships were more frequently expressed by the caregivers of children (72.3%) than those of adults (61.1%). There were no significant differences between age groups in terms of acquiring knowledge (about ASD, specialized interventions, and the sensory and cognitive functioning of the person with ASD), acquiring skills to communicate with the person with ASD, or finding psychological or social support (see Table 3).

Finally, analyses were conducted to compare the responses of mothers versus those of fathers. Overall, mothers expressed a greater need of psychological support (76.1%) than fathers (66.4%), $X^2(1, N = 947) = 3.99$, $p < 0.05$. Fathers expressed a greater need to acquire skills to communicate with the person with ASD (86.9%) than mothers (79.2% of the mothers), $X^2(1, N = 947) = 5.4$, $p < 0.02$.

Table 2 Participant Characteristics (n = 1013) in %

Age	
Under 20	0.1
From 20 to 29	3.1
From 30 to 39	24.2
From 40 to 49	39.1
From 50 to 59	21.8
Over 60	11.7
Relationship with the person with ASD	
Mother	81.4
Father	12.1
Other (grand parent, sibling, partner, legal guardian)	6.5
Marital status	
Married/civil partnership/partner	74.8
Separated/divorced	18.1
Single	5.9
Widower	1.2
Study level	
College, graduate school	45.8
Baccalaureate + 2 years	19.7
Baccalaureate	17.3
High school	14.5
Other	1.3
No answer	1.5
Socio-professional category	
Employee	28.4
Manager, engineer, or doctor	24.3
No professional occupation	22.8
Intermediate occupation	9.8
Retired	8.1
Craftsman, sale worker, or entrepreneur	4.9
Worker	1.2
Agricultural worker	0.5

There were no significant differences between mothers and fathers in terms of other needs.

Discussion

This descriptive and declarative cross-sectional study of the needs of the caregivers of people with ASD was conducted to develop and promote TPE in France. We identified multiple needs: the acquisition of knowledge (i.e., information concerning ASD) and skills (i.e., caring skills and the capacity of adaptation) and the identification of available resources and sources of socio-emotional support.

First, we found that two-thirds of caregivers considered their self-estimated level of information about ASD to be sufficient. However, the caregivers of people with ASD who did not benefit from specialized interventions perceived their level of information to be lower, suggesting that parental education is of particular interest for this population. We also found that caregivers of adolescents perceived their

Table 3 Links between Caregivers' Needs (% of respondents interested) and their Child's Age

	All N = 1013	Chil- dren N = 499	Adoles- cents N = 231	Adults N = 283	Pearson X ² (ddl = 2)	p-value	post-hoc test*
		G1	G2	G3			
Acquiring knowledge about ASD (diagnosis and clinical characteristics)	79.2	81.8	75.3	77.7	4.5	0.1	
Acquiring knowledge about specialized interventions for ASD	88.7	89.6	89.2	86.9	1.3	0.5	
Acquiring knowledge about sensory and cognitive functioning in ASD	93.7	94.6	94.4	91.5	3.1	0.2	
Acquiring skills to communicate with the person with ASD	79.9	83.0	76.6	77.0	5.9	0.05	
Acquiring skills to create a structured environment (visual schedules, timer, ...)	75.2	83.6	69.7	65.0	38.2	0.0001	G1 ≠ G2, G3
Acquiring skills to manage challenging behaviors	86.2	91.0	84.8	79.2	21.9	0.0001	G1 ≠ G2, G3
Acquiring skills to develop the self-help abilities of the person with ASD	80.2	87.8	75.3	70.7	37.6	0.0001	G1 ≠ G2, G3
Acquiring skills to prepare the person with ASD for a medical examination	62.9	68.3	59.3	56.2	13.1	0.001	G1 ≠ G2, G3
Identifying available resources	89.1	93.8	89.6	80.6	32.7	0.0001	G1 ≠ G2 ≠ G3
Finding psychological support	74.6	76.2	74.9	71.7	1.9	0.4	
Finding social support / sharing my experience with other parents / caregivers	77.8	79.8	77.5	74.6	2.8	0.2	
Finding support to manage sibling relationships	68.1	72.3	67.5	61.1	10.5	0.005	G1 ≠ G3

*Bonferroni correction

level of information to be lower than those of adults, highlighting the specific needs of caregivers during adolescence, a critical period for people with ASD, during which parents tend to express greater concern about the future (Rattaz et al., 2014).

Second, most parents and caregivers expressed multiple needs. Acquiring knowledge about the functioning of the person with ASD and identifying available resources were among the most often cited needs (93% and 88% of respondents, respectively). Previously published studies also show a better understanding of the specificities of the person with ASD to be a crucial need (Cappe & Poirier, 2016; Farmer & Reupert, 2013; Preece et al., 2017), as well as better identifying resources concerning specialized intervention services, trained professionals, and financial support, which appears to be higher than for control parents (Brown et al., 2012; Derguy et al., 2015). In our study, parents and caregivers also expressed a need concerning knowledge on how to develop communication and self-help skills for the person with ASD, as well as how to manage challenging behaviors. Such needs, which relate to the acquisition of skills, have also been previously reported (Papageorgiou & Kalyva, 2010; Pejovic-Milovancevic et al., 2018; Preece et al., 2017). Needs in terms of social/emotional support were less often expressed than needs concerning the acquisition of knowledge, even if they were still expressed by a majority of the respondents (between 74 and 77%). These needs have also been less reported than other needs in the literature (Cappe & Poirier, 2015), but were shown to be more important for parents of children with ASD as compared to

control parents (Derguy et al., 2015). Overall, parents and caregivers expressed numerous and various needs, with needs concerning the acquisition of knowledge the main priority.

Third, parents or caregivers' needs appeared to vary as a function of the age of the person under their care. Parents or caregivers of children with ASD expressed more needs in terms of acquiring skills (create a structured environment, handle challenging behaviors, develop the self-help abilities of the person with ASD, prepare the person with ASD for a medical examination). It is possible that the parents of adolescents or adults either had already developed some of these skills or had fewer demands requiring such skills as their child, in some cases, no longer lived with them. Differences in the needs of caregivers depending on the age of the person with ASD have also been reported in the literature. Papageorgiou & Kalyva (2010) found that parents of older children expressed more concerns about problems with self-help skills, self-occupation, and behavioral problems, whereas parents of younger children were more concerned about communication problems. Gibson et al., (2017) showed that parents of adolescents expressed more needs concerning information about sexuality, professional insertion, and independence, whereas those of children were more interested by information on ASD diagnosis and specialized interventions. In our study, needs concerning the acquisition of knowledge about ASD and social / relational support, which have been described as crucial needs in the literature (Derguy et al., 2015; Samadi et al., 2012), were expressed independently of the age of the person with ASD.

These results suggest that such needs have to be addressed, regardless of the age of the child, throughout the life of the person with ASD.

Fourth, certain self-reported needs of parents or caregivers differed according to their gender. In our sample, mothers expressed a greater need for psychological support, whereas fathers expressed a greater need to acquire skills to communicate with their child. The few studies that have explored this issue found no differences between the needs of mothers and fathers (Frye, 2016; Papageorgiou & Kalyva, 2010). However, differences concerning the impact of ASD on psychological well-being have been reported in the literature to depend on the caregiver's gender (Gau et al., 2012). Coping strategies have been shown to differ between mothers and fathers, with fathers tending to withhold more than mothers from their colleagues at work (Papageorgiou & Kalyva, 2010) and mothers using more emotion-focused coping and social support-seeking (Vernhet et al., 2019). These differences in coping strategies may explain our results, showing more expressed needs of social support by mothers and more expressed needs concerning the acquisition of skills by fathers.

Strengths and limitations

A particular strength of the present study was the large sample of caregivers, with more than 1,000 respondents from throughout France. This large number of respondents also reflects the importance of the issue of caregivers' needs in the field of ASD. However, selection bias cannot be ruled out, as participation was voluntary. Another limitation was the absence of data on the clinical characteristics of the person with ASD under care, for example the intellectual level or comorbidities, which may have influenced the needs of parents or caregivers. The time span of the diagnosis of ASD was also very large in our sample and might have affected the results. Then, the proportion of fathers in our total review sample was too limited to draw conclusions about needs depending on gender, and the results might be related to the different roles that fathers and mothers fill in the family in general rather than the different needs that arise when caring for a child with ASD. Further studies about gender differences are required. Finally, this study describes caregivers' needs in France and the results must be extrapolated with care because of differences between countries in terms of the type of specialized intervention and health services (DePape & Lindsay, 2015; Gau et al., 2012).

Conclusions and perspectives

The high level of needs expressed by caregivers of individuals with ASD suggests a strong willingness to acquire

knowledge and develop skills to manage the person with ASD under their care, with the goal of increasing their empowerment. These results highlight the need to promote education programs for parents or caregivers in the field of ASD. Differences in caregivers' needs as a function of the age of the person with ASD under their care were found, which should allow adaptation of TPE programs as a function of the population.

The goal of providing information is to promote caregiver empowerment and tailor optimal support to each person with ASD and their caregivers to reduce perceived stress and improve quality of life. Future studies still need to be conducted to determine the specific needs according to the characteristics of the person with ASD and their caregivers and to assess the effectiveness of TPE programs. In this perspective, qualitative research using open-ended questions or interviews would be relevant to address some caregiver-specific needs. Finally, our data suggest we need to expand service access for caregivers across the lifespan. They also indicate a still high level of unmet service need for caregivers around acquisition of knowledge about specialized interventions and sensory/cognitive functioning and identifying resources. A more accurate knowledge of the caregivers' needs could help to better tailor the interventions and services provided to the persons with ASD in the future.

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