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Facilitators' perspectives on a psychoeducational program for parents of an autistic child

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Lay abstract

The recent increase of diagnosed cases of autism spectrum disorders (ASD) has led to a considerable rise in the demands for autism-related services and interventions. Caring for an autistic child can be perceived as an enrichment, which coexists with stress in parents. Parents express the need to access relevant information about their child's difference and parent support interventions appear to respond effectively to this demand, as they are knowledge-focused and offer indirect support to the child. The aim of this study was to capture the subjective experience of facilitators who implemented a psychoeducational program called *Beyond ASD: parental skills within my reach*. This program is based on the acknowledged fact that parents of autistic children play a central role in their child's development. Its main goal is to help parents of autistic children under the age of eight to identify, develop, and update their parenting competences. This program broaches different topics: (1) specific features of an autistic child, (2) post-diagnostic parental adjustment, (3) communication and social relationships, (4) importance of providing the child with a structured environment, and (5) parental emotions and perceptions that impact everyday life. Structured interviews of the facilitators provided insight on institutional support, issues related to the program itself, required and/or recommended professional background, personal experience and competences, and difficulties linked to recruitment and research criteria. Recommendations aiming to enhance program implementation and delivery were then created using facilitators' feedback on these aspects.

Abstract

The recent increase of diagnosed cases of autism spectrum disorders (ASD) has led to a considerable rise in the demands for autism-related services and interventions. Parents express the need to access relevant information about their child's difference and parent support interventions appear to respond effectively to this demand, as they are knowledge-focused and offer indirect support to the child. The aim of this study was to capture the subjective experience of facilitators who implemented a psychoeducational program called *Beyond ASD: parental skills within my reach*. Structured interviews of the facilitators (N=18) provided insight on institutional support, issues related to the program itself, required and/or recommended professional background, personal experience and competences, and difficulties linked to recruitment and research criteria. Recommendations aiming to enhance program implementation and delivery were then created using facilitators' feedback on these aspects.

Keywords: autism spectrum disorder, parent support program, psychoeducation, facilitators' feedback, implementation

Facilitators' perspectives on a psychoeducational program for parents of an autistic child

Autism spectrum disorder (ASD) is a multifaceted and life-long neurodevelopmental condition and has complex effects on various areas of parents and caregivers' everyday life (Karst and Van Hecke, 2012). Caring for an autistic child can be perceived as an enrichment (McConnell, Savage, Sobsey, & Uditsky, 2015), which coexists with stress in parents (Phelps, McCammon, Wuensch, & Golden, 2009).

Many researchers acknowledge the importance of parent-training programs in autism to promote optimal child development (Nevill, Lecavalier, & Stratis, 2018) and recent systematic reviews have highlighted their effectiveness (Bearss, Burell, Stewart, & Scahill, 2015; Schultz, Schmidt, & Stitche, 2011); for example increasing parental knowledge, enhancing competence in advocating for the child, decreasing parental stress, and reducing the sense of isolation (Bearss et al., 2015).

In autism, the term parent-training program is used to describe a large range of interventions. Bearss et al. (2015) taxonomically identify two main categories of parent-training programs: parent-mediated interventions and parent support interventions. Parent-Mediated interventions are skill-focused programs that mostly involve the child-parent dyad. The child is the direct beneficiary of the program and the parent is perceived as a mediator (Bearss et al., 2015; Schultz et al., 2011). Parent support interventions – which are the focus of the current study – are knowledge-based and offer indirect support to the child. This category encompasses care coordination and psychoeducational interventions (Bearss et al., 2015). Care coordination is considered a useful element in clinical management in autism, with the goal of connecting families to available services (Bearss et al., 2015). Psychoeducational interventions respond to one of the most frequently unmet needs of parents shortly after their child's diagnosis: the access to quality information and guidance about autism and related effective interventions, behaviors, and conducts (Hamilton, 2008).

Understanding autism is a key theme for parents of autistic children (Crane et al., 2018).

Parents of the study of Galpin et al. (2018) also highlighted the need for personalized post-diagnostic support. Satisfaction with post-diagnostic support contributes to parents' overall satisfaction with the diagnostic process (Eggleston, Thabrew, Frampton, Eggleston, & Hennig, 2019). Psychoeducational interventions do not generally exceed 12 sessions, can be addressed individually or in groups, and are delivered by a wide range of professionals.

Although a range of parent-training programs is now available, research calls for the need to identify specific variables that serve as indicators for desired outcomes for parents of autistic children (Schultz et al., 2011). Parents mostly express the need to access relevant information about their child's difference and about available services, presently and in the future (Hodgetts, Zwaigenbaum, & Nicholas, 2015; Siklos and Kerns, 2006), as well as the need for professional or social support and guidance (Cappe and Poirier, 2016; Derguy et al., 2015; Hartley and Schultz, 2015; Papageorgiou and Kalyva, 2010; Russa, Matthews, & Owen-DeSchryver, 2015).

Several authors highlighted the necessity of developing the science of implementation (Fixsen, Blase, Naoom, & Duda, 2013), especially in early childhood intervention studies (Durlak, 2010; Wolery, 2011). Proctor et al. (2011) insist on the importance of implementation data, which helps us to reflect how programs are applied. Furthermore, the evaluation of implementation benefits our understanding of factors influencing the effectiveness of a program. In the area of autism, few authors have evaluated the implementation of their program (Schmidt and Stichter, 2012; Wainer and Ingersoll, 2013), even though some authors emphasize the importance of doing so (Oono, Honey & McConachie, 2013; Schultz et al., 2011; Wainer and Ingersoll, 2013).

This qualitative study focused on facilitators' experiences and expectations regarding the implementation of a psychoeducational program for parents of an autistic child, which

addresses a contemporary issue (Alain and Dessureault, 2009). More precisely, we aimed to gather information on the program's strengths and weaknesses and on unexpected situations facilitators came across while delivering the program. The results enabled us to issue recommendations aiming to improve overall implementation and delivery.

Method

Description of the program

"Beyond PDD: Parental skills within my reach" is a psychoeducational program for parents of autistic children created in Quebec in 2004 and later revised in 2008 by the *Centre de Réadaptation en Déficience Intellectuelle et en Troubles Envahissant du Développement de la Mauricie et du Centre-du-Québec – Institut Universitaire*, a healthcare and social services institution. This program is based on the acknowledged fact that parents of autistic children play a central role in their child's development (Guralnick, 2001). Its main goal is to help parents of autistic children under the age of eight to identify, develop, and update their parenting competences. It offers five, bimonthly, 2.5-hour-long interventions in groups not exceeding eight participants and is facilitated by two psychologists. In addition, the program includes five individual meetings with an educator, after each group intervention. Each group intervention is focused on a different topic: (1) specific features of an autistic child, (2) post-diagnostic parental adjustment, (3) communication and social relationships, (4) importance of providing the child with a structured environment, and (5) parental emotions and perceptions that impact everyday life (Sankey, Derguy, Clément, Ilg, & Cappe, 2019a; Stipanivic, Couture, Rivest, & Rousseau, 2014). Structured around 31 different activities (theoretical presentations, group discussions, graphic metaphors, introspection and relaxation-related activities, as well as group, individual, and home exercises), the program provides three handbooks for facilitators, participants, and educators (Sankey et al., 2019a; Stipanivic et al., 2014). It was delivered and evaluated in France in several care units and medical institutions

from 2013 to 2018 (Cappe et al., under review; Sankey, Girard, & Cappe, 2019b). In order to take part in the program, parents have to be able to understand, speak, read, and write in French, for information is provided both orally and in writing. To take part in the research, parents could not be involved in another autism-related intervention for parents and had to have only one child diagnosed with autism in the year preceding their inclusion in the research project (for more details concerning the parents' characteristics see Cappe et al., under review; Cappe, Stipanivic, Rousseau Couture, & Rivest, in press; Sankey et al., 2019a). In France, some care units dispensed the complete version of the program (five group interventions and individual meetings with an educator), while others dispensed a shortened version of the program (five group interventions only), due to a lack of personnel.

Participants

Participants were psychologists (17 females, 1 male, mean age=38.11±4.74 years old) specialized in autism (8 had a masters degree, 2 a *PhD* in psychology). Half of them worked part-time in the service where the program was implemented. They all had recently dispensed the program at least once (five times maximum) to 4,33±2,26 parents. Detailed characteristics are presented in Table 1.

They were given an informative letter about the study and provided written consent to take part in the research. This research was approved by the *Conseil d'évaluation éthique pour les recherches en santé (CERES)* of the *Université Paris Descartes* (IRB number: 20135400001082).

Table 1

Facilitators' characteristics (N = 18)

	Complete version <i>n</i> = 10	Shortened version <i>n</i> = 8	Total <i>N</i> = 18
Females (<i>n</i> ; %)	9; 90%	8; 100%	17; 94,5%
Number of groups facilitated <i>M</i> (<i>SD</i>) [range]	1.70(1.34) [1-5]	1.67(1) [1-4]	1.78(1.39) [1-5]
Professional experience as a psychologist in years <i>M</i> (<i>SD</i>)	6.7(4.7)	8.3(3.9)	7.4(4.3)
Experienced with autistic children or adolescents <i>n</i> ; %	10; 100	8; 100	18; 100
Experienced with parents of autistic children <i>n</i> ; %	9; 90	5; 63	14; 77,78
Experience in autism in years <i>M</i> (<i>SD</i>)	8.1(5.3)	8.4(4.2)	8.2(4.8)
Additional training in			
Autism <i>n</i> ; %	7; 64	5; 63	12; 63
TEACCH ² <i>n</i> ; %	2; 18	4; 50	6; 32
PECS ³ <i>n</i> ; %	7; 64	4; 50	11; 58
ABA ⁴ <i>n</i> ; %	1; 8	4; 50	5; 26
Group facilitation <i>n</i> ; %	3; 28	1; 13	4; 21

²Treatment and Education of Autistic and related Communication handicapped CHildren³Picture Exchange Communication System⁴Applied Behavior Analysis

Data Collection

Three clinical psychologists, familiar with clinical and research interviews, but with no links to the clinical services where the study took place, carried out the eighteen interviews face-to-face (16) or over the phone (2). The 18 interviews recorded lasted on average 68 minutes. Interviewers followed a structured guideline, complemented by several questions according to the interviewee's responses (see interview outline in appendix), which referred to the program (planning and framework, handbooks and tools), activities, facilitation, participant involvement and group dynamics, program training, and general impressions and recommendations. Given the inductive model that was used here (described below), no bracketing and no reflective journals were used during data analysis.

Data analysis

For this qualitative and exploratory study, we chose a general inductive method (Thomas, 2006). It provides precise procedures to produce knowledge and elaborate meaning from data obtained in an original context. Thomas' method has three main objectives: (1) concentrate extensive and various text data into a brief summary format, (2) simplify links between research objectives and findings, and (3) build models about the underlying structure of experiences. This approach, derived from grounded theory, can be differentiated by the researchers' choice to expose categories that emerge from their analysis, instead of elaborating a theoretical model (Blais and Martineau, 2006). Researchers using the inductive approach agree that the intended outcome of coding is to generate three to eight categories, which are meant to capture the most relevant themes given the research objectives (Campbell et al., 2003). It is important to bear in mind that the objective was to explore facilitators' point of view regarding the delivery of a psychoeducational program for parents of an autistic child. More precisely, we aimed to gather information on the program's strengths and weaknesses and unexpected situations facilitators came across while delivering the program. To analyze

data, the two first authors prepared the transcripts, before thoroughly reading the raw data several times, in order to gain a global perception of emerging themes. First, they each built an individual analysis grid, on three interviews. They met to discuss discrepancies regarding categories' definitions. They then made sure they were assigning the same text segments to the same categories on the three interviews. They subsequently reviewed the grid. Once the two authors reached consensus, the amended grid was independently applied by each author on all interviews using the free and open-source software *Weft-QDA*. Following this global analysis, one participant was asked to comment on a preliminary version of the results by e-mail, as recommended by Thomas (2006).

Results

Four main recurring themes emerged from data analysis: (1) institutional support and commitment, (2) issues related to the program, (3) professional background, personal experience and competences, and (4) issues linked to recruitment and research criteria (see Box 1).

Box 1

Emerging themes and related emerging elements

Main Themes	Emerging elements
Theme 1: Importance of institutional support and commitment	<ul style="list-style-type: none">• Time consumption and conflict with other institutional projects• Peers experience with the program aided facilitation for implementation• Importance of facilitators' voluntary delivery
Theme 2: Issues linked to the program itself	<ul style="list-style-type: none">• Exchange with parents: time consumption and expressed needs• Need for continuity after delivery• Difficulties with activities involving abstraction, relaxation, and mental imagery• Unexpected themes and need for practical information• Handbook instructions and homework• Program facilitation training and supervision

Theme 3: Professional background, personal experiences and competences	<ul style="list-style-type: none">• Knowledge in autism• Clinical experience with parents and caregivers• Specifics of psychoeducation practices• Psychologists: only facilitators qualified for program delivery?• Experience or training for group program delivery• Benefits of co-facilitation
Theme 4: Difficulties linked to parents' recruitment according to inclusion criteria	<ul style="list-style-type: none">• Physicians' involvement• Language skills and social-economical context• Heterogeneity of children's characteristics• Participant availability and issues linked to access to childcare services• Psychological enrolment and mental health issues

Importance of institutional support and commitment.

Institutional support appeared to be a key element in facilitating the program's implementation, in *particular to recruit parents into the groups*. First, hierarchical support emerged as a first step in acquiring institutional adherence. Medical team support acted as a pivotal role within certain institutions. Five facilitators reported that medical doctors were greatly committed in recruiting potential participants and explaining the program to families.

This involvement was appreciated and perceived as a *beneficial way of dividing tasks*. More generally, the entire team was seen not only as a *precious technical aid*, but also as a source of *psychological support* for facilitators:

I felt supported by the institution, even if they were not very actively involved in preparation, it was mostly moral support.

For six professionals, providing a spacious room on a suitable recurring time window was a marker of institutional support. However, this was not the case for other professionals in institutions without sufficient available space. Three facilitators were concerned about the *impact of program preparation on their institutional work time*. The program was perceived as time consuming with a *necessary period of material preparation*, understanding the handbook, and program training.

Six facilitators mentioned that by delivering the program after some of their colleagues, *they benefit from a pre-existing, well-organized framework that needed no further organization*, in comparison with their predecessors:

I was in the third program group in the institution. So... I was not really involved in... all of those questions referring to the exact location. The space was already pre-defined, the time-schedule was already defined, the day during which the program was held was defined, and participants' selection had already been done in the first group I co-delivered...

As eight facilitators explained, this anticipation was greatly eased by close teamwork between colleagues who had facilitated the program in the past and those who were presently doing so.

Issues related to the program itself.

Eight facilitators stated that *groups of four parents were ideal* to deliver the program, leaving enough time for every participant to exchange during sessions. Ten facilitators considered that *leading a group of six parents or more was challenging*. The standard of eight parents per group prescribed by the original program was rarely met. A facilitator explained:

The fact that we only had four parents, I think it may be a bad ratio for the institution, but it was a very good ratio for group dynamics because it allowed to soften the gap between the children's forms of autism.

A facilitator said they could have included more parents, had research participation criteria been less restrictive. Some parents were interested but could not participate because of *family and/or professional constraints*. An important issue was to schedule the program on a suitable day and time for parents as well as facilitators. Asking parents to come on their days off obstructed the time they had with their child and family. Weekdays did not appear as a solution, as parents would often arrive late after picking up their child at school or coming from work. All in all, finding a time slot during which parents were not with their child was reported as challenging. The issue of providing childcare in the absence of the parent was brought up three times. A facilitator also highlighted that parents who were isolated at home with no childcare services were denied access to the program.

Parents' demands and participation had a significant impact on the time spent on different activities. This issue often required adjusting and shortening the time spent on some actions, such as scheduled breaks and end-of-session feedback. Nine facilitators would have appreciated to have *more flexibility to adapt their intervention to the parents' expressed difficulties and demands*. Exchanges were not always related to the child or autism, but often centered on parental experiences and testimonies. Ten facilitators perceived these parental interferences as a genuine need.

These families don't have the opportunity to exchange. For that matter, they have to capitalize on this time to exchange about their daily lives, to discuss about their worries and challenges.

Five facilitators reported that the time spent on unscheduled free-talks was more important when the question of the child's diagnosis was involved. Parents would bring forward their personal experiences, which seemed to help them reflect on how the diagnosis affected their family, and compare their experience to the experience of others. These

exchanges were not always easily facilitated and *could lead to exceeding the allocated time of the workshop by 10 to 30 minutes*. It was also reported twice that, for some parents, *psychological support in-between sessions would have been beneficial*.

Digressions were never spent speaking about totally different things. They spoke about their lives... In any case, it made them move forward on the question of going through the diagnosis, this stage that is described, that is necessary, and that is obviously experienced differently.

Eleven facilitators perceived *the need to provide participants with continuity*. Three of them suggested offering group meetings or support groups every six months after program completion. Two suggested conducting an individualized report to encompass the demands of all parents and answer their questions.

Seven facilitators estimated that *the quantity of information was appropriate* for 2.5-hour sessions, mentioning that extending the program's duration or density of content could challenge facilitators' and parents' energy and focus.

Several issues were raised concerning the program's content. First, five facilitators reported that *activities involving mental imagery, abstraction, introspection, and relaxation techniques could be challenging for some parents, as well as for some professionals*. These reflective tools aim to improve the participant's understanding and awareness regarding uncomfortable or threatening situations he or she may come across. These tools generally enable better memory of relevant information, which is the reason they are used throughout the program and they contribute to the program's specificity as well.

...there are some activities that are not accessible, not really understandable by all families. And when it comes to language, to explaining, I think some families are not used to self-questioning, or to think in a more elaborate or abstract way. Some activities may not be useful, or at least they are not very accessible.

Also, eight facilitators felt *parents would have appreciated additional contents*, as they regularly brought up specific topics that are not specifically addressed in the program (no

workshop was specifically dedicated to these topics), thus displaying their need for more information. For instance, they often asked for information on how to interact with relatives, friends and strangers, and managing others' perceptions of their child. Parents' topics of interest also included behavioral, sleep, and eating disorders, as well as learning difficulties. They also frequently had questions regarding schooling and education. On a broader scale, parents often sought practical solutions to manage their daily lives and deal with the difficulties they encountered.

We feel that everything practical/situational could be worked on more. They [the parents] are keen to get a lot of practical information, on everyday situations, things that work and things that do not. And here, actually, we are on strategies, but we see that they are trying to use what is said for practical situations, to move forward with those elements.

However, although it did not globally impact program delivery, *home exercises were not always completed in-between sessions*. Three facilitators believed that *instructions were not always understood and required further explanations*. Additional group time could have helped to ensure a good understanding of instructions. However, *parents' challenging lives may be another reason why they did not always complete homework*.

Four facilitators felt *the handbook for parents was not adapted to participants who had difficulties speaking, reading, and/or writing in French*. As a result, these participants were exposed to failure and left the study after several sessions, as mentioned by one facilitator:

It happened several times. Some just left after one or two sessions. The participants who left had never written, had never participated, and could not really read French well, or write it, or maybe both. It is not adapted to people who cannot read or write in French.

Six facilitators suggested that *the handbook for parents should be more visual for people expressing difficulties with language skills*. Nevertheless, two reported that even for participants with no particular language difficulties, *facilitators had to frequently reformulate and explain content*.

In addition, there were significant differences in program training and preparation across formats. Only two facilitators were able to discuss the situations met during the program with peers. Eight facilitators relied on colleagues and peers who had previously facilitated sessions to gather information and personal experiences. *Those who did not benefit from this guidance expressed interest in accessing something similar* in the future. Three facilitators felt that *discussing with colleagues was effective and supportive* and they did not express the need to be officially supervised.

Seven facilitators had to *review certain theoretical aspects before dispensing the program*. Five agreed on the fact that the handbook was not sufficient to facilitate the program without prior training. One facilitator who had the opportunity to watch videotaped sessions said it was a useful way to prepare the program.

Professional background, personal experience, and competences.

All facilitators agreed that *having a strong background in autism was essential*. According to the interviewees, extended knowledge in this domain should include: *experience in evaluations and support of autistic children, expression of early signs of the disorder, stress adjustment, coping methods, quality of life, and patient care*. The handbook did not appear to be sufficient without this background. Furthermore, parents' specific questions required up-to-date knowledge about autism. Five facilitators specified that it was also *important to have clinical experience with parents*. Two others reported that *being experienced with a population of typically and atypically developing children was of use*.

I think it is necessary to have very good knowledge about autism. It is very important to follow current updates, and to know the movement of family associations, their latest fights, their latest claims, to know the governmental plan for autism. Finally, to know the context around autism... I find this essential.

Content related to mental imagery was challenging for some facilitators and demanded self-training to adapt reading pace and voice tone. *The very structured content also*

required organization skills. All agreed upon the need to have *competencies or experiences in group facilitation*. Six facilitators viewed competences related to group facilitation as inherent to psychologists' practices, whereas two thought these skills were not specific to the profession. One facilitator commented:

We need to be at the same time attentive and benevolent, while being sufficiently consistent so that it does not go beyond boundaries, to maintain this psychoeducational notion. It is not a support group session.

This program was co-facilitated, which required psychologists to forge *a strong and complementary work alliance*. Ten facilitators reported that they did not receive group facilitation training, and seven of them were anxious about delivering the program. Teamwork was seen as beneficial as facilitators felt supported and learned from the experience of their partner:

It was my first group experience and I was happy to see how she presented the theoretical content and connected it to practical examples, so it could give me some ideas. (*sic*) It also helped me to articulate the content with my practice on the following sessions.

Co-delivery also implied dividing tasks. This was usually achieved according to personal interests and competences. Five facilitators said they inverted task distribution in successive sessions so they could experiment every aspect of the program.

Difficulties linked to parents' recruitment according to inclusion criteria.

Physicians reported that they were frequently involved in recruitment. In some services, physicians were the only professionals informing families on research criteria. In other institutions, recruitment was carried out in a more collaborative manner by preselecting families with the psychologists delivering the program. According to two facilitators, the close involvement of physicians was due to their crucial role in diagnosis evaluations. Indeed, they have facilitated access to families and potential participants. Families were generally informed of the program when physicians noticed that parents had difficulties adjusting to the

recent diagnosis. However, two facilitators questioned their involvement in the recruitment process:

When you know the program, you can easily adjust group composition. But doctors that haven't seen the program cannot know. You can tell when you are familiar with the content, you can quickly imagine what the family can or cannot do. (*sic*) If I meet a family, I can anticipate if it corresponds to their needs or not. It could be important to associate people who know the program well in the initial recruitment.

Two facilitators reported that parents who had a child in joint custody needed more time to apply the knowledge they received in sessions. They did not necessarily have the child with them regularly or frequently enough to experiment and apply what they had learned.

Five facilitators raised the issue of poor language skills, and writing, reading and comprehension difficulties that affected some parents' participation. Several of them left the program. A facilitator suggested that a social-cultural evaluation should be carried out before including parents in the program. Indeed, *participants with precarious economic and social conditions had difficulties to identify with other parents' experiences.*

Four facilitators also reported that *important disparities in children's characteristics and disorder severity could impact parents when comparing their child to the testimonies of others in the group:*

When we read the "characteristics" on the paper, we could not have anticipated that the gap would be so important. So, we have to be cautious about age gaps, severity, and forms of autism [in the parent's children].

This program required a strong emotional investment from parents. Two facilitators insisted on the fact that parents had to be psychologically available to invest the program. Some parents were stated as showing signs of depression and their pessimistic views and negative emotions affected not only their participation, but also other participants in the group. Some parents also exhibited emotional reactions towards the content of some activities, more specifically when referring to diagnosis adjustment. As one facilitator explained:

The second session was the most problematic one because we discussed parental coping strategies and it was not a simple session, especially for parents who just received a diagnosis a short time ago. We have to talk about shock, denial, depression, feeling of despair, about not knowing what to do, *etc.* So, for parents who are in this phase, in denial or in despair, it is something that just violently impacts them.

Discussion

Psychoeducational interventions are recognized as a necessity for good quality post-diagnostic care (Johnson and Myers, 2007). Nowadays, parents are perceived as key components of an effective treatment (Lord and McGee, 2001) and numerous educational programs include them as “co-therapists” in various pathological fields (Haine-Schlagel and Escobar Walsh, 2015). Most of the programs have failed to consider the importance of evaluating implementation (Schultz et al., 2011). This research is one of the few studies that used a qualitative approach to explore professionals' perspectives on a training program for parents of autistic children.

In depth exploration of facilitators' views provided a more comprehensive understanding of the subjective experience of program delivery. Our findings highlighted the complexities of the program and its internal dynamics. Facilitators often demonstrated difficulty in monitoring exchanges with parents and refocusing participants on the prescribed activities and timing. Many reported the importance they gave to listening to what parents had to say and creating a space for open dialogue. This allowed them to discuss topics that were not specifically addressed in this program but were nevertheless important, such as meals, sleep, schooling, etc. Some other programs specifically address these issues (Ingersoll and Wainer, 2011; Kirkpatrick et al., 2019; Sharp et al., 2014). Palmer et al. (2019) have recently used semi-structured interviews to explore facilitators' and parents' point of view on a group-based psychoeducational program for parents of children with autism. They tested the acceptability of a program and its associated research procedures, for parents and facilitators, with the aim to assess feasibility of a more pragmatic, controlled trial of autism-related

parent-support programs. In their study, facilitators also reported that parents required more time to discuss topics such as behavior management, and that parents felt inhibited by the set structure of the interventions. They also noted that having too many participants resulted in insufficient time for discussion and affected parents' ability to engage with the intervention material. As Myers and Johnson (2007) noted, support groups can be perceived by participants as an opportunity to acquire knowledge and skills while sharing and bonding with others. The social support provided by other parents of autistic children can improve parental well-being (Catalano, Holloway, & Mpofuet, 2018; Derguy, Michel, M'Bailara, Roux & Bouvard, 2015; Hock, Yingling and Kinsman, 2015; Lovell, Moss & Wetherell, 2012; Samadi, McConkey & Kelly, 2012).

In addition, the fact that facilitators considered it relevant to give parents' voices a more significant place may have influenced the way they responded to the program's guidelines and therefore affected implementation. In the area of education, practitioner interpretation (Hudson et al., 2016) or adherence (Cook and Odom, 2013; Sheridan, Rispoli, & Holmes, 2013) may indeed influence the implementation of evidence-based practices. The program was elaborated in Quebec, where it is facilitated by psycho-educators. These professionals are specialized in prevention and intervention with people who have psychosocial adjustment difficulties. These fully recognized facilitators have certified knowledge in individual maladjustment and environmental dysfunctions, and possess specific skills in psychoeducational intervention planning and conduct (Renou, 1998). This aspect could explain why psychologists with no training or specific knowledge in this field could experience difficulties delivering the program. Giving facilitators more information about the objectives of psychoeducational interventions could help them understand how to deliver such a program. However, it is unlikely that one intervention could respond to the needs of all children and their parents, and it is equally unlikely that they all learn in the same manner

(Siller et al., 2013); hence the important role played by facilitators in providing individual support tailored to each participant, in order to facilitate a positive trajectory and the acquisition of new skills (Ilg et al., 2018). All of this could explain the value and time some facilitators gave to shared experiences and participants' comments.

Although the prescribed number of participants was rarely met, facilitators felt anxious about having to facilitate groups of eight parents. According to Palmer et al. (2019), groups of 6 to 10 parents are manageable and cost-effective, as well as large enough for discussion. Furthermore, taking part in the research could have been a barrier for the recruitment of some parents, but most parents easily accepted it. In France, parents are sadly rarely offered any kind of support (Sankey et al., 2019a). Indeed, results showed that the main barriers to parents' participation were making time in their professional or personal schedule and finding childcare solutions. Facilitators also often referred to the need to have more information on group facilitation and to benefit from supervision. Although the program does not officially include supervision, some facilitators found it beneficial to discuss with peers who had previous experience in program delivery, as their discussions were perceived as a form of guidance. Telesupervision could be a valuable tool, as this technology shows an amplified value for health professionals who work in areas where access to supervisors within their professional environment is diminished (Martin, Kumar, & Lizarando, 2017). Furthermore, viewing videotaped sessions could help illustrate the program's content and facilitation and possibly reduce the time required to understand the program.

Despite the immediate and mid-term benefits of the program on parental stress and quality of life (Cappe et al., under review), facilitators suggested providing parents with continuity after the program. Indeed, parents are prone to become isolated from friends and relatives who may struggle to understand the child's disorder (Rao and Beidel, 2009). Moreover, immense demands associated with their child also require sustained support from

external sources (Khanna et al., 2011). Group interventions have the added value of encouraging social support and sharing experiences (Farmer and Reupert, 2013).

Alongside psychoeducational interventions, parent-mediated interventions could provide a complementary assistance in helping parents to acquire the knowledge and strategies that enable them to interact more effectively with their child (Ilg et al., 2018). For example, *L'ABC du comportement d'enfants ayant un TSA: Des parents en action!* is a program based on the general principles of applied behavioral analysis (ABA) and emphasizes naturalistic intervention strategies that respond to parents' need for more practical solutions (Ilg et al., 2018). Another example, in the field of autism, is the PACT, which is a parent-mediated intervention focused on social communication. This intervention has clear benefits for parent-child dyadic social communication, especially with regard to parental synchronous response to the child, child initiations with parent and parent-child shared attention (Green et al., 2010). Such parent-mediated interventions focus on acquiring behavioral techniques and produce some positive language and behavioral change in children, and increased parental knowledge, skills and performance (McConachie and Diggle, 2007). Applying behavioral strategies to manage behavioral problems in autistic children also reduces parental stress (Iadarola et al., 2018; Ilg et al., 2018).

Considering the prevalence of mental health issues amongst these parents (Bonis, 2016; Da Paz and Wallander, 2017), providing continuity with an intervention that responds specifically to their psychological distress is essential. Problem-solving education in individualized sessions has proven to diminish parental stress and maternal depressive symptoms and could be an effective way to navigate this critical post-diagnosis period (Feinberg et al., 2014). Positive adult development (positive psychology practice) and mindfulness-based stress reduction group interventions have also shown to significantly

reduce stress, depression and anxiety, and improve life satisfaction amongst the primary caregivers of autistic children (Dykens et al., 2014; Jones et al., 2018).

Given that this program is delivered in multidisciplinary structures, physicians were often involved in recruitment, but the facilitators' involvement varied depending on the institution. Some facilitators were concerned about physicians' lack of familiarity with the program, which questions how the program was presented to parents. It seems that close collaboration of physicians and psychologists could help expand consideration of bio-psychosocial dynamics that impact health and healthcare (Gagne, 2005). Indeed, psychologists are experts in the evaluation and treatment of mental illnesses and are trained to work in tandem within an interdisciplinary team (Farmanova, Grenier, Chomienne, Hogg, & Ritchie, 2017). By working collaboratively with physicians, facilitators could evaluate aspects that could interfere in program delivery, such as parental mood, adjustment to the diagnosis announcement, needs, social-cultural background, language skills, and motivation to participate. Moreover, interdisciplinary medical teams that include psychologists facilitate access to effective treatments and lower healthcare costs (Blount et al., 2007). Despite the fact this collaborative concept is well understood, its implementation is hampered by organizational constraints in many institutions.

Finally, an important issue frequently raised was the impossibility for some parents to access the program because of family and professional constraints. As stated above, one of the main barriers cited was the difficulty to access childcare services, which was often due to the challenge of including typically developing peers and to the absence of resources to address the child's needs (Mereoiu, Bland, Dobbins, & Niemeyer, 2015). Ideally, an adjoining childcare service during program delivery could address this issue. Simultaneously providing sibling-mediated interventions should also be considered, as sibling involvement can lead to positive outcomes for an autistic child, including increases in skill acquisition or decreases in

problematic behavior (Shivers and Plavnick, 2015). Yet, this demands both logistical and human resources. Telehealth also represents a conceivable solution to limited access. It has been shown to be acceptable for parents of autistic children, and therapists could reliably deliver treatment (Bearss et al., 2018). Recent studies support an initial evidence-based efficiency of these interventions when delivered by computer with the presence or absence of therapist assistance for these parents. For example, self-directed and therapist-assisted telehealth-based parent-mediated interventions have been shown to help parents in intervention fidelity, self-efficacy, stress, and positive perceptions of their child, with greater gains for the therapist-assisted group in parent fidelity and positive perceptions of their child (Ingersoll, Wainer, Berger, Pickard, & Bonter, 2016). This alternative delivery method deserves further consideration for isolated or busy parents interested in the program.

Limitations and strengths

Most facilitators were contacted several weeks after delivering the program, which may have diminished the level of detail in the information reported. In addition, we did not control for the facilitators' level of experience or specialization. This might have influenced the way they implemented the program. In particular, some more than others, may have felt it was important to spend time on topics that parents brought up even though they were not formally covered in the program. Indeed, some authors underline the importance of taking into accounts take holders' skills when implementing a program and providing additional training if needed, in order to bolster skill level and to ensure high quality implementation (Stith et al., 2006). In addition, the analysis was performed on all interviews, with no distinction between services where parents received additional individual support and those where they did not. This difference may have influenced the facilitation experience. Furthermore, our study did not consider parental perceptions of the program. Literature on parents' perspectives and their views on the effectiveness of autism-related programs is

scarce. Hence, the need to evaluate parents' point of view on the support they are receiving, and on the type of support and services they would like to receive in the future (Galpin et al., 2018). Including an assessment of the parents' experience using quantitative and qualitative data could also provide precious support for successful implementation (Stahmer et al., 2017). Therefore, future evaluations of the program should consider placing family at the heart of decision-making and grasp their views on how the program may respond to their specific needs.

Our study also presents important strengths. The expanding interest in autism-related programs for parents requires gaining deeper understanding of the elements impacting implementation in order to seek program optimization. Cook and Odom (2013) underlined that the majority of published researches in special education did not provide much information about real-life program intervention context. This study focuses on data such as participant mobilization, program adaptability to changes and unexpected events, and professionals' perceptions on program functionality and needed resources. It presents an important environmental sensitivity for which a qualitative approach is perfectly suited. The results of this study contribute to our understanding of the factors influencing fidelity of implementation (Hudson et al., 2016; Sheridan, Rispoli, & Holmes, 2013) and therefore to improve the assessment of effectiveness of psychoeducational programs for parents of autistic children. These results add to the quantitative findings previously obtained in our larger research project, including more explicit measures of social validity and fidelity of implementation (for more details, see Sankey et al., 2019b and Cappe, et al., in press). This study also provides practical information for the field, as well as useful information for professionals involved in the implementation and delivery of psychoeducational programs. Even though this study fills a gap by highlighting facilitators' perspectives, further qualitative research should include the perspectives of all program stakeholders (parents and/or

physicians), rather than just those of the facilitators. In the area of education, parents and facilitators may identify different features of programs as important, and parenting programs developers should therefore also seek the views of parents as a factor influencing parental engagement (Mytton, Ingram, Manns, & Thomas, 2014).

Conclusion

The increasing prevalence of diagnosed cases of autism in the population has considerably increased the number of services and programs (Brugha et al., 2011). Commonly used early interventions such as the *TEACCH* or *Early Start Denver* program (Dionisi, 2013; Schroder et al., 2015) no longer specifically focus on the child, but consider parents as active and precious allies in autism treatment, as they are prone to practice skills with their child throughout their everyday lives (Nevill et al, 2018). Psychoeducation addresses this need to involve parents in the child's care and management. Qualitative studies may help issue recommendations to improve psychoeducational programs delivery and implementation. Doing so may improve the program's quality and accessibility, and help bridge the gap between research and practice. Recommendations to optimize the program's implementation and delivery are presented in Box 2.

Box 2

Recommendations to optimize the program's implementation and delivery

- | | |
|---|--|
| 1. Optimize program comprehension and facilitation for facilitators | <ul style="list-style-type: none">• Provide further information to clarify the specifics of psychoeducation model and related group facilitation methods.• Facilitate program comprehension with visual tools such as videotaped sessions.• Provide access to a form of telesupervision. |
| 2. Respond to parents' need to be offered a form of continuity | <ul style="list-style-type: none">• Offer access to parent-training programs focused on the acquisition of behavioral competences, such as <i>L'ABC des comportements : des parents en action !</i>• Recommend group interventions to alleviate psychological distress such as Positive Adult Development or Mindfulness-Based Stress Reduction programs and/or individualized sessions of Problem Solving Education. |
| 3. Optimize program recruitment | <ul style="list-style-type: none">• Include facilitators in a multidisciplinary approach in the recruitment process, in order to identify parents' bio-psychosocial characteristics that could impact program delivery. |
| 4. Facilitate program access | <ul style="list-style-type: none">• If possible, offer the access to an adjoining |

childcare service during sessions.

- Consider providing access to a telehealth format to expand access to more isolated parents.

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Table 1

Facilitators' characteristics (N= 18)

	Complete version <i>n</i> = 10	Shortened version <i>n</i> = 8	Total <i>N</i> = 18
Females <i>n</i> ; %	9; 90%	8; 100%	17; 94,5%
Number of groups facilitated <i>M(SD)</i> [range]	1.5(1.2) [1-5]	1.6(1.1) [1-4]	1.55(1.15) [1-5]
Professional experience as a psychologist in years <i>M(SD)</i>	6.7(4.7)	8.3(3.9)	7.4(4.3)
Experienced with autistic children or adolescents <i>n</i> ; %	10; 100	8; 100	18; 100
Experienced with parents of autistic children <i>n</i> ; %	9; 90	5; 63	14; 77,78
Experience in autism in years <i>M(SD)</i>	8.1(5.3)	8.4(4.2)	8.2(4.8)
Additional training in			
<i>Autism n</i> ; %	7; 64	5; 63	12; 63
<i>TEACCH</i> ¹ <i>n</i> ; %	2; 18	4; 50	6; 32
<i>PECS</i> ² <i>n</i> ; %	7; 64	4; 50	11; 58
<i>ABA</i> ³ <i>n</i> ; %	1; 8	4; 50	5; 26
<i>Group facilitation n</i> ; %	3; 28	1; 13	4; 21

¹ Treatment and Education of Autistic and related Communication handicapped CHildren² Picture Exchange Communication System³ Applied Behavior Analysis

Appendix

Interview outline

Tell me how the program went.

Tell me about how you set up the group(s) you facilitated.

If you came across difficulties in the planning stage, what were they? How did you overcome them? How did you work with your fellow facilitator?

Let's now talk about how the workshops went.

Did you have to adapt/amend some activities? (If so, explain which ones, why and how).

Which activities were the easiest/most difficult to facilitate?

According to you, did participants' characteristics influence the organization of workshops, and if so, how?

Let's now talk about the training you should have received before facilitating the program during the program. How did it influence the program as a whole?

To conclude, what are your general impressions on the program?

Are there any comments or recommendations you would like to share with us?