FREQUENT BEHAVIOURAL CHALLENGES IN CHILDREN WITH FETAL ALCOHOL SPECTRUM DISORDER: A NEEDS-BASED ASSESSMENT REPORTED BY CAREGIVERS AND CLINICIANS

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ABSTRACT

Objective
Despite substantial research characterizing the brain injury, a significant gap still exists in providing timely and effective care for children with Fetal Alcohol Spectrum Disorder (FASD). The objective of this study was to conduct a needs assessment that could help inform intervention programs and appropriate strategies to manage challenging behaviours targeted to families impacted by FASD.

Methods
Sixty caregivers and 26 clinicians from across Canada completed a semi-structured telephone interview.

Results
Caregivers reported that the most challenging behaviour categories were "Externalizing Behaviours", "Cognitive Difficulties", and "Social Difficulties/Maladjustment", whereas the most successful parenting strategies were "Parental Reflection", "Routine/Structure/Consistency", and "Environmental Modification". Clinicians reported that "Insufficient Support/Knowledge from Health and Social Professionals and Agencies" and "Behavioural Difficulties/Challenges" were the most common concerns from caregivers of children with FASD.

Conclusions
The number and extent of challenges reported make it evident that there are many unmet needs that compromise the quality of life for these caregivers, their children, and their families. These data will be used to inform the development of an intervention program that will provide a family-centered approach to training, education, and support for children with FASD and their families.

Key Words: *Fetal Alcohol Spectrum Disorder; child behaviours; parenting strategies; support*

Consumption of alcohol during pregnancy can be harmful to the developing fetus and lead to long-lasting disability. The term Fetal Alcohol Spectrum Disorder (FASD) has been widely adopted as an umbrella term to capture the full range of adverse developmental outcomes that may occur in individuals with prenatal alcohol exposure.[1,2] FASD is the leading non-genetic cause of developmental disability in Canada and a major public health issue.

The brain injury associated with FASD can manifest as cognitive difficulties in areas such as working memory and executive functions[3-5], and various secondary disabilities such as maladaptive behaviour, psychiatric conditions, and problematic alcohol/drug use[6-9], especially when untreated. Depending on the severity of their disability, individuals with FASD can struggle to live independently and often require lifetime supports to meet the demands of everyday life.

To date, there is a paucity of research on interventions for FASD that are evidence-based. Of the therapeutic programs available, many lack the necessary scientific rigor needed to show demonstrable efficacy.[10-12] Moreover, most interventions have not been tailored to the FASD population and have not benefited from the insight of caregivers, whose firsthand experiences could be used to develop customized intervention and treatment programs for FASD.

Present Study

The goal of the present study was to conduct a needs-based assessment of caregivers who have children with FASD between the ages of 4 and 12 years, to collect information about FASD from the perspectives of caregivers and also from clinicians with expertise in the field. This age range was targeted because interventions provided during childhood and adolescence can help to prevent the development of secondary disabilities (e.g., disabilities not present at birth).

METHODS

Study Design

The study protocol and procedures were reviewed and approved by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board and the IWK Health Centre Research Ethics Board. Established research collaborations[13,14] served as the vehicle for recruiting caregivers and clinician participants affiliated with diagnostic clinics and community support groups across Canada (Children’s Hospital of Eastern Ontario, Hotel Dieu Hospital Kingston, St. Michael's Hospital Fetal Alcohol Spectrum Disorder Diagnostic Clinic, Manitoba FASD Centre, Saskatchewan FASD Support Network, and the Healthy Generations Family Support Group – Community Living Sioux Lookout). Additional participants were recruited through web-based advertisements and word of mouth.

Participants

The sample consisted of 60 caregivers of children with FASD, aged 4-12 years and 26 clinicians from across Canada, with extensive expertise in FASD. Demographics for caregivers, children and clinicians are presented in Tables 1, 2 and 3, respectively.

TABLE 1 Caregiver Demographics

Characteristics	**Total Sample (N=52)**
Sex of primary caregiver, n (%)	
Male	5 (9.6)
Female	47 (90.4)
Age of primary caregiver (y), n (%)	
20-29	1 (1.9)
30-39	9 (17.3)
40-49	21 (40.4)
50-59	17 (32.7)
>60	4 (7.7)
Marital status, n (%)	
Married/common law	39 (75)
Single, separated, or divorced	12 (23.1)
Widowed	1 (1.9)
Highest level of education, n (%)	
Some high school	2 (3.8)
High school diploma	6 (11.5)
Some College/Diploma	22 (42.3)
Some University/Degree	20 (38.5)
Professional/graduate	2 (3.8)
Relation to child, n (%)	
Biological parent	4 (7.7)
Biological relative	8 (15.4)
Adoptive parent	33 (63.5)
Foster care	7 (13.5)
# Of children in family home, n (%)	
1-2	29 (55.8)
3-4	15 (28.8)
≥5	8 (15.4)
# Of children in family home diagnosed with FASD, n (%)	
1	28 (53.8)
2	14 (26.9)
3	3 (5.8)
≥ 4	4 (7.7)
Undiagnosed**	3 (5.8)

TABLE 2 Child Demographics

Characteristics	Total Sample (N=52)
Child sex, n (%)	
Male	28 (53.8)
Female	24 (46.2)
Child age (y), n (%)	
4-6	13 (25)
7-9	17 (32.7)
10-12*	22 (42.3)
# Of comorbid condition(s), n (%)	
0	18 (34.6)
1	14 (26.9)
2	9 (17.3)
≥ 3	11 (21.2)
Age of FASD diagnosis (y), n (%)	
At birth	6 (11.5)
1-4	12 (23.1)
5-8	21 (40.4)
9-12	9 (17.3)
Undiagnosed**	3 (5.8)
Did not report	1 (1.9)
Foster care placements, n (%)	
0	19 (36.5)
1	16 (30.8)
2-4	11 (21.2)
>4	6 (11.5)

*3 of the children had turned 13 by the time of the interview
**Suspected/Awaiting diagnosis

TABLE 3 Clinician Demographics

Description	Total Sample (N=26)
Job Title, n (%)	
Medical doctor	11 (42.3)
Clinical (Psychology/Neuropsychologist	4 (15.4)
Occupational Therapist	2 (7.7)
Social Worker	3 (11.5)
Other (Support personnel etc.)	6 (23.1)
Years in the field, n (%)	
< 5	4 (15.4)
5-10	3 (11.5)
11-15	5 (19.2)
16-20	2 (7.7)
> 20	10 (38.5)
Did not report	2 (7.7)
Categories for Client with FASD, n (%)	
All ages	5 (19.2)
Infants, Children, & Teens	5 (19.2)
Infants & Children	2 (7.7)
Children & Teens	5 (19.2)
Children, Teens, & Young adults	4 (15.4)
Other	3 (11.5)
Did not report	2 (7.7)

Of the 60 caregivers who participated in the study, forty-one provided their own and forty provided their child's ethnic background. Thirty-one (52%) caregivers were Caucasian and ten (17%) were Aboriginal (12% First Nations, 3% Metis, and 2% not specified). Sixteen children were Caucasian (27%) and twenty-four (40%) were Aboriginal (22% First Nations, 3% Metis, 2% Inuit, and 13% not specified).

Thirty-four children (65%) had one or more comorbidity (Table 2). Attention Deficit/Hyperactivity Disorder (60%) and Oppositional Defiant Disorder/Conduct Disorder (19%) were the two most common comorbidities.

Twenty-six clinicians participated in the study, from a variety of professional backgrounds, with between 5 and more than 20 years of experience in treating children, youth and young adults with FASD (Table 3).

MEASURES

Child Behaviour Checklist (CBCL)

Caregivers were asked to complete the CBCL. The CBCL consists of eight syndrome scales (anxious/depressed, withdrawn/depressed, somatic complaints, social problems, thought problems, attention problems, rule-breaking behaviour, and aggressive behaviour), which are grouped into two higher order factors: internalizing and externalizing behaviours. CBCLs were mailed to each caregiver and, upon completion, they were instructed to return the forms to the research team using the self-addressed, stamped envelope provided.

Center for Epidemiologic Studies Depression Scale (CES-D)

Caregivers were asked to complete the CES-D over the telephone with the interviewer. The CES-D is a screening measure that was developed to identify current depressive symptomatology related to major or clinical depression in adults and adolescents. A CES-D score above twenty-one is indicative of major depression and caregivers scoring in this range received a letter urging them to seek medical attention. A CES-D score between fifteen and twenty-one is indicative of mild to moderate depression.

PROCEDURE

Information on FASD Behaviours (IFB) Telephone Questionnaires

To conduct the needs-based assessments, two comprehensive telephone questionnaires were developed in-house: one for caregivers (Table 4) and one for clinicians (Table 5). All questions were designed to be open-ended to ensure that participants could elaborate on their personal experiences, as they felt it related to the question. Twelve caregivers opted to provide written responses to the questions. Consent was obtained for all participants, except in the case of two caregivers, who opted to send written responses to the interview questions and with whom no further follow-up was possible. Their data sets were excluded from the results.

During the interview phone call with the clinicians, demographic information was collected and the IFB questionnaire for clinicians was conducted. Five clinicians provided written responses to the questionnaire. All other interviews, both caregiver and clinician, were recorded for later transcription and coding.

TABLE 4 Information on FASD Behaviours – Caregivers

Main Question	Follow Up Questions
1. What situations are the hardest for you and your child with FASD?	What happened? Where it happened? When it happened? And, if you know Why it happened? Are there any other different situations?
2. What did you do?	What do you think was a good response? What do you think was a bad response?
3. What types of things make it hard for you to have a child with FASD (e.g., the reactions of others, lack of help from teachers, doctors etc.)?	
4. What things make it easy for you to care for your child with FASD (e.g., special help at school, support groups)?	
5. Do you currently feel that you are getting enough support to deal with your child with FASD?	
6. What do you think the government or other FASD groups could do to make helping your child with FASD easier?	
7. What would be the best way to deliver this assistance to you (e.g., support groups, telephone, professional, the internet)?	Why?

TABLE 5 Information on FASD Behaviours – Clinicians

Main Question	Follow Up Questions
1. In your experience with the FASD population, can you please describe the major challenges and concerns that parents/caregivers express (i.e., specific behaviours or trouble with school etc.) when dealing with their affected child(ren)?	Please include how you support them with these challenges and concerns.
2. What are the major limitations that parents/caregivers report when it comes to obtaining services and supports for their children?	
3. What are the major limitations that you have encountered when providing care and support for families affected by FASD (i.e., Do they forget their appointments? Is there not enough time to spend with them? Are you unsure where or to whom to refer them?)	
4. Based on your experience, do you think an online/internet-based intervention is appropriate for the FASD population?	Why or why not? If yes, what is the most important feature to include/incorporate into the design of this intervention?
5. What could the government or FASD advocacy groups do to help you support and care for children with FASD and their families?	

Data Analysis

Descriptive content analysis was chosen for this study, as the goal was to further understand the experiences of the parents and clinicians through narrative rather than statistics. The data generated from the IFB was compiled and analyzed to identify common themes among responders. *In vivo* coding was chosen over *a priori* coding, as the goal of the research was to capture the major challenges that the caregivers identified in living with a child with an FASD. A coding manual was created after randomly selecting a sample of IFB transcripts, which were reviewed by three members of the research team, to create an initial set of categories and subcategories that captured the participant's responses to the IFB interview. Categories were generated to organize the answers (e.g., externalizing behaviours), and when needed, sub-categories were included to add further specificity to the data (e.g., hyperactivity). Categories were generated based on the manifest content of the interviews and therefore low inference descriptions of the content were used. After the creation of the initial set of codes, the remaining IFB transcripts were coded accordingly.

Separate analyses were performed for Caregiver and Clinician interviews. The coding team was comprised of three members of the research team and each team member coded one third of all the interviews (i.e., 2 coders per interview). Due to the design and open-ended nature of the questions in the IFB, participants could provide more than one answer to each question. Inter-rater reliability for the coded interviews was evaluated in a randomly selected sample (from both the caregiver and clinician groups) using Cohen's kappa coefficient (SPSS 21, IBM Software, Armonk, NY, USA).

RESULTS

Demographics

For the caregiver interviews, participants resided in Alberta, British Columbia, Manitoba, Northwest Territories, Ontario, and Saskatchewan. For the clinician interviews, there were representatives from Alberta, British Columbia, Manitoba, New Brunswick, Nunavut, Ontario, Prince Edward Island, and Saskatchewan.

Child Behaviour Checklist (CBCL)

Forty-one CBCLs were completed and returned; however, the data from one participant was excluded as too many questions were left unanswered and appropriate scores for each category could not be computed. The mean ± SEM T-scores for 40 children with FASD are presented in Figure 1. There were two categories in the borderline clinical range (Social Problems and Rule-Breaking Behaviour) and three categories were clinically significant (Thought Problems; Attention Problems; and Aggressive Behaviour).

The average T-scores for the three remaining categories: “anxious/depressed”, “withdrawn/depressed”, and “somatic complaints” were near the borderline clinical range.

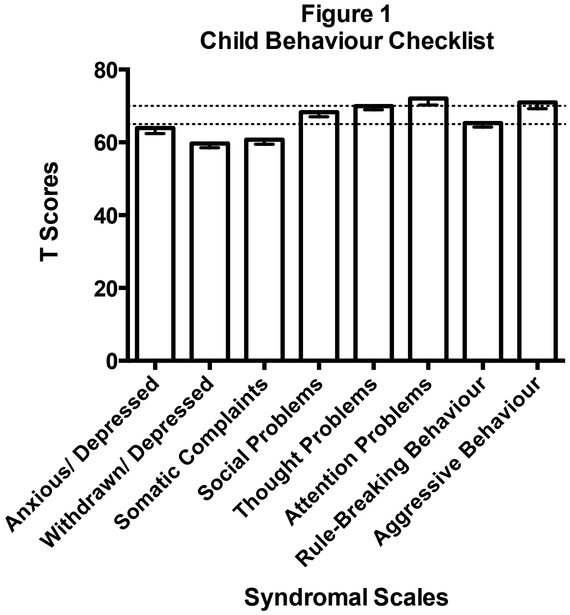

Figure 1: Caregiver ratings of children with FASD obtained from the Child Behavior Checklist (CBCL). Data are presented as the mean ± s.e.m. of the standardized (T-score) results obtained from 40 CBCL questionnaires. In this cohort of children with FASD, caregivers identified three behavioural categories (Thought Problems, Attention Problems, Aggressive Behaviour) that were in the clinically significant range (T-score > 70), whereas two categories (Social Problems, Rule-Breaking Behaviour) scored in the borderline clinically significant range (T-score between 65-69). The borderline clinical range is delineated between the two dotted lines and clinically significant behaviours are above the second dotted line

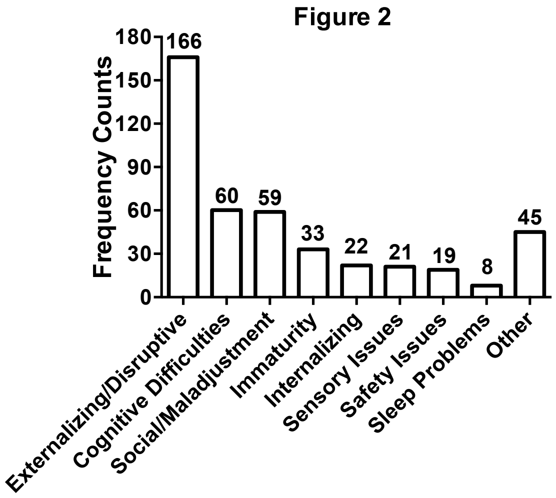

Figure 2: Caregiver responses to the question “What situations are the hardest for you and your child with FASD? **What** happened (i.e., types of behaviours/difficulties)?” Interview data were coded and scored by two independent raters, and are presented as frequency counts (number of occurrences) in the eight major categories defined in the coding manual.

Center for Epidemiologic Studies Depression Scale (CES-D)

Fifty-two caregivers completed the CES-D. Six (11.5%) caregivers had a clinical score (>21) indicative of Major Depression; nine (17.3%) scored within the Mild-Moderate or threshold range (15-21) and thirty-seven (71.2%) were below the clinical range.

Information on FASD Behaviours (IFB) Telephone Questionnaires

The open-ended format of the caregiver telephone interviews resulted in an extensive amount of qualitative data. On average, each interview lasted 1.5 hours and caregivers readily elaborated on their personal experiences, which were categorized using the in-house developed coding manual. In the cases where inter-rater reliability was "fair" or "moderate", the raw data scores for the "expected count" (i.e., what would be expected based on the parameters and null hypothesis) were compared to the "observed count", and in all cases the rater agreement level was above chance.

Figure 3

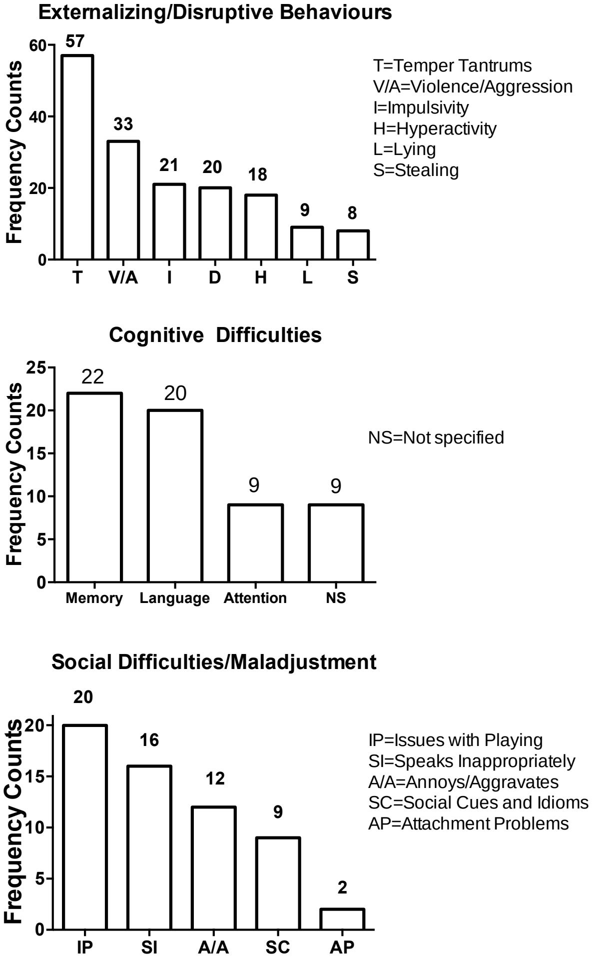

Figure 3: Caregiver responses to the question "*What situations are the hardest for you and your child with FASD?* ***What*** *happened (i.e., types of behaviours/difficulties)?"* Interview data were coded and scored by two independent raters. Data from the top three categories (Externalizing/Disruptive Behaviours; Cognitive Difficulties; Social Difficulties/Maladjustment) are further broken down into specific behaviours/deficits and reported as frequency counts (number of occurrences).

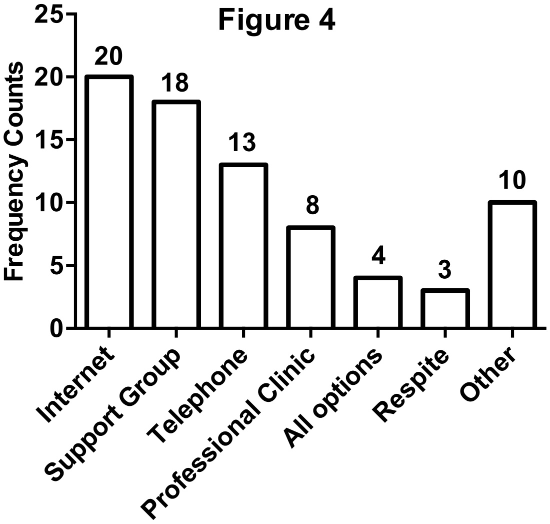

Figure 4: Caregiver responses to the question "*What would be the best way to deliver this assistance to you (e.g., support groups, telephone, professional, the internet) and why?"* Interview data were coded and scored by two independent raters, and are presented as frequency counts (number of occurrences).

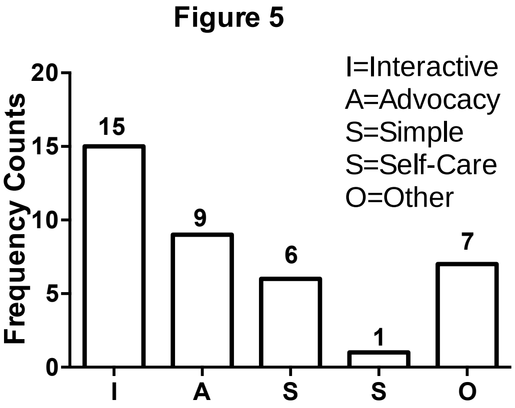

Figure 5: Clinician responses to the question "*What is the most important feature to include/incorporate into the design of this [an on-line] intervention?"* Interview data were coded and scored by two independent raters, and are presented as frequency counts (number of occurrences).

TABLE 6 Parental Responses to Child Behaviour

a) Good Responses

Code	**Included**	**Count**
Parental Reflection Strategies	Learning from previous experience Having realistic expectations Putting yourself in the child's shoes Pin pointing what is right for your child Remaining calm Understanding what is and isn't in the child's control	61
Using Verbal Situation Specific Instruction/Explanation/ Encouragement	Instructions used for reminders or prompting Instructing child how to do something Explaining why something is wrong Encouraging child to try something new	55
Provide Routine/Structure/Consistency	Visual schedules Count downs Timers Reminders Prompts	48
Environmental Modification	Leaving or avoiding a situation Going to places at specific times Changing child's personal space	33
Extinction Strategies (Providing no negative reinforcements)	Using distraction/diversion Ending an argument and leaving Letting a bad behaviour run its course Not overemphasizing a bad behaviour Not acting embarrassed	25
Sensory and Calming Techniques (Reducing sensory overload)	Using headphones Breathing techniques Deep pressure Specific food preparation	25
Use Visual Aids (excluding visual schedules)	For calming, communication and/or instruction	19
Providing Safety and Using Supervision		18
Provide Medication and/or Supplements		14
Advocate/Public Education	At school/daycare In community and/or with family	14
Change School and/or Educational Setting		9
Other		33

TABLE 7 The most common challenges and concerns reported by parents to clinicians

Code	Included	Count
Behavioural difficulties & problems	Social skills Sensory integration Externalizing behaviour Executive function	20
Issues with professional institutions	Problems with Children Aid Society (CAS) Problems with school system Lack of advocacy by professionals Interventions are unsuccessful/partially successful	18
Lack of……	Diagnostic capacity Respite Services/Supports Funding Knowledge	13
Emotional impact on caregivers	Parents are blamed and misunderstood Parents feel isolated Future worries about their child Expresses concern/worries	11
Confusion	Parents do not know what is wrong with their child Parents do not know what they need (i.e., supports etc.)	9
Relationships	Challenges of building positive relationships Effects on marriage and family	6
Inequalities in service delivery	Non-integrated services Segregated services by regions	3
Other		1

TABLE 8 Major limitations reported by caregivers to clinicians when accessing services and supports for their child

Code	Included	Count
Lack of knowledge, awareness and training	Within the education system By service providers Marginalization/blame of parents	18
Services/Supports are not accessible	Services are full or unaffordable Geographic barriers Long waitlists No/not enough funding	16
Services/Supports do not exist* *(*Explicitly had to say "no", "lack" or "do not")*	No family focused interventions Lack of diagnostic clinics	15
Parental knowledge and capacity	Trouble accessing/navigating the system Parents do not know what to ask for/where to go	11
Other		1

Caregiver Interviews

Selected data sets where the inter-rater reliability was moderate to good are presented in Figs. 2-4 and Tables 6-8.

***Question 1:** What situations are the hardest for you and your child with FASD? **What** happened (i.e., types of behaviours/difficulties)?*

The three top response categories were "External/Disruptive Behaviours" (166 counts), followed by "Cognitive Difficulties" (60 counts) and "Social Difficulties/Maladjustment Issues" (59 counts) (Fig. 2). The sub-category breakdown for each is presented in Figure 3. Daily behavioural challenges were extremely common for most parents who were interviewed and occurred at home, in public, and at school. The following quotations are examples of situations describing the types of challenging behaviours exhibited by children with FASD.

At home:

"For X, it changes moment by moment. X has a lot of yelling, like X yells, X doesn't talk. So if X wants something, X yells at you, X demands it."

In public:

"I think it's probably just the general public. You know, you're out shopping and they see X having a fit, and you're just, yeah, okay, keep going, come on."

At school:

"They [school] still don't understand…..how to effectively support a child with FASD, with X's specific issues. Because X tends to have disruptive behaviour, so they can't deal with that very well."

Cognitive difficulties are commonly associated with an FASD diagnosis. For caregivers that were interviewed in this study, these difficulties were sub-categorized into "memory", "attention", "language", and "learning disabilities". In the following example, the parent expresses confusion and frustration over the child's behaviour as to whether the child is "acting out" or whether the behaviour is due to memory deficits. In this quotation, the parent and child were working on a journal of their trip on the train.

"And with fetal alcohol, it's hard to know sometimes if X's playing dumb or if X really doesn't know. And I think that's the hardest thing for me…..where we're having memory issues, they have good days and bad days. …..And we're sitting and we had the notes, we'd read the notes and I said, okay, make a sentence so we can describe this. Well, I don't remember. Well, okay, here's the words, and if you can't read them, I'll read them to you. You know we got on a train. Do you remember we were going on the train? No. And it's like, I said, okay, it's written right here. What's this word? And X can read at grade six level, [but] X comprehends at a grade two level."

For many children with FASD, their chronological age does not reflect their mental (functional) age. This can make social situations and interactions difficult, particularly with friendships. In this quotation, the parent expresses concern for her child at school: "… it's not elementary school any more, and how is X going to keep up with the rest of the group? It's going to be hard, because socially as well, X's more of a loner. In terms of, X'll be playing [by himself/herself], X'll be very happy, but with other people it's kind of hard."

***Question 2:** What do you think was a good response? What do you think was a bad response?*

Table 6 outlines the most common "good" and "bad" parenting responses reported by caregivers when dealing with difficult behaviour. The top "good" response was "Parental Reflection", which included "learning from previous experience", "having realistic expectations", "remaining calm", and "trying to see things from the child's point of view".

One parent described their strategy for dealing with challenging behaviours in this way: "I think, I take time, I walk away, I go to my visual fix, or I pick up the phone. So the phone thing we've done, for one of us to call somebody we know to talk to, to get us out of it, or we've also trained X to use the phone. We dial it, but then X has four people X can call to de-escalate." "Aggression", which included teasing, bullying, raising voice, becoming frustrated, losing patience, and force were the most frequent “bad” responses reported by parents.

In this example, a parent describes a “bad” response to difficult situations: “….so if I rush X and if I become angry and frustrated, that doesn’t help.”

Question 7*: What would be the best way to deliver this assistance to you (e.g., support groups, telephone, professional, the internet) and why?*

After asking caregivers ways of delivering assistance to them, the most common response category was “Internet” (20 counts), followed by “Support Groups” (18 counts), and then “Telephone” (13 counts) (Fig. 4). Interestingly, providing information via the Internet was the top response because of the versatility, convenience, and online resources.

One parent stated: “Again, that isolation thing, the Internet might be the best……because you can do so much more than [just] read text on a website. There’s YouTube and the videos you can post, and the podcasts and audio, so there are a number of tools that…..can be done.”

Clinician Interviews

Selected data sets are presented in Tables 7 and 8 and Figure 5.

Question 1a: *In your experience with the FASD population, can you please describe the major challenges and concerns that parents/caregivers express (e.g., specific behaviours or trouble with school etc.) when dealing with their affected child(ren)?*

Clinicians reported that the most common challenges and concerns reported by parents were “Behavioural Difficulties and Problems” and “Insufficient Support/Knowledge from Health and Social Professionals and Agencies” (Table 7).

As described by one clinician: “So it’s that philosophical shift that Diane Malbin talks about, from “won’t” to “can’t”, and from understanding this is a brain injury…They don’t habituate, they don’t generalize, they have memory problems, they confabulate all over the place. They’re not lying; it feels like lying, but they’re confabulating because it’s filling in the gaps of your memory in the presence of brain injury.”

Question 2: *What are the major limitations that parents/caregivers report when it comes to obtaining services and supports for their children?*

The top limitation reported by clinicians when it came to accessing services and supports was a “Lack of knowledge, Awareness, and Training” (Table 8). It was also apparent that clinicians find a lack of cohesiveness among services and within ministries as it relates to supporting individuals with FASD and their families.

This was frustrating for all involved, as several clinicians reported: “We’ve got the skills and knowledge out there, it’s just in little piles, and they don’t talk to each other…..The ministries don’t talk to each other either” and “Lack of understanding. The people aren’t there to support them properly because they don’t understand the disability.”

Question 4b: *What is the most important feature to include/incorporate into the design of this [an on-line] intervention?*

Clinicians provided several important suggestions for developing an online intervention tool. Most important was the inclusion of “Interactive Features” (Fig. 5). “And I think the potential for perhaps even interactive stuff, some new modules and things that would kind of show up or having some responsiveness to what people are wanting, I think that could be great.”

As well, “Advocacy and Family Relationships”, which included teaching parents how to support one another was also suggested as an essential component to the program. Because caring for a child with FASD can pose significant strain on the family, it is critical that parents learn appropriate skills that can help them maintain positive relationships with their partners and support persons.

As one clinician said: “….the first thing to do to help parents is to help them get on the same page. I think that’s the most important thing, because the individual issues of the kid are going to change and evolve. I mean, [the child's] problems and need for support is not going to go away. But what could go away is his parents as a couple. And so, how do we more effectively and continuously support parents in just their relationships?"

Finally, clinicians felt that ensuring the program was "easy to use and clear" was critical to its overall success. "I think it just needs to be easy – families need to be able to easily manoeuvre through whatever program that you set up for them. Again, less is more I think for a lot of our families, because they are dealing with so many issues on a daily basis."

DISCUSSION

The purpose of this qualitative descriptive study was to obtain a better understanding of the challenges and concerns facing primary caregivers of children with FASD. The CBCL revealed clinically significant behaviours that are associated with an FASD diagnosis, whereas the CES-D questionnaire illustrated that caregivers might be at risk for moderate to severe depression. Whether these symptoms are the direct result of parenting children with FASD remains to be further elucidated; however, it is clear from the interviews that parents are struggling to meet their child's complex needs and that caring for them is an extremely exhausting experience. This may adversely affect not only their physical and emotional well-being, but also their ability to parent.

Recently, the "lived" experiences of fourteen participants with FASD (ages 14-37) were described.[15] The responses were categorized into six themes that included: "daily challenges in the classroom"; "daily challenges in the workplace"; "coping with mental health issues"; "memory issues"; "socialization issues"; and "involvement with the law and authority". Several of these themes are consistent with the major categories that were identified in this study, suggesting that without appropriate intervention, problems arising during childhood and early adolescence can persist into adulthood and extend into other facets of life, including vocation and justice.

In another study that examined the "lived" experiences of biological mothers who gave birth to a child(ren) with FASD, a range of issues and concerns related to the health, social, educational and judicial systems, as well as, a lack of knowledge by professionals and problems with diagnosis, oppression, and stigmatization were revealed.[16] Specific concerns included attention-deficits, absence of fear, diminished memory and comprehension, and an inability to understand consequences – many of which manifested as distinct behaviours such as excessive or no crying as a baby, lying, stealing, hyperactivity, destructiveness, sexual promiscuity, and having few friends. Again, the major commonalities to the data collected in this study indicate that an intervention program could also benefit biological mothers, despite their limited participation in this study.

Of note, the involvement of caregivers has been suggested as a key piece to the overall success of intervention programs for children with FASD. Using a parent-assisted protocol of the Children's Friendship Training program, O'Connor and colleagues demonstrated improvements in knowledge of appropriate social behaviours, improved overall social skills and a reduction in problem behaviours for children with FASD compared to a delayed treatment control condition.[17,18] The reliance on parents as facilitators of the program was highly successful and capitalized on their ability to teach their children how to translate learned social skills to naturalistic settings involving peer interactions. FASD education for caregivers, specific training on parenting strategies, and collaborations with community services are predictive for the success of intervention programs targeted for the FASD population.[11] Similarly, the Coaching Families program, which provides support, education, advocacy, and referrals to families of children with FASD, also revealed that family involvement was integral to the success of the program.[19] Moreover, there was a significant decrease in overall levels of caregiver stress after completing the program.

Due to the diversity of psychological and behavioural needs, it is important to recognize the fundamental role that caregivers play, not only in supporting treatment strategies for their children, but also as active players in program delivery. Moreover, caregiver involvement has the added benefit of achieving positive changes for their own quality of life. Caregivers report considerable stress and anxiety associated with caring for their children with FASD, at great personal expense (e.g., physical and mental health problems, relationship difficulties, compromised career aspirations, and financial burdens). It is anticipated that, with effective interventions that are family-centered, both children and their caregivers would experience profound and positive changes to their quality of life.

Caregivers interviewed in the current study indicated a preference for the Internet as the medium for delivery of intervention services, followed closely by support groups and the telephone. This may suggest that families are primarily looking for a better understanding of the disorder, which could be delivered using Internet-based resources, and a support network. Interestingly, this theme was paralleled by the clinician reports, which suggested that the lack of training and awareness (better understanding) and the lack of cohesion of services (support network) were the greatest challenges faced by families. Clearly, the accessibility and availability of services continues to be a major problem for families affected by FASD. Resources are provincially and territorially based, and can vary considerably within these geographical settings. For example, there are significant discrepancies in the types of services that are available to families who reside in rural parts of Canada compared to urban city centers. An intervention program that can overcome barriers to care[20,21] and provide effective healthcare support to the FASD population is therefore urgently needed. The current healthcare delivery model needs to change and extend beyond the traditional medical office. Healthcare service delivery needs to make use of current technological advancements to make programs more efficient and customizable. Distance healthcare treatment programs that provide telephone support have been associated with the development of a positive relationship with the support provider and a greater willingness on the part of the participant to disclose information.[22] Interestingly, 97% of participants who had completed a distance treatment program reported a preference for the distance treatment option compared to conventional face-to-face healthcare delivery[22], suggesting that distance delivery systems may be a promising approach to primary healthcare.

CONCLUSION

The number and extent of challenges reported in this study suggest that there are many unmet needs for children with FASD and their families. By capturing the unique perspectives of caregivers and clinicians with specific expertise and first-hand experience, this study has produced a large body of information that can be incorporated into intervention programs to meet the needs of the FASD population and their families.

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