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ORIGINAL PAPER

Building Circles of Support, an Education Series About Children and Adolescents with Prenatal Alcohol Exposure: A Preliminary Program Evaluation

Kristene Cheung[1,2] · Jen Theule[3] · Lisa Balcaen[4] · Laura Bennett[2] · Caelan Budhoo[3] · Ana Hanlon-Dearman[2,5] · Jo Ann Unger[1,2] · Meghan Dobie[2] · Michelle Ward[1] · Samantha Rennie[1]

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Abstract

Objectives The aim of the study was to learn if participating in an education series about Fetal Alcohol Spectrum Disorder (FASD), the Building Circles of Support (BCS) series, changes participants' (1) understanding of FASD, (2) understanding of child behavior, and (3) thoughts about themselves as caregivers. It also investigated participants' impressions of the program.

Methods Participants were recruited across three consecutive BCS series. Participants were eligible for the study by attending at least one BCS session. Six caregivers and eight supporters of children with FASD and prenatal alcohol exposure (PAE) were recruited. Data were collected before and after the series.

Results Participants reported enjoying and learning from the series. They suggested additional sessions on strategies, sleep, community resources, and time for connecting as attendees be included in future BCS series. There was not enough information to determine if caregivers' understanding of child behavior and thoughts about themselves as caregivers changed after the series; however, there were promising results to indicate an improvement in a caregiver's sense of competency post-series.

Conclusions This study highlighted that caregivers and supporters value an educational series about PAE and FASD, which may lead to improved caregiving. It also uncovered insights that can be used to improve the BCS series and future research studies.

Keywords Fetal Alcohol Spectrum Disorder · Education series · Prenatal alcohol exposure · Intervention · Program evaluation

Individuals with prenatal alcohol exposure (PAE) may be diagnosed with Fetal Alcohol Spectrum Disorder (FASD) if they exhibit clinically significant difficulties in at least three areas of functioning (e.g., cognition, academics, language; Cook et al., 2016) with or without physical features. FASD is one of the most prevalent neurodevelopmental disorders

✉ Kristene Cheung
Kristene.Cheung@umanitoba.ca

Jen Theule
Jen.Theule@umanitoaba.ca

Lisa Balcaen
fourfasd@icloud.com

Caelan Budhoo
budhooc@myumanitoba.ca

Ana Hanlon-Dearman
ahdearman@rccinc.ca

Jo Ann Unger
junger1@hsc.mb.ca

Meghan Dobie
mdobie@rccinc.ca

Michelle Ward
mward6@sharedhealthmb.ca

Samantha Rennie
Sammi.Rennie@umanitoba.ca

1 Department of Clinical Health Psychology, University of Manitoba, Winnipeg, Canada

2 Manitoba FASD Centre, Winnipeg, Canada

3 Department of Psychology, University of Manitoba, Winnipeg, Canada

4 4 FASD MB Inc., Lorette, Canada

5 Department of Pediatrics and Child Health, University of Manitoba, Winnipeg, Canada

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in Canada (Flannigan et al., 2018). Families of children and adolescents with PAE and FASD often experience a myriad of challenges (Balcaen, 2017), including high levels of caregiver stress (Ilchena et al., 2023) and strain on family relationships (Balcaen, 2017), both of which are related to child behavioral difficulties (Theule et al., 2013). Children with PAE and FASD may also be at higher risk for placement breakdown when living with foster families, which accounts for many families seen at Canadian diagnostic clinics (Canada FASD Research Network, 2019; Cook, 2022). Therefore, effective intervention and services for these families are imperative.

Caregiver attributions, that is, how caregivers explain a child's behavior (Weiner, 1985), fall on a continuum from willful/intentional to unintentional (i.e., neurodevelopmental or brain-based). Research has shown that caregivers who attribute their child's behavior to willfulness or intentionality have higher levels of caregiver stress (Eng et al., 2025; Rogerson et al., 2024), lower levels of caregiver sense of competence (Mash & Johnston, 1990; Steding, 2016), and experience more difficult child behavior (Arikan et al., 2019). The authors of one study found that caregivers of young children with PAE who used neurodevelopmental attributions were more likely to engage in proactive behavior strategies and reported greater success and confidence in their caregiving than those who used willful/intentional attributions (Petrenko et al., 2016). A greater understanding of FASD was also associated with a greater likelihood of using neurodevelopmental attributions, suggesting that more information about the disorder shifts caregivers' perceptions of their child's behavior.

Education-based programs have been shown to increase understanding of FASD, improve child behavioral functioning, and reduce caregiver stress (Petrenko & Alto, 2017). Building Circles of Support (BCS) is an 8-week educational series on FASD offered twice a year (once in-person and once virtually) to caregivers and service providers of children and adolescents with PAE. The program is geared towards and advertised only in Manitoba, based on the resources discussed/provided. BCS was created over 10 years ago as a community-based/meso-level iteration and extension of post-diagnostic follow-up for the FASD diagnostic clinic. Post-diagnostic follow-up is recommended in various studies (Lim et al., 2022) and the Canadian diagnostic guidelines (Chudley et al., 2005; Cook et al., 2016). This program was expected to help (a) increase FASD awareness in Manitoba, (b) service providers and caregivers feel better equipped to support children and youth with FASD, and (c) Manitobans develop a better understanding of the stigma associated with FASD and alcohol use during pregnancy. Each session focused on a separate topic of interest to caregivers and featured a guest speaker with expertise in that particular area. Caregivers were provided with handouts and other information concerning that specific topic. The sessions consisted of an educational component as well as a time for the audience to share or ask questions.

The series currently consists of eight 2-h sessions presented by clinicians, a caregiver of a child or adolescent with FASD, and adults with FASD. The sessions provide information on how FASD affects behavior, school performance, and social interactions; how to help others understand FASD; and how to assist children in understanding FASD and developing their strengths (please see Table 1 for a list of the sessions and topics). All sessions are scheduled in the afternoon on a weekday.

The frequency and duration of the series have remained the same over the years; however, the series was previously offered in the evenings rather than the afternoons. Some

Table 1 Description and attendance of sessions

Session[a]	Topic(s)	Most helpful[b]	Presenter	Attendance ($N=10$)		
				Live	Recorded[c]	Absent
1	Introduction of FASD	1	Clinical Specialist Occupational Therapist	90%	10%	0%
2	Sensory Processing	3	Occupational Therapist	90%	10%	0%
	Motor Skills	3				
3	Medications/Medical Issues	2	Developmental Pediatrician	70%	0%	30%
4	Psychology Assessments	2	Clinical Psychologist	80%	0%	20%
5	Speech and Language Pathology	2	Speech-Language Pathologist	80%	10%	10%
6	How to Talk to My Child about FASD	3	Social Worker(s)	100%	0%	0%
7	Parent's Experience with FASD in the Family	4	Caregiver of a child/adolescent with FASD	80%	0%	20%
8	Experiences of Adults with FASD	3	Adults with FASD	90%	10%	0%

[a]The order of sessions 2 to 7 varies based on presenter availability. Depending on presenter availability, the Sensory Processing and Motor Skills topics were sometimes paired with a different topic

[b]Number of participants who specifically identified this topic as the most helpful

[c]Not all sessions were recorded

topics and the length of the topics have evolved over time, including the addition of a session on psychology assessments. Previous iterations of the series included up to four sessions led by the diagnostic clinic's social worker(s), covering topics such as how parents can talk to their child about their disability, managing behaviors, and navigating adolescent issues. During this iteration, presentations from individuals with lived and living in-home and in-body experiences were not offered.

Previous BCS attendees have informally reported a greater understanding of FASD and their child's behaviors (i.e., attributions) and an improved sense of competence as caregivers following the program. Aside from these conversations, no formal evaluation of this program has been conducted. Moreover, it was unknown whether some participants benefit more from BCS than others or whether certain factors are related to greater gains from attending BCS. For example, attendees are encouraged to attend all sessions; however, caregivers often identify time restraints, a lack of resources, and stress as barriers to engaging in programming. Furthermore, caregivers at a recent public engagement event on FASD initiatives emphasized the importance of expanding services and support for children and families, including increased support for those without an FASD diagnosis (EngageMB, 2021). While BCS was initially offered only to caregivers of children and adolescents diagnosed with FASD at the diagnostic clinic, the series is currently open to anyone who supports children and adolescents. Given that children with PAE with and without FASD experience similar difficulties (Cheung et al., 2021, 2025), the content of many of the sessions may be relevant for caregivers of children with PAE without a formal diagnosis of FASD. Therefore, an educational program such as BCS may be beneficial for families on diagnostic clinic waitlists. Considering the length of the diagnostic clinic's waitlist, the stress experienced by caregivers on general neurodevelopmental service waitlists (Penner et al., 2024), and the desire for additional services—including education around FASD (EngageMB, 2021)—offering such a program to these families may provide some interim support and strategies. That said, it is currently unknown whether BCS is, in fact, beneficial to those who support children with PAE and/or FASD.

Objectives and Hypotheses

The objectives of this study were to examine whether attending BCS changes (1) participants' understanding of PAE and FASD, (2) caregivers' attributions of child behavior, and (3) levels of caregiver sense of competency. Based on limited research (Petrenko et al., 2016) and conversations with caregivers within the clinical context and at previous BCS sessions, we anticipated that attending the BCS series would (1) improve participants' understanding of PAE and FASD, (2) shift caregivers' attributions of challenging child behavior from maladaptive/negative to adaptive/positive attributions, and (3) increase caregiver sense of competency. The fourth objective was to identify potential gaps between what the participants hoped to learn and the information provided in the series.

Methods

Participant Eligibility

Any caregiver or service provider who attended at least one session of the BCS series was eligible to participate in this study. FASD diagnostic coordinators who support families in the diagnostic process were eligible to participate if they were new to their role (less than 9 months from their start date). For this study, "participants" refers to individuals who participated in the current study, and "attendees" refers to individuals who participated in the series regardless of whether they participated in the study. Informed consent to participate in this study was collected at the outset. Approval for this study was obtained from the University of Manitoba Bannatyne Research Ethics Board (HS25748, H2022:358) on February 16, 2023. This approval was most recently renewed on February 14, 2025. We also received approval from the Specialized Services for Children and Youth (SSCY) Research and Evaluation Committee (SSCY Centre Research Access – Ref #2209) to conduct this study on March 8, 2023.

Measures

We created the pre-series and post-series surveys in collaboration with our family partner, a caregiver of an adolescent diagnosed with FASD. We also consulted the Elder at the SSCY Centre about the surveys to ensure that the terminology used and constructs examined were acceptable, which led to changes in the wording of the questions (specifically adding a question about participants' understanding of PAE, not just FASD).

Pre-series Survey

The pre-series survey asked participants about their (1) role (caregiver or supporter/non-caregiver), (2) gender, (3) geographical location (rural or urban), (4) previous attendance at BCS, (5) reason for attendance, and (6) hopes for the series. We also asked caregivers about (1) their relationship to the child (birth, adoptive, or foster parent; or extended birth family); (2) the number of children/dependents in the home; (3) access to other FASD-related supports; (4)

whether they attended the session with another caregiver; (5) the age, gender, and sex of the child with PAE; (6) child diagnoses; (7) FASD diagnostic assessment status (referred, waitlist, or post-diagnosis); and (8) date of diagnoses, if applicable. Supporters/non-caregivers in this study did not identify as caregivers of children or adolescents with PAE or FASD, but they supported children or adolescents with PAE or FASD in a non-caregiving role; however, they may also serve as caregivers in other capacities. Supporters included educators in the education system, service workers, and other professionals who support individuals with PAE or FASD. To address Objective 1, all participants were asked about their understanding of PAE and FASD. Without a validated questionnaire that aligns with the Language Guide to promote the dignity of those with FASD and their families (MB FASD Coalition Inc., 2017) or recommendations for common messages (Canada FASD Research Network, 2024), understanding of FASD was assessed using this open-ended question: *Tell us about FASD. For example, what are some symptoms or behaviors related to FASD, what does it look like, or how does it present itself?*

To address Objectives 2 and 3, the pre-series survey also included two questionnaires to assess caregiver outcomes. We assessed caregivers' sense of competency using the Parenting Sense of Competence Scale (PSOC; Gibaud-Wallston & Wandersman, 1978; Johnston & Mash, 1989), which has been previously used with caregivers of children with FASD (Kautz et al., 2020; Petrenko et al., 2016; Roger, 2015). The PSOC has also been previously used with caregivers of children with intellectual disability (Jandrić & Kurtović, 2021), autism, and attention-deficit/hyperactivity disorder (ADHD; Schiltz et al., 2022). Caregivers were asked to rate the extent to which they agreed or disagreed with 17 statements about their satisfaction with caregiving and self-efficacy in their caregiving role. Scores ranged from 17 to 102, with higher scores representing a greater sense of competency. There are no average scores or cut-off scores for this measure. Caregiver attributions for child behavior were measured using the Written Analogue Questionnaire (WAQ; Johnston & Freeman, 1997), also known as the Thinking about Children's Behaviour Scale (TCB). The WAQ has been used in the past for caregivers of children with various developmental delays (e.g., Jacobs et al., 2017), ADHD (Chen et al., 2008; Johnston et al., 2006), and behavioral difficulties (Johnston et al., 2006). To the best of our knowledge, the WAQ has not been previously used among caregivers of children with FASD. Measures of caregiver attribution for child behavior are typically vignettes, symptom-based, or statement-based about general behavior (Eng et al., 2025; Rogerson et al., 2024). Both our family partner and the Elder at the SSCY Centre suggested using the vignettes over the other measure formats because the vignettes provide context to the situations. After reading 11 scenarios about challenging child behavior, caregivers answered eight questions on a 10-point Likert scale. The children in the scenarios were not described as having PAE or a diagnosis of FASD. To our knowledge, an attribution measure specifically describing children with PAE or FASD does not exist. Four of the questions were related to dimensions of causality, including locus (1 = *something about the child* to 10 = *something about the situation*), stability (1 = *a one time thing* to 10 = *will happen again*), controllability (1 = *completely within the child's control* to 10 = *not at all within the child's control*), and specificity (1 = *specific to the situation* to 10 = *happens in many situations*). The other four questions measured the degree to which caregivers believed the behavior was a problem (i.e., problem perception, 1 = *not at all* to 10 = *very much*), they were responsible for the behavior (1 = *completely* to 10 = *not at all*), the child was responsible for the behavior (1 = *completely* to 10 = *not at all*), and the child behaved on purpose (i.e., intentionality, 1 = *very much on purpose* to 10 = *not at all on purpose*).

Post-series Survey

After the series, participants were also asked (1) how many sessions they attended, (2) whether they viewed the live or recorded virtual sessions, (3) their thoughts about the series (the most and least helpful topics and topics of interest that the series did not cover to address Objective 4), (4) whether they experienced barriers to attending the sessions or completing surveys, (5) to identify any barriers they experienced (work, family responsibilities, lack of childcare, lack of time, or other), and (6) to identify anything that would reduce or remove barriers to attend the series or complete the survey. To address Objective 1, participants were also asked about their understanding of PAE and FASD again. Caregivers were asked to answer the PSOC and WAQ again to address Objectives 2 and 3.

Recruitment

Due to limited participation in the first offering of the series, we continued to collect data across three consecutive series. Recruitment methods evolved across the three series in an attempt to increase study participation. Please refer to Table 2 for further details on the differences in recruitment and procedures across the series. Given the difficulties with recruitment during series 1, our family partner suggested changing our recruitment and data collection strategies to reduce potential barriers for caregivers. First, she suggested incorporating elements of self-care and well-being during data collection as a recruitment strategy, sharing that offering refreshments or a meal may increase participation. Second, she recommended building in time for collecting data directly before the first session and after the last session,

Table 2 Description of study procedures and participation across the three series

	Series #1 (virtual)	Series #2 (in-person)	Series #3 (virtual)
Study recruitment method The research assistant described the study at the first and last sessions across all three series	• Brief written study description in reminder email about the series	• Online and in-person advertisements • Lunch offered before the first session • Refreshments offered after the last session	• Online advertisements • Study verbally described when attendees registered for the series
Survey administration options The options for completing the surveys: The research assistant was available to assist participants across all three series	Online survey through REDCap, or as an interview via Microsoft Teams or phone	Paper survey only (complete in-person or via mail)[a]	Online through REDCap, and paper surveys (via mail)
Survey administration How participants completed the surveys	Online survey. Responses entered into REDCap and exported into SPSS	Paper survey. Responses entered manually into SPSS	Online survey. Responses entered into REDCap and exported into SPSS
Pre-survey collection	All online	• Completed or picked up surveys in person • Surveys returned in person at the end of the session or the next session	All online
Post-survey collection	All online	• Completed or picked up surveys in person • Surveys returned in person during refreshments or mailed back with self-addressed stamped envelopes	All online
Study response rate[b]	6.25% (2/32)	58.33% (7/12)	50.00% (5/10)
Survey attrition rate[c]	N/A	16.67%[d]	75.00%

[a]Three surveys were mailed out to individuals who did not attend the session

[b]Response rate was calculated based on the number of people who completed at least one survey at any time point and the average number of people who attended the series

[c]Attrition rate was the percentage of participants who completed the pre-series survey but not the post-series survey. *N/A*, not applicable because no one completed the pre-series survey

[d]One participant completed the post-series but not the pre-series survey

noting that families may be more likely to complete the survey if the time was already set aside, as it may be challenging for families to have the time and resources to participate in research with their demanding caregiver roles. Finally, she encouraged us to collect data in person instead of online and to have a research assistant available for support.

Data Collection

For the virtual series, all online survey data were collected and securely stored using the Research Electronic Data Capture (REDCap) tools hosted within the University of Manitoba (Harris et al., 2009, 2019). Data from REDCap were exported to IBM® SPSS® Statistics software (Version 29). Paper surveys were distributed and collected for the in-person series. Data from the paper surveys were then entered manually into SPSS. We offered participants different options to participate in this study to reduce barriers and enhance the accessibility of participation by (1) completing the online survey independently or (2) conducting a phone or virtual interview over Microsoft Teams with a research assistant. Prospective participants were also encouraged to connect with the research assistant if they were interested in the research but experienced barriers. None of the participants opted to complete the survey with the research assistant over the phone or as a virtual interview. We invited participants to complete the survey before the first session (pre-series survey) and within 1 month of the last session (post-series survey). Informed consent was collected before the survey was administered. Participants received an EverythingCard gift card each time they completed a survey. Supporters were offered a $10 gift card, while the caregivers received $15 because they completed two more questionnaires than the supporters.

Analyses

All data was considered together to reduce the chances of identifying participants. We used IBM® SPSS® Statistics software (Version 29) for statistical analyses. First, descriptive statistics of participant demographics and BCS-specific information were computed. Second, descriptive statistics were calculated to assess participants' understanding of FASD, caregiver sense of competency, and caregiver attributions. We defined the "standard definition" of PAE in terms of alcohol exposure before birth. Participants' responses about their understanding of FASD were quantitatively coded based on the Canada FASD Research Network's definition of FASD:

> Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe the impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges. (Canada FASD Research Network, 2024, p. 3)

Responses were coded by two independent coders as 0 (too general and does not include any aspect of the definition), 1 (includes some but not all aspects of the definition), or 2 (covers all aspects of the definition).

Results

Participants

Table 2 provides the response and attrition rates across the three series. The overall response rate for this study was 25.93%. Table 3 provides information about the 14 participants. Most participants identified as women (86%), were supporters (57%), resided in rural areas (71%), and attended the in-person series (50%). Table 4 provides more details about the caregivers who participated in the study. The ages of the children of the caregivers ranged from 6 to 13 years ($M = 10.00$, $SD = 2.74$). All caregivers had children recently diagnosed with FASD (age at diagnosis, $M = 9.75$, $SD = 2.49$). The caregivers also cared for other children, ranging from one additional child part-time to five children.

Table 3 Participant characteristics

	N (%)
Gender	
Male	**2 (14.29%)**
Female	**12 (85.71%)**
Caregiver	**6 (42.86%)**
Virtual	1 (16.67%)
In-person	5 (83.33%)
Supporter	**8 (57.14%)**
Virtual	6 (75.00%)
In-person	2 (25.00%)
Urban	**4 (28.57%)**
Virtual	1 (25.00%)
In-person	3 (75.00%)
Rural	**10 (71.43%)**
Virtual	6 (60.00%)
In-person	4 (40.00%)

Bold values represent the total sample ($N = 14$). Non-bolded values represent a smaller subset

Table 4 Caregiver characteristics and support history[a]

	n (%)
Caregiver's Gender Identity	
Man	1 (17%)
Woman	5 (83%)
Relationship to the child	
Birth parent	2 (50%)
Foster parents	2 (50%)
Residence	
Urban	2 (40%)
Rural	3 (60%)
Other caregiver involvement	
Yes, another adult helping look after the child	3 (75%)
No other adult helping look after the child	1 (25%)
Yes, other adults attending BCS	1 (25%)
No other adult isn't attending BCS	3 (75%)
Support	
Accessed support in the past	3 (75%)
Not accessed support in the past	1 (25%)
Currently accessing supports	2 (50%)
Not currently accessing supports	2 (50%)
FASD assessment experience	
Gone through the assessment process with another child	2 (50%)
Gone through the assessment process three times	1 (25%)
Sex of Child Assigned at Birth/Child's Gender Identity	
Male/Boy	2 (50%)
Female/Girl	2 (50%)
Diagnoses of children	
FASD	4 (100%)
ADHD	2 (50%)
Survey completion	
Pre-surveys only	1 (17%)
Post-surveys only	2 (33%)

[a]Although six participants identified themselves as caregivers, data across these variables is missing because one completed the supporter survey, and the other completed the post-series survey, which did not include the initial demographic survey

None of the caregivers indicated they cared for a dependent 18 years or older. Table 5 provides a breakdown of the survey completion.

Reasons for Attending and Hopes for the Series

Most caregivers attended the series to learn more about FASD, while supporters attended to provide support to individuals and families. Others participated in the series because it was recommended by others. Caregivers were interested in learning about how to help their child, acquiring additional skills and strategies, and accessing available resources. Most supporters wanted to learn more about FASD in general and how to support those they care for. See Table 6 for more details and quote excerpts.

Table 5 Survey completion

Pre-survey only	**4 (28.57%)**
Caregiver, *n* (%)	1 (25.00%)
Supporter, *n* (%)	3 (75.00%)
Post-survey only	4 (28.57%)
Caregiver, *n* (%)	2 (50.00%)
Supporter, *n* (%)	2 (50.00%)
Pre- and post-surveys	6 (42.86%)
Caregiver, *n* (%)	3 (50.00%)
Supporter, *n* (%)	3 (50.00%)
Series #1 (virtual)	2 (14.29%)
Post-survey only, *n* (%)	2 (100.00%)
Series #2 (in-person)	7 (50.00%)
Pre-survey only, *n* (%)	1 (14.28%)
Post-survey only, *n* (%)	1 (14.28%)
Pre- and post-surveys, *n* (%)	5 (71.43%)
Series #3 (virtual)	5 (35.71%)
Pre-survey only, *n* (%)	3 (60.00%)
Post-survey only, *n* (%)	1 (20.00%)
Pre- and post-surveys, *n* (%)	1 (20.00%)

Participation and Barriers

Across the three series, seven of the 10 participants who completed the post-series survey attended or watched a recording of all eight sessions ($M = 7.20$, $SD = 1.40$). See Table 1 for attendance rates across sessions.

Barriers to Attending the Series

Half of the participants who completed the post-series survey reported experiencing barriers to attending the series, including work ($n = 3$), family responsibilities ($n = 2$), and a lack of childcare ($n = 1$). Other unique barriers identified included disruptions at work, prior commitments, and personal and work obligations. Most participants who endorsed barriers provided suggestions for reducing or removing barriers, including providing transportation ($n = 1$) and childcare ($n = 1$), changing the location (wanting it closer to their home where they lived rurally; $n = 1$), attending the virtual sessions in an alternative location ($n = 1$), and timing of the sessions (preference for morning over afternoon; $n = 1$). This participant also stated that they appreciated the recorded sessions.

Table 6 Reasons for attending and hopes for the series

Reasons for attending		Example of quote excerpt(s)	n^a
Caregivers ($n=4$)	To learn more about FASD	"I have some knowledge of FASD but feel that I don't have enough"	3
	To learn different or more strategies	"To learn different/more strategies to help [with] my children"	1
	To connect with other caregivers	"I also hope to connect with others who are also caregivers."	1
	Recommended by others	"This was suggested post assessment."	1
Supporters ($n=6$)	To help and better support others	"I think it is important to be knowledgeable in many different ways so that people I support will get the most out of our time together."	5
	Educational opportunity	"…I always accept any educational opportunities offered."	1
	Professional growth	"I think I am a better counsellor when I am always continuing to learn & grow."	1
	To learn about the series	"As a new employee working with families + youth + FASD dx … I wanted to attend to see what [the] series is about."	1
	Recommended by others	"…I was provided information regarding resources and programs that will benefit the care providers as well as myself"	2
	To connect with other clinicians	"Building connections with OT's (networking)."	1
Hoping to learn			
Caregivers ($n=4$)	How to help their child	"How to help my child navigate growing up, school and life in general"	1
	More skills and strategies	"More skills to navigate behaviors"	2
	Resources	"Also hoping to learn what resources are available for my child"	2
	Nothing specified	"Also hoping to learn what resources are available for my child."	1
Supporters ($n=6$)	How to teach others about FASD	"I am hoping to learn how the educational series explains FASD (i.e., how is depth) so that I can use what makes sense to teach others about FASD (i.e., not too complicated or simplistic)."	1
	More about medications	"I am excited to learn more about medications…"	1
	New/updated information	"…up-to date evidence of FASD/neurodiversity."	2
	A better understanding of FASD	"Proper terminology"	3
	How to help others	"Practical ways to provide support to clients and caregivers."	3

[a]Number of participants who endorsed each idea

Barriers to Study Participation

Two of the 10 participants who completed the post-series survey endorsed barriers to completing the surveys. One participant noted that the timing of the post-series survey coincided with a busy period in their work and family life. The other participant indicated that their computer restarted before they finished the survey. Another participant did not endorse barriers but noted that their answers were brief because they had a work obligation immediately after the last session.

Understanding of PAE and FASD (Objective 1)

Participants' responses about PAE varied at the pre-series, with most participants offering the standard definition ($n=5$). Some participants described PAE as a disorder or effects related to PAE ($n=2$), while others noted that PAE results in FASD ($n=2$). One participant defined confirmed PAE based on the Canadian diagnostic guidelines (Cook et al., 2016). At the post-series, most participants provided the standard definition of PAE ($n=5$). Some definitions included FASD but differentiated between FASD and PAE ($n=3$), while others described FASD and PAE interchangeably ($n=1$) or FASD as being a developmental progression from PAE ($n=1$). One participant's definition of PAE shifted away from the behavior of the birth mother to the substance of alcohol.

The six participants who completed the surveys at both time points had similar scores for understanding FASD after ($M=1.33$, $SD=0.52$) and before ($M=1.17$, SD = 0.75) the series; however, formal analysis could not be conducted due to low power. The average score across all participants at pre- and post-series was 1.00 ($SD=0.95$, $n=10$) and 1.25 ($SD=0.46$, $n=8$), respectively. Most participants provided symptoms and behaviors related to FASD, but did not mention other aspects, such as FASD requiring confirmed PAE, being a life-long disability, and differences between individuals with FASD, including strengths and difficulties. The wording of some answers suggested that participants were describing the child or adolescent they support with FASD.

Caregiver Outcomes (Objectives 2 and 3)

Only one caregiver (caregiver A) completed the PSOC and WAQ across time points. Their post-series score on the

PSOC of 69 was higher than their pre-series score of 62. Supplementary Table 1 shows the results of the WAQ. Some of caregiver A's WAQ scores shifted over time, including the degree to which they attributed the behaviors to being something about the child rather than something about the situation (locus; from 6.09 to 1.00) and believing that the behavior is more likely to happen in many situations than being specific to the situation (specificity; from 5.55 to 8.18). After the series, the degree to which caregiver A believed the behavior was a problem lessened (problem perception; from 8.55 to 4.82). The degree to which they believed that they, as the caregiver, were responsible for the behavior also shifted closer towards *not at all responsible* (caregiver responsibility; from 7.18 to 9.82). All other scores did not seem to change before and after the series. Caregiver B's WAQ scores were generally consistent over time, with a slight shift for controllability (i.e., closer to the behavior being in the child's control; from 4.18 to 3.11), child responsibility (i.e., closer to child being responsible; from 3.64 to 2.78), and caregiver responsibility (i.e., closer to caregiver not being responsible; from 4.55 to 5.78).

Thoughts About the Series (Objective 4)

Topics Offered

Feedback about which topics were most helpful varied. Three of the 10 participants reported that all the sessions were helpful. At least two participants identified each topic as being the most helpful, with the living experiences (caregiver's experience with FASD in the family and the experiences of adults with FASD) receiving the most accolades (see Table 1).

When asked which sessions were not as helpful or they would prefer less of, four of the 10 participants described all sessions as being valuable, informative, and/or helpful. One participant shared that although most of the information was not new because they had previously attended BCS and researched FASD for years, the series was still a good refresher. Two participants identified the Psychology and Speech and Language Pathology topics as the least helpful because they were knowledgeable in these areas due to their job; however, they acknowledged the importance of these topics and recognized that they may benefit others without prior knowledge.

Regarding the length of the sessions, one participant felt that the Sensory Processing topic could be longer, and another thought the Psychology session could be longer. One participant felt that some sessions could be more than 2 h, but did not specify which ones. Another participant described the 2-h session lengths as perfect and recommended not changing the length, except possibly making them longer. Only one participant felt that the caregivers' experience with FASD in the family could be shorter than 2 h.

Suggestions for Future Topics or Sessions

Three caregivers did not recommend any additional topics. One participant shared that "this [was their] first time with FASD training, and [it] helped [them] very much, [and] would love to learn more." Specific recommendations included more strategies to bring back to a school team to better support students, more on how the symptoms present themselves within the different brain domains, sleep, preventing stigma, educating their child's school about FASD and advocating for them, information about resources (e.g., daycares knowledgeable about FASD), and supports available as children age. One participant wished for a roundtable discussion to address additional questions, experiences, and concerns, as well as more small-group interaction and workshop-style sessions for personal/professional learning. Most of the specific recommendations described above have since been incorporated into the sessions, including discussions on strategies and symptom presentation, stigma that draws from the Manitoba FASD Strategy, and resources (e.g., recreation opportunities, websites, podcasts). Subsequent series have also allowed for more time to address additional questions, experiences, and concerns. There are also plans to add a section on school advocacy and consider incorporating sleep into a session.

Conclusion

In general, this study found that a small group of caregivers and supporters with varying levels of previous education and support appreciated attending the BCS series.

Participation and Barriers

The sessions were well-attended by participants in this study, regardless of whether the series was held virtually or in person. This is surprising, given that 50% of the participants endorsed experiencing barriers to attending the series. This finding highlights the need and desire for FASD knowledge among caregivers and supporters, underscoring the importance of this learning series. Interestingly, a multitude of barriers were related to work-related demands. Given that most participants were women, this may reflect the added burden women experience in balancing work and caregiving roles—often as the primary caregivers. It is not surprising that they find it challenging to engage in other activities outside of these multiple demanding roles.

Suggestions for removing or reducing barriers ranged from participant-related (e.g., providing transportation and

childcare) to program-related (e.g., the location and timing of the series) factors. Future funding applications for the series could include transportation and childcare costs, whether reimbursing families or offering on-site care. Program-related factors would be more challenging to address, as most presenters work in the building where the series is offered, and finding a suitable rural location that accommodates multiple people can be difficult. This suggestion supports continuing with the virtual series option or creating a hybrid option (a combination of in-person and virtual). Having two virtual options throughout the year would improve program accessibility. The timing of the series is also challenging, as schedules likely vary across participants, especially based on their role as a caregiver or supporter (e.g., offering the series during the school day can be helpful for caregivers with school-aged children but may be difficult for educators in the school system).

Understanding of PAE and FASD

It was promising to see that one participant's definition of PAE shifted away from the behavior of the birth mother to the substance of alcohol, which aligns with the language and common messages guides (Canada FASD Research Network, 2024; MB FASD Coalition Inc., 2017). Not all participants accurately defined PAE, even after the series was completed. Anecdotally, it is not uncommon for individuals to use the terms PAE and FASD interchangeably, with some children described as having FASD when they were referred to our diagnostic clinic. This misunderstanding may be one reason caregivers and others seem confused about the lengthy assessment process. As a diagnostic clinic, we could offer additional resources about the assessment process at the outset, such as *A Caregiver's Guide to FASD Diagnosis* (Canada FASD Research Network, 2020). Participants' understanding of FASD did not seem to improve after attending the series; however, upon further review of the wording of the question and responses provided, most participants answered our question by describing symptoms and behaviors related to FASD. Therefore, making any conclusions about program efficacy regarding this specific outcome may be premature. We could rephrase this question in the future to ensure it accurately assesses the study construct.

Caregiver Outcomes

Despite the low response rate limiting our ability to determine whether the series improved caregiver outcomes, the survey responses are promising. For example, one caregiver's sense of competency increased over time. Additionally, some of the caregivers' attributions were more understanding of multiple causes of behavior, rather than just internal to the child (viewing the challenging child behavior as something about the situation and less likely to be within the child's control) than caregivers of children with neurodevelopmental disorders in other studies (e.g., Moulton, 2005). Without additional data, it is challenging to attribute this to the series or common messaging seen in FASD resources (e.g., brain-based differences; Canada FASD Research Network, 2024; Pakozdy & Pakozdy, 2022). Overall, these trends are important to highlight for caregivers of children with FASD (Ilchena et al., 2023) and PAE (Rennie et al., 2024), as higher levels of caregiving/parenting sense of competency (Janis et al., 2021) and adaptive/positive caregiver attributions (Eng et al., 2025; Rogerson et al., 2024) are associated with lower levels of parenting stress.

General Thoughts About the Series

Overall, the feedback about the series suggests that all topics offered were helpful, with the sessions about in-home and in-body living experiences voted the most helpful. This finding aligns with the consensus from the FASD community, which continually emphasizes the importance of learning from first-hand experiences (CanFASD Blog, 2024; Reid et al., 2022a,b). The constructive feedback reflected the diversity of the participants who support children and adolescents with PAE and FASD who participated in this study. Only supporters felt some sessions were less helpful, noting that the content was a review of previously learned information. Indeed, BCS was initially designed for caregivers of children diagnosed with FASD at the diagnostic clinic, and these comments could highlight some issues with broadening the audience. These comments also suggest a potential recommendation to host different sessions—one for caregivers and one for supporters. At the core, the underlying information and concepts remain the same, but the strategies and specifics could be tailored to the audience. Presenters at BCS typically lean more towards using home- or family-specific information for the series, as that is the intended audience. When some of our follow-up service team members present in schools, their examples, resources, and handouts differ from those provided to caregivers. Moreover, the Government of Manitoba and the Manitoba FASD Coalition have started a pilot project to do multi-day FASD workshops in rural school divisions. This initiative aims to address the need for access to FASD information in rural settings, with a particular focus on educators. The first pilot took place in November 2024 and February 2025.

It may also be helpful for supporters to know what caregivers and the families they support are learning about PAE and FASD through the session materials or the questions and comments raised during the sessions. Using similar language and terminology about PAE and FASD can also be helpful for families and supporters. Additionally, not all supporters felt that the content was

a review of previously learned information, and at least one supporter identified as being new to their role. The diversity of supporters participating in BCS, along with their experiences with PAE and FASD, suggests a need for additional strategies beyond hosting different sessions. For example, the facilitator for our most recent virtual series provided participants with a description of the upcoming sessions, allowing them to learn more about the session content before attending. More practically speaking, limited resources, including the time and commitment of the presenters, also somewhat dissuade the possibility of hosting different sessions for caregivers and supporters.

Several ideas for additions to the series were highlighted, as well as the wish for some sessions to be longer than 2 h and multiple means of accessing the information (e.g., hybrid, virtual, and recordings). We did not receive any comments about the number of sessions offered, which would be helpful to know before adding sessions in the future. For example, the recommendation about more interaction and connection could be incorporated into an additional session or sprinkled throughout established sessions. This suggestion could also be a call for additional opportunities for caregivers and supporters of children with PAE and FASD to connect. The diagnostic clinic that hosts BCS offers a monthly support group for birth families of children with PAE and FASD, though there is no equivalent program for non-birth families.

This study offered other important findings regarding study and program design and has implications for future program evaluations, including reevaluating BCS. The in-person series was notably more successful than the online series in terms of response and attrition rates. This finding could be related to the in-person nature of the series, differences in registration and recruitment between the in-person and virtual series, the data collection process with built-in time to complete the surveys, or the completion of paper surveys rather than online ones. Another important difference in the data collection method between the in-person and online series was the human connection, which our family partner strongly recommended. Although research staff were available to answer any questions throughout the series, it was probably easier to ask in person than to reach out by phone or email while completing an online survey and then return to it later. A recent meta-analysis on caregiver-related outcomes among caregivers of children with PAE also found that all but two studies collected data in person, with one study conducting an online survey and the other study requiring participants to complete the surveys at home or in person, depending on the intervention trial (Rennie et al., 2024). Researchers in this area have also considered incorporating a self-care component in the data collection process. For example, the C.A.R.E. Study—Caregiver Approaches, Resiliencies, and Experiences Raising Individuals with FASD incorporated self-care activities throughout its online survey (Flannigan et al., 2024).

Strengths

Despite challenges with recruitment, the present study resulted in several learnings that can be built upon in future research. First, this study reemphasized the importance of having a family partner with an in-home living experience on the research team and subsequently adjusting recruitment and data collection methods. The response rates improved from 6% to over 50% once we implemented her suggestions. Second, consulting with an Elder encouraged us to be mindful about the terminology used and include PAE in addition to FASD. Third, working to balance traditional scientific best practices (e.g., researchers/presenters unaware of which attendees were participating in the research study) with recommendations from Indigenous leaders around the importance of building relationships (e.g., sharing a meal; University of Manitoba, 2021) encouraged us to continually reflect on current Western research practices and their impact on research outcomes. For example, we learned that participants were eager to connect with the research team, some of whom were also BCS presenters and part of the diagnostic assessment team. Western research practices often discourage multiple roles; however, continuing along this path creates a larger gap in knowledge translation between research and clinical practice.

Limitations and Future Research

This study has several limitations; however, each can provide insight into future research directions, including reevaluating BCS. First, we encountered issues with recruitment and survey completion. Anecdotally, some participants communicated that they attempted to complete the post-series surveys, but life circumstances interfered with their ability to do so. Indeed, we anticipated that a larger portion of participants would endorse barriers to participating in the study when completing the survey; however, the response and attrition rates may better reflect barriers experienced, especially during the third series. It is also important to consider that some caregivers attended the series closely after the diagnostic process, which involves completing several questionnaires and could have reduced their eagerness to complete additional paperwork. Our family partner highlighted that cognitive capacity is a finite resource and caregivers may not be able to participate in more work related to FASD unless they are very supported and there are tangible benefits. Future offerings of the series could incorporate some aspects of caregiver burnout and stress to validate the experiences of engaging in more work. Clinically, we have also noticed that some caregivers benefit from additional reminders and

support in completing questionnaires. Although research staff were available for support, the offer was general rather than personalized. We also did not remind participants to complete or return surveys. Future evaluations of the series could also offer reminders and direct support to complete the surveys, similar to our clinical process.

Second, although some participants endorsed barriers to attending the series and completing the surveys, individuals who experienced additional barriers were likely not captured in this data, as they would be less likely to participate in the series or the study. Participants who attended more sessions might have more resources or time to participate in the study. Additionally, those who attended fewer sessions may have felt less inclined to offer feedback. Therefore, we cannot determine whether our limited sample was representative of the series attendees or whether it was subject to selection bias, as we lack information about the attendees who did not participate in this study. We also do not know what barriers they experienced. The BCS facilitators have previously collected informal feedback about the series through a short survey (i.e., not a formal research study). Their response rates were around 100% for the in-person series and 10–60% for the virtual series, all of which are higher than the response rates for the current research, suggesting that some aspects of this study may have interfered with participation (e.g., consent forms or the length of the survey). Hosting an engagement activity or asking one or two questions about barriers to research might help us learn ways to reduce them for future research. Some researchers have partnered with organizations to recruit participants through Living Labs (e.g., the Young Minds Research Lab at the University of Manitoba). A similar method could be attempted at physical locations where caregivers and supporters of children with PAE and FASD frequent, such as programs for children with PAE or FASD, or FASD community events or conferences.

Third, only caregivers of children with FASD participated in this study, and therefore, we do not know if this program is beneficial to caregivers of children with PAE without a diagnosis of FASD. Given some overlap in symptom presentation of children with and without FASD (Cheung et al., 2021), participants may benefit from attending BCS regardless of whether they support children or adolescents with FASD. Future program evaluations could examine whether any of the following factors impact the benefit of attending BCS: other child diagnoses, age of the child, gender of participant, and number of sessions attended. Future evaluations could also examine other variables, including caregiver/parenting stress or supporters' attributions for challenging child behaviors.

Fourth, upon reflection, our caregiver surveys lacked important demographic questions, including how many other children in the home also had a formal diagnosis of FASD. While we learned that at least four of the six caregivers had previously gone through the FASD diagnostic assessment process with another child in their care (see Table 4), we did not obtain information about the outcome. It would be valuable for future research to collect this information and other key demographics about individuals in the home that could impact caregiving (e.g., number of children with additional needs and/or diagnoses) to provide a more complete picture of the family experience.

Conclusion

Given the varied experiences and challenges families with a child with PAE or FASD can face, ensuring they have access to accurate information and support through an educational series has the potential to impact child, caregiver, and family outcomes positively. In this study, we learned that caregivers and supporters found the BCS program valuable and informative. Initial pilot data indicated trends towards improving caregiver attributions of children's behavior and increased caregiving sense of competence. Adding interactive components for attendees may increase its value. Important lessons were learned about how to reduce barriers for future participation in the series and future research projects.

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Data Availability Ethics approval for this project did not include thetransmission of data outside of our study team and institution, the SSCY Centre. Based on the ethics approval of this project, all data was required to remain on-site and to be physically housed and accessed internally at the SSCY Centre.

Declarations

Ethics Approval This study was approved by The University of Manitoba Research Ethics Board and the Specialized Services for Children and Youth (SSCY) Research and Evaluation Committee.

Consent to Participate Informed written consent was obtained from all individual participants included in the study.

Competing interests The authors declare no competing interests.

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