



Caregiver needs and stress in caring for individuals with fetal alcohol spectrum disorder



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ABSTRACT

Objective: Individuals with FASD experience neurodevelopmental impairments and adverse outcomes, which can result in stress on the caregiver. However, there is little research on the needs of caregivers supporting individuals with FASD and whether they are associated with caregiver stress.

Method: 125 caregivers of individuals with FASD completed a survey with questions adapted from the Family Caregiver Survey and the Perceived Stress Scale.

Results: Caregivers reported a range of needs and concerns, and high levels of stress. In many areas of caregiver well-being concerns tended to be higher among caregivers with adolescents and adults compared to those with children. Foster parents reported fewer well-being concerns than biological/kinship and adoptive parents. Caregivers who cared for the individuals for longer periods of time reported the most well-being concerns and lowest satisfaction with supports. Caregivers with the lowest income reported higher levels of stress than those with higher incomes. Higher reported stress was highly correlated with more needs/concerns.

Conclusions: Caregivers of individuals with FASD have multiple areas of need and concern, and experience high levels of stress. Reducing demands on caregivers and providing resources may help reduce caregiver needs and stress, particularly for those caring for adolescents and adults, and those with lower incomes.

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1. Introduction

Fetal Alcohol Spectrum Disorder (FASD) refers to individuals who have physical, cognitive, behavioral, and/or learning disabilities related to prenatal exposure to alcohol (PAE; Chudley et al., 2005). In Canada, FASD is estimated to occur in 1% of the population (Alberta Alcohol & Drug Abuse Commission, 2013; Health Canada, 2008; Stade, Unjar, Stevens, Beyene, & Koren, 2006), and in the United States of America the rate is 2–5% (May et al., 2009). Individuals with FASD frequently

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require extensive support services with significant economic costs. In Canada, an estimated \$5.3 billion is spent annually on supporting individuals with FASD, equivalent to \$14,342 per individual (Stade et al., 2006).

Individuals with FASD experience a number of neurodevelopmental impairments in the areas of learning, memory, executive functioning (e.g., inhibition, decision making, flexible thinking), attention, intelligence and language, as well as behavioral problems (Kodituwakku, 2007), including elevated rates of inattentive, hyperactive, and aggressive behavior (Mattson & Riley, 2000; Nanson & Hiscock, 1990; Paley, O'Connor, Kogan, & Findlay, 2005). Streissguth et al. (2004) found high rates of adverse outcomes in children and adults with FASD, including mental health issues, delinquency, legal troubles, and confinement. Protective factors against these adverse outcomes include an early diagnosis, receiving services for disabilities, no exposure to abuse or domestic violence and living in a stable home environment. Given the variety of impairments and adverse outcomes associated with FASD, the types of services and supports needed are extensive and span health, social, education, and justice sectors.

Providing care for children with disabilities involves significant time and energy, disruption to family activities and routine (Plant & Sanders, 2007; Seltzer & Heller, 1997; Shultz & Quittner, 1998), and, not surprisingly, resultant increased levels of personal stress in caregivers. Plant and Sanders (2007) found that caregiving tasks and advocating to professionals on behalf of their child contributed to caregiver stress among families of pre-school aged children with developmental disabilities. Moreover, the difficulty of the caregiving task, the child behavior problems during these caregiving tasks, and the extent of the child's disability contributed most significantly to caregiver stress.

Autism Spectrum Disorder (ASD) is often cited as the most stressful disability for parents (Abbeduto et al., 2004; Pisula, 2007). Watson, Coons, and Hayes (2013) compared caregiver reported stress of families of children (aged 1–36 years) with ASD ($n = 25$) to families of children with FASD ($n = 25$) using two stress measures: the Friedrich version of the Questionnaire on Resources and Stress (QRS-F) and the Parenting Stress Index-Short Form (PSI-SF). No overall significant group differences were found on the QRS-F, although caregivers of children with FASD reported significantly more stress on the Pessimism subscale. However, on the PSI-SF, parents of children with FASD reported significantly more overall stress than parents of children with ASD. The authors then conducted a qualitative analysis to examine the issues faced by families of children with FASD and ASD. Four main themes contributing to parental stress in both groups emerged: (1) the need for a timely formal diagnosis in order to access services and supports; (2) the diagnostic process; (3) the need to deal with the behavioral issues in their children; and (4) the multiple roles of the caregiver to advocate for the best services and supports for their children. The FASD group had some unique challenges regarding the diagnostic process, including having to travel to see specialists, difficulty confirming maternal alcohol use during pregnancy, and the absence of phenotypic facial features. Additionally, although both groups of parents expressed concerns with behavioral issues, the parents raising children with FASD expressed concerns regarding delinquent behaviors and difficulties choosing appropriate friends (Watson, Hayes, Coons, & Radford-Paza, 2013).

Paley, O'Connor, Frankel and Marquardt (2006) used the PSI (Abidin, 1995) to measure caregiver stress related to parental characteristics (parent-related stress) and child characteristics (child-related stress), among children with FASD (aged 6–12 years). Internalizing and externalizing behaviors, executive and adaptive functioning difficulties, and being an adoptive parent were all associated with more child-related stress. Biological parent custodial status and fewer family resources were the only significant predictors of increased parent-related stress (Paley et al., 2006).

There is a growing amount of literature regarding experiences and impact on families and caregivers in parenting individuals with FASD, and subsequent perceived familial needs (Olson, Oti, Gelo, & Beck, 2009). Morrisette (2001) performed a narrative analysis on interview data about the experiences of caregivers ($n = 6$) raising foster and adoptive children with FASD in the United States. Seven predominant themes emerged from this data: (1) the need for constant vigilance to ensure the child's well-being; (2) the effect of stress and strain on marriages; (3) child management concerns including manipulative and unmanageable behavior, their children's attempts to disguise their disability, and the importance of sequence and routine; (4) parental issues including a feeling of inadequacy and subsequent adjustment; (5) interactions with the professional community such as physicians, teachers and social workers; (6) medical implications secondary to FASD; and (7) transition and emancipation concerns.

Recently, a needs assessment was conducted to inform the development of an online intervention for families affected by FASD in Canada (Green et al., 2014). The number and extent of challenges reported by caregivers made it clear that there were many unmet needs that impacted the quality of life for caregivers, their children, and their families. Caregivers reported that the most challenging behavior categories were "Externalizing Behaviors" (ex. rule breaking/aggressive behavior), "Cognitive Difficulties" (ex. memory/attention/language/learning difficulties), and "Social Difficulties/Maladjustment" (ex. issues with attachment and getting along with others), whereas the most successful parenting strategies were "Parental Reflection" (ex. remaining calm, having realistic expectations, learning from past experiences), "Routine/Structure/Consistency" (ex. visual schedules, timers, prompts), and "Environmental Modification" (ex. leaving/avoiding a particular situation, changing the child's personal space). The authors concluded that parenting programs must provide a family-centered approach to training, education and support for children with FASD and their families (Green et al., 2014).

Adverse outcomes in FASD could be potentially prevented or lessened by better understanding, appropriate interventions and stable caretaking environments, and caregiver education or training about FASD has been identified as an important element for successful interventions for children with FASD (Bertrand, 2009). Leenaars, Denys, Hennevel, and Rasmussen (2012) evaluated a mentoring program for caregivers raising children with FASD, which helped families connect with various

services and resources for FASD. They found a significant decrease in needs and caregiver stress, in addition to increased caregiver goal attainment, after providing the program.

There is a critical need for more information characterizing the needs of caregivers supporting individuals with FASD and how these needs impact caregiver stress. We examined the needs (in terms of Well-Being and Support) and the stress of caregivers supporting individuals with FASD across the lifespan ranging from infancy to adulthood. We also explored whether the needs and stress of caregivers varied depending on various demographic variables including: the age and gender of their child with FASD; caregiver status (e.g., foster, adoptive, biological, etc.); caregiver income; the length of time they had cared for the individual; the total number of individuals with FASD for whom they provided care; and their current residential location (rural vs. urban). Finally, we observed whether caregiver needs were associated with caregiver stress, hypothesizing that those with a greater number of needs would have higher stress. Such information is critical to further inform both the care of individuals with FASD and the associated impact on their caregivers. If we can accurately describe the needs of caregivers supporting individuals with FASD, then interventions and resources can be better customized, leading to reduced caregiver stress and anxiety.

2. Method

This study was a joint project involving researchers from the University of Alberta and the Canada FASD Research Network (CanFASD). Ethics approval was obtained from the University of Alberta Research Ethics Board, Edmonton, Alberta, Canada.

2.1. Procedure

Participants completed an online survey, which was administered electronically using a commercially available survey platform entitled FluidSurveys™. The survey was advertised through media and communication forums directly related to FASD including: websites, newsletters, community agencies, posters, and community outreach events and activities, and caregivers were recruited through FASD specific organizations across Canada, including the Canada FASD Research Network and its Family Advisory Committee. The survey was open to any caregiver residing in Canada who provided primary care for an individual with FASD. The survey included basic demographic questions about the individual with FASD and caregiver, questions regarding caregiver needs that were modified based on the Family Caregiver Survey (FCS; [Schizophrenia Society of Canada, 2014](#)), and the ten-item Perceived Stress Scale (PSS; [Cohen & Williamson, 1988](#)). The survey was open online from October 2014 to January 2015, and closed after reaching sufficient response size ($n = 125$), at which point responses were felt to be saturated and no novel information was expected. Data was anonymous, and caregivers reported their child's FASD diagnosis; however, due to the anonymity of respondents there was no way to medically verify this.

2.2. Participants

A total of 125 caregivers of individuals with FASD participated in the study including biological parents, foster parents, adoptive parents, step-parents, custodial grandparents, kinship/relative caregivers, and community support workers (see [Table 1](#)). In order to participate in the survey, caregivers had to have at least one child diagnosed with FASD, and if caregivers had more than one child with FASD, they were asked to respond based on their experiences and needs related to their child with the most significant challenges.

2.3. Measures

Participants completed questions from two stress and needs-related questionnaires: (1) the Family Caregiver Survey (FCS; [Schizophrenia Society of Canada, 2014](#); and (2) the Perceived Stress Scale (PSS; [Cohen and Williamson, 1988](#)), each of which are described below.

2.3.1. Family Caregiver Survey (FCS; [Schizophrenia Society of Canada, 2014](#))

The FCS was originally developed for the Schizophrenia Society of Canada by the University of Leuven and the European Federation of Associations of Families of People with Mental Illness to assess caregiver respite needs and the respite needs of people living with Schizophrenia. Concepts and questions contained in the FCS were chosen for use in this study based on the available respite literature, and additional questions were added by the research team and through consultation with the CanFASD Family Advisory Committee to ensure that key questions were not overlooked. From this point forward in this paper, "the FCS" will refer to our adapted version of the Family Caregiver Survey.

The FCS contained 110 total questions, and was divided into 4 parts (Part A through D). **Part A** included demographic information about the child with FASD as well as the caregiver. **Part B** examined the general well-being of the caregiver, with sub-categories about their role as a caregiver; their relationship with the person for whom they provided care, their family, and their friends; the caregiver's financial situation; physical health; emotional well-being; stigma and discrimination; the safety of the caregiver along with the safety of the person for whom they provided care; and the overall experience of caregiving. **Part C** assessed satisfaction with the support the caregiver received to help them in their role as a caregiver, with

Table 1
Participant demographics.

	N (%)
Child Characteristics	
Age (years)	
0–12	53 (43.1)
13–18	42 (34.1)
18+	28 (22.8)
Gender	
Male	82 (65.6)
Female	43 (34.4)
Caregiver Characteristics	
Gender	
Male	10 (9.9)
Female	91 (90.1)
Relationship to Child	
Biological Parent	5 (4.0)
Adoptive Parent	86 (68.8)
Foster Parent	16 (12.8)
Kinship/Relative	11 (8.8)
Other	7 (5.6)
Marital Status	
Married/Common-law	95 (76.0)
Divorced	10 (8.0)
Separated	3 (2.4)
Single	12 (9.6)
Widowed	3 (2.4)
Did Not Wish to Report	2 (1.6)
Highest Level of Education	
K-12	18 (14.4)
Some Post-secondary	46 (36.8)
Bachelor's Degree	25 (20.0)
Master/Doctoral/Professional Degree	24 (19.2)
Other	11 (8.8)
Did Not Wish to Report	1 (0.8)
Household Income	
\$10,000–\$49,999	27 (21.6)
\$50,000–\$99,999	48 (38.4)
\$100,000–\$150,000+	37 (29.6)
Did Not Wish to Report	13 (10.4)

*Other includes: Step parents, "other" (unspecified), caregivers through community agencies, in-home caregivers, and friends of the family.

sub-categories including information and advice; involvement in treatment and care planning; and support from medical and/or care staff. **Part D** examined the caregiver's needs for support.

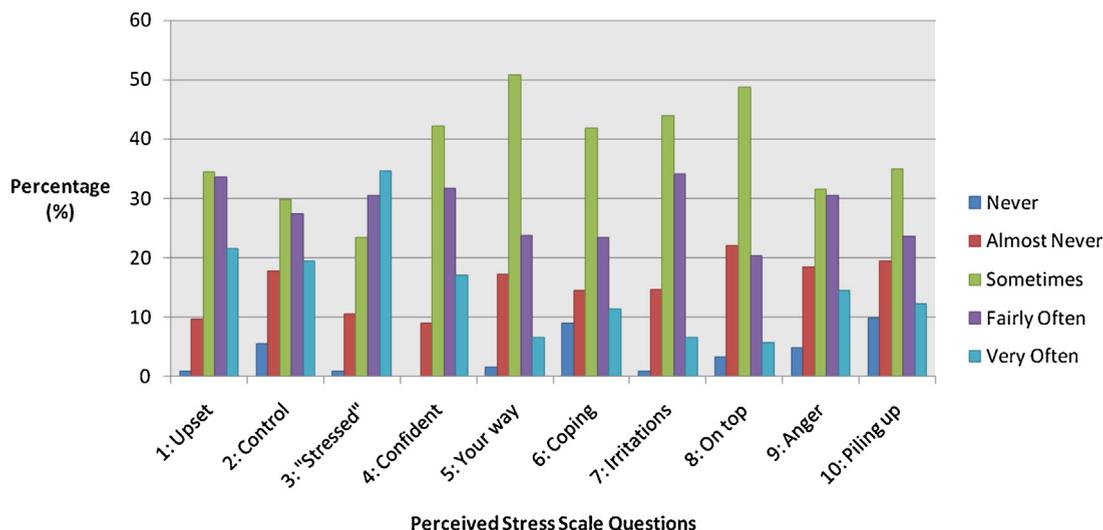
2.3.2. Perceived Stress Scale (PSS; Cohen & Williamson, 1988).

Caregivers also completed the PSS (Cohen & Williamson, 1988), which is widely used to measure the perception of stress and the degree to which situations in one's life are considered stressful, designed for use in community samples. The PSS contains 10 questions, each rated on a 5-point scale ranging from Never (0) to Very Often (4), about thoughts and feelings during the last month. Positively worded items (questions 4, 5, 7, and 8) are reverse scored, and the ratings are combined such that higher overall scores indicate more perceived stress. See Fig. 1 for a list of PSS questions.

2.4. Data analysis

Descriptive statistics (frequencies) were calculated to determine demographic characteristics of participants and the individuals for whom they provided care, as well as response patterns for all questions in the FCS and the PSS. General response patterns for subcategories of Parts B (Well-Being) and C (Support) were calculated as follows: First, given that all responses in these sections fell on a Likert scale of 1–5, the frequency of people who responded strongly on one end of the Likert scale (i.e., 4–5 out of 5, or 1–2 out of 5) was calculated for each question, as high percentages of these responses are thought to represent relevant areas of strength or concern. For some subcategories with varied response patterns across questions within the subcategory, a range of frequencies were calculated. Part D "Support" scores were excluded from this analysis, as all questions in Part D were Yes/No questions.

For all ANOVA and correlation analyses, only participants who answered at least two-thirds of the questions within a section/subsection were included in the analysis in order to exclude response patterns that may skew the results due to missing information. Separate two way ANOVAs were completed to examine the effects of age and gender (of the individual with FASD) on the summary scores for Parts B and C (mean score responses across all questions in Parts B and Section C),



Perceived Stress Scale Questions

1. How often have you been upset because of something that happened unexpectedly?
2. How often have you felt that you were unable to control the important things in your life?
3. How often have you felt nervous and "stressed"?
4. How often have you felt confident about your ability to handle your personal problems?
5. How often have you felt that things were going your way?
6. How often have you found that you could not cope with all the things that you had to do?
7. How often have you been able to control irritations in your life?
8. How often have you felt that you were on top of things?
9. How often have you been angered because of things that were outside of your control?
10. How often have you felt difficulties were piling up so high that you could not overcome them?

Note: Questions 4, 5, 7, and 8 are positively stated items, and scored on a reverse scale, with a lower score indicating higher perceived stress.

Fig. 1. Responses to perceived stress scale questions.

excluding "Experience of Caregiving" in Part B, as higher scores on these questions indicated more positive responses, unlike other questions in this section. This analysis was also completed for each subcategory in Parts B and C. Separate one-way ANOVAs were completed to examine the effects of several family level variables in Parts B and C summary scores and the PSS total score. Correlations were calculated to examine the relationship between each subsection in Parts B and C and the PSS total score.

3. Results

3.1. Part A—Demographics

Caregivers (90.1% female) of 125 individuals aged 0–18+ years with FASD responded to the survey. Participants were recruited from across the country, with the highest representation from British Columbia, Ontario, and Alberta (31.2%, 26.5%, and 18.4%, respectively). As evident in Table 1, the majority of respondents were married or living in a common-law relationship (76%). Over two-thirds (68.8%) of respondents were adoptive parents, 12.8% were foster parents, and 8.8% were kinship/relative caregivers.

Among the individuals with FASD (65.6% male), 43.1% were aged 0–12 years, 34.1% were 13–17 years, and 22.8% were 18+ years old. A total of 16% (n = 20) of individuals had been in their caregiver's care for <5 years, while 30.4% (n = 38) had been in their care for 6–10 years, and 53.6% (n = 67) for >10 years. Finally, 89.4% (n = 110) of individuals with FASD lived with their caregiver the majority of the time, the rest (10.6%) (n = 13) belonged to the 18+ age group and lived in the community. The majority of caregivers (58.1%, n = 72) were caring for only one individual with FASD, while 22.6% (n = 28) were caring for 2 individuals with FASD and 19.4% (n = 24) were caring for three or more individuals with FASD.

3.2. Caregiver needs

3.2.1. Part B—Well-Being

First, the rates of caregiver responses to survey questions were analyzed using descriptive statistics (see Tables 2 and 3 for Well-Being response patterns). As evident in Table 2, many caregivers were quite concerned about their role as a caregiver, their relationship with the person for whom they provided care, their relationships with family and friends, their own

Table 2
Summary of responses to “Well-Being” section of Family Caregiver Survey.

Your role as a caregiver	Percentage of Caregiver Responses (%)				
Over the last year, how concerned were you about:	Not at all	A little	Moderately	Quite a bit	A lot
1. not having enough time to yourself?	4.8	11.3	28.2	29.8	25.8
2. having to put the needs of the person you care for ahead of your own needs?	4.8	7.2	17.6	25.6	44.8
3. not being able to take a break from caring?	3.2	8.9	21.0	29.8	37.1
4. not being able to plan for the future?	2.4	8.8	11.2	35.2	42.4
5. not being able to continue caring due to reasons beyond your control (e.g., becoming ill yourself, looking after very young children) ?	21.6	12.8	22.4	17.6	25.6
Your relationship with the person you care for					
Over the last year, how concerned were you about:	Not at all	A little	Moderately	Quite a bit	A lot
6. strains in your relationship with the person you care for?	9.6	20.0	15.2	24.0	31.2
7. the person you care for being too dependent on you at the moment?	9.6	12.8	22.4	25.6	29.6
8. the person you care for becoming too dependent on you in the future?	4.8	10.4	19.2	28.0	37.6
9. the person you care for saying things that upset you?	12.9	16.9	14.5	24.2	31.5
10. feeling irritable with the person you care for?	4.8	24.0	24.0	21.6	25.6
11. reaching a ‘breaking point’, where you feel you cannot carry on with things as they are?	12.8	20.0	18.4	24.8	24.0
Your relationships with family and friends					
Over the last year, how concerned were you about:	Not at all	A little	Moderately	Quite a bit	A lot
12. strains in your relationships with family and friends, because of your caring responsibilities?	12.0	11.2	20.0	29.6	27.2
13. “drifting apart” from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	12.0	12.0	21.6	20.8	33.6
14. feeling isolated and lonely because of the situation you are in?	8.0	16.0	16.8	24.8	34.4
15. not getting the support you need from family and friends?	13.8	13.8	21.1	22.8	28.5
Your financial situation					
Over the last year, how concerned were you about:	Not at all	A little	Moderately	Quite a bit	A lot
16. your own financial situation?	13.6	15.2	30.4	19.2	21.6
17. the financial situation of the person you care for?	19.4	8.9	17.7	21.0	33.1
18. having to cover extra costs of caring (e.g., extra help in the home, trips to hospital) ?	13.7	16.1	21.8	25.0	23.4

Table 2 (Continued)

Your role as a caregiver	Percentage of Caregiver Responses (%)				
Your physical health					
19. your own physical health?	6.4	19.2	29.6	21.6	23.2
20. your caring role making your physical health worse?	16.3	13.0	25.2	25.2	20.3
Your emotional well-being					
21. being unable to cope with the “constant anxiety” of caring?	8.8	14.4	21.6	29.6	25.6
22. feeling depressed?	17.6	24.8	19.2	23.2	15.2
23. being unable to see anything positive in your life?	32.5	22.8	18.7	11.4	14.6
24. lack of sleep brought about through worry or stress?	12.2	22.8	21.1	14.6	29.3
25. lack of sleep caused by the person you care for keeping you awake at night?	28.8	17.6	19.2	15.2	19.2
26. feeling so exhausted that you cannot function properly?	19.4	19.4	24.2	16.1	21.0
Stigma and discrimination					
Over the last year, how concerned were you about:					
27. people treating you differently because of the illness/condition of the person you care for?	Not at all	A little	Moderately	Quite a bit	A lot
	23.2	22.4	15.2	23.2	16.0
Stigma and discrimination					
Because I got in contact with professional help for the person I care for:					
28. I started to feel inferior	Totally disagree	Rather disagree	Neither agree or disagree	Rather agree	Fully agree
	50.8	14.2	23.3	10.0	1.7
29. I sometimes started feeling useless	47.5	15.0	19.2	15.0	3.3
30. I started feeling less capable than before	45.0	14.2	17.5	18.3	5.0
31. I started doubting myself	41.3	14.9	14.9	22.3	6.6
32. I sometimes am ashamed for this	54.5	7.4	19.8	12.4	5.8
Your own safety					
Over the last year, how concerned were you about the person you care for:					
33. accidentally doing something that puts you at risk (e.g., leaving the gas on)	Not at all	A little	Moderately	Quite a bit	A lot
	30.4	15.2	21.6	16.0	16.8
34. being aggressive or threatening towards you (e.g., verbal threats, sexual aggression, physical intimidation) ?	29.6	16.8	18.4	15.2	20.0
The safety of the person you care for					
Over the last year, how concerned were you about the person you care for:					
35. harming themselves?	Not at all	A little	Moderately	Quite a bit	A lot
	15.3	31.5	15.3	19.4	18.5
36. getting themselves into dangerous situations?	4.0	16.1	16.1	24.2	39.5
37. relapsing or deteriorating, such that it puts their safety at risk?	13.7	17.7	14.5	20.2	33.9

Table 3
Summary of responses to “Well-Being: Experience of Caregiving” section of Family Caregiver Survey.

Over the last year, how often have you thought:	Never	Rarely	Sometimes	Often	Nearly always
38. I have learnt more about myself	1.6	4.1	30.1	45.5	18.7
39. I have contributed to others understanding of the illness	0.8	4.0	25.6	46.4	23.2
40. I have contributed to his/her wellbeing	1.6	1.6	12.8	40.8	43.2
41. That he/she makes a valuable contribution to the household	5.7	19.5	30.1	25.2	19.5
42. That he/she has shown strengths in coping with his/her illness	3.2	15.2	36.0	26.4	19.2
43. I have become more confident in dealing with others	4.0	4.0	33.9	40.3	17.7
44. That he/she is good company	4.1	15.4	34.1	27.6	18.7
45. I have become more understanding of others with problems	1.6	4.0	10.4	43.2	40.8
46. I have become closer to some of my family	12.2	31.7	29.3	17.9	8.9
47. I have become closer to friends	16.9	35.5	29.0	16.1	2.4
48. I share some of his/her interests	0.8	20.8	42.4	23.2	12.8
49. I feel useful in my relationship with him/her	2.4	9.6	18.4	35.2	34.4
50. I have met helpful people	4.0	12.0	28.8	32.8	22.4
51. I have discovered strengths in myself	3.2	5.6	28.8	32.0	30.4

financial situation, their own physical health and emotional well-being, and the safety of the person for whom they were providing care. However, caregivers tended to report less concerns with stigma and discrimination and most caregivers had positive responses in their ‘Experience of Caregiving’ (see Table 3).

3.2.2. Part C—Support

Caregivers satisfaction with the supports they received varied across questions (see Table 4). The majority of caregivers felt that they had enough information about FASD to enable them to feel confident in providing care, and that it was easy to understand the information they had been given. Caregivers were generally quite satisfied with their involvement in making important decisions about treatment and care-planning but many still found it quite difficult to get help and support from medical and/or care staff for the person in their care. Finally, caregivers reported varying levels of satisfaction with the levels of support from various professionals.

3.2.3. Part D—Need for support

Finally, in Section D, 89% of caregivers responded that they would like more support to help them in their role as a caregiver. In terms of specific needs, caregivers were asked to answer “yes” or “no” to what support they needed from the FASD networks, organizations and agencies. Caregivers reported wanting these organizations to represent their family members at the policy level (86%); raise public awareness on the impact of mental illness (95%); provide individual emotional (92%) and financial (80%) support; provide individual information (92%) and practical support (96%); offer respite care (90%), provide the opportunity to meet and share knowledge and experiences with other family members and informal caregivers (94%) and professional caregivers (94%).

3.3. Caregiver stress

Overall, caregivers reported high levels of stress (see Fig. 1), with a mean total stress score of 29.5 (SD = 7.3). Over half (55%) of caregivers reported feeling upset sometimes, often, or very often because of something that happened unexpectedly; 47% felt that they were unable to control the important things in their life; 65% felt nervous and “stressed”; just under a third of respondents (30%) felt that things were going their way and that they were on top of things (26%).

3.4. Age and gender effects

Separate two way ANOVAs examining effects of age group (0–12; 13–17; 18 and older) and gender (of the individual with FASD) on each subsection and summary score from the FCS, as well as the total score on the PSS, were conducted. Alpha was set at .01 due to the number of analyses conducted. Overall, on the entire well-being section, there was an effect of age group, $F(2, 117) = 10.32, p < .001$, partial eta square = .15, such that caregivers of adolescents ($M = 3.56, SD = .84$) reported more needs/concerns, than either caregivers with children aged 18+ ($M = 3.34, SD = .73$) or those with children aged 0–12 ($M = 2.78, SD = .77$). There were no significant gender effects or interactions on the overall well-being score.

Data on the well-being subscales is presented in Fig. 2. Significant age effects ($p < .01$) were observed on subscales measuring “caregiver’s relationship with the person being cared for”, “caregiver’s physical health” “caregiver’s emotional well-being”, “stigma and discrimination”, “caregiver safety,” and “safety of the individual being cared for.” In general, the most concerns were among the adolescent age group (age 13–17), followed by the 18+ age group, and then children (age 0–12). There were no gender effects or interactions, except for on “safety of the individual being cared for”, where there was a significant interaction between age and gender, $F(2, 116) = 6.67, p < .01$. The source of the interaction appears to be due to the finding that males and females had similar scores in the 0–12 years of age range (Males: $M = 2.59, SD = 1.09$; Females: $M = 2.77, SD = .97$); however, during adolescence (13–18 years), caregivers reported more concerns for males than

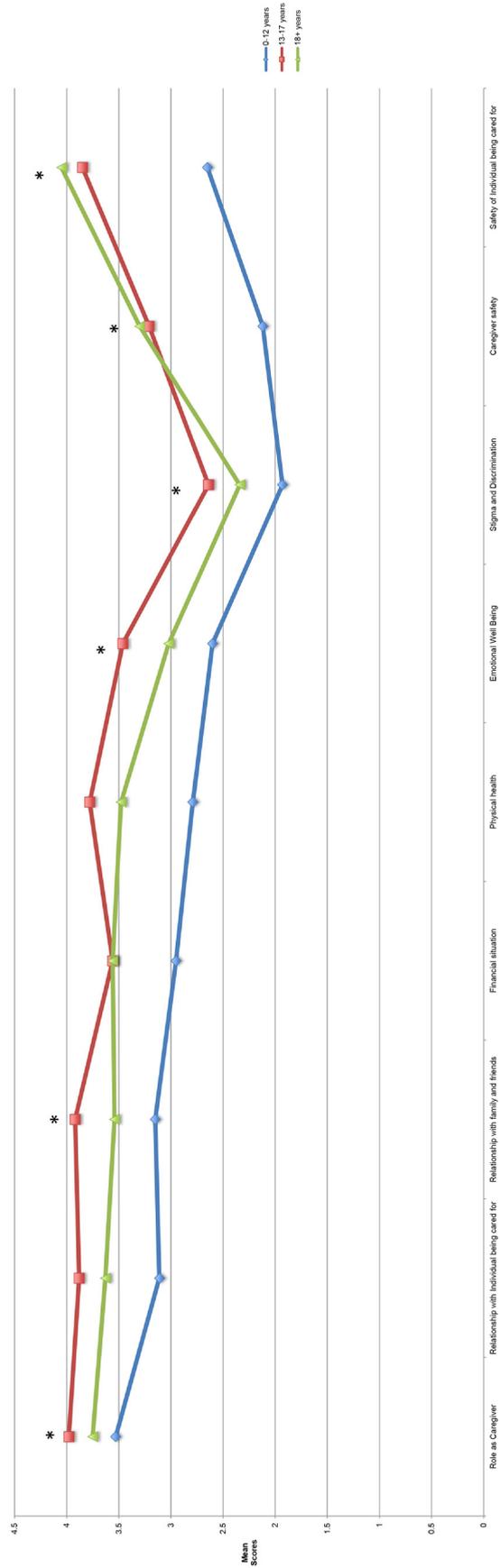


Fig. 2. Mean scores for “Well-Being” subscale questions of FCS.
 *: denotes significance, $p < .01$

Table 4
Summary of responses to “Support” section of Family Caregiver Survey.

Information and advice for caregivers	Percentage of Caregiver Responses (%)				
	Very dissatisfied	Somewhat dissatisfied	Not satisfied and not dissatisfied	Somewhat satisfied	Very satisfied
In general, how satisfied are you:					
1. that you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?	1.6	10.4	8.8	48.0	31.2
2. that you have enough information about how their condition/illness is likely to develop in the longer-term?	8.0	15.2	17.6	37.6	21.6
3. that you can get whatever information you need when you need it (e.g., through your doctor or on your own) ?	10.5	22.6	11.3	29.8	25.8
4. with how easy it is to understand the information you have?	1.6	11.2	18.4	38.4	30.4
5. with the amount of advice available to you (e.g., from healthcare workers or other caregivers) ?	17.6	24.8	20.0	22.4	15.2
6. that you are clear about who to go to for the information and advice you need?	17.6	24.0	12.0	30.4	16.0
7. that you are clear about who to contact if there is an emergency and you need help right away?	21.8	16.9	13.7	28.2	19.4
8. that you are clear about who to call if you have a routine inquiry?	16.8	20.0	10.4	34.4	18.4
Your involvement in treatment and care planning					
9. your involvement in important decisions (e.g., medication, hospitalization) ?	8.9	11.4	13.8	22.8	43.1
10. your ability to influence important decisions? Support from medical and/or care staff	8.9	12.1	10.5	33.9	34.7
11. how easy it is to get help and support from staff for the person you care for (e.g., to prevent relapse) ?	20.3	30.9	19.5	18.7	10.6
12. how easy it is to get help and support from staff for yourself (e.g., advice on how to deal with certain behaviors) ?	21.1	26.0	17.9	19.5	15.4
13. the quality of help and support from staff for the person you care for?	19.7	22.1	18.0	23.0	17.2
14. your relationships with key staff who support the person you care for?	11.4	13.8	24.4	27.6	22.8
15. how well the staff you have contact with are communicating with each other (i.e., that they share important information) ?	20.3	18.7	21.1	26.0	13.8
16. how seriously staff take what you say to them?	11.5	18.9	18.0	25.4	26.2
17. the level of understanding staff have of what it must be like to be in your situation?	24.6	21.3	18.9	17.2	18.0
In general, how satisfied are you with the support you received from					
18. Doctors	14.0	22.3	14.9	32.2	16.5
19. Nurses	11.8	16.4	40.0	23.6	8.2
20. Patient/Caregiver Organizations	10.7	15.2	28.6	29.5	16.1
21. Insurance company	16.3	12.5	59.6	9.6	1.9
22. Social Workers	26.4	20.7	19.8	16.5	16.5
23. Workplace	15.2	8.0	41.1	20.5	15.2
24. Pharmaceutical companies	17.6	10.2	47.2	16.7	8.3

females (Males: $M=4.17$, $SD=.97$; Females: $M=3.27$, $SD=1.31$); a finding which showed the opposite pattern in adults (Males: $M=3.75$, $SD=.94$; Females: $M=4.67$, $SD=.66$). However, such results must be interpreted with caution due to the small sample size in each sub-group. Finally, on the “experience of caregiving” subscale, not depicted in Fig. 2 because it is on a reversed scale (higher scores are better), there were no significant age or gender effects and no interactions, $ps > .08$.

There were no significant age or gender effects and no interactions, $ps > .07$ on the overall “Support” score. The “Support” subscales are presented in Fig. 3. Significant age effects were observed on the subsection “involvement in treatment planning and care” with caregivers of young children reporting more satisfaction than those caring for adolescents and adults. There were no interactions or effects of gender or age on the other two subscales. Lastly, on the Perceived Stress Scale, there were no significant age or gender effects and no interactions, $ps \geq .08$.

3.5. Family-level variables

In this section, to reduce the number of comparisons, analyses are only reported for the two main summary scores on the Family Caregiver Survey (Well-Being and Support) and the overall caregiver stress score on the PSS. Thus alpha was set at .05. First we examined whether results differed across caregiver type (biological/kinship, foster, or adoptive caregiver), with separate one way ANOVAs. There was a significant effect of caregiver type on the overall Well-Being score, $F(3, 121) = 3.34$, $p < .05$, where foster parents generally reported fewer concerns ($M = 2.57$, $SD = .70$) than biological/kinship

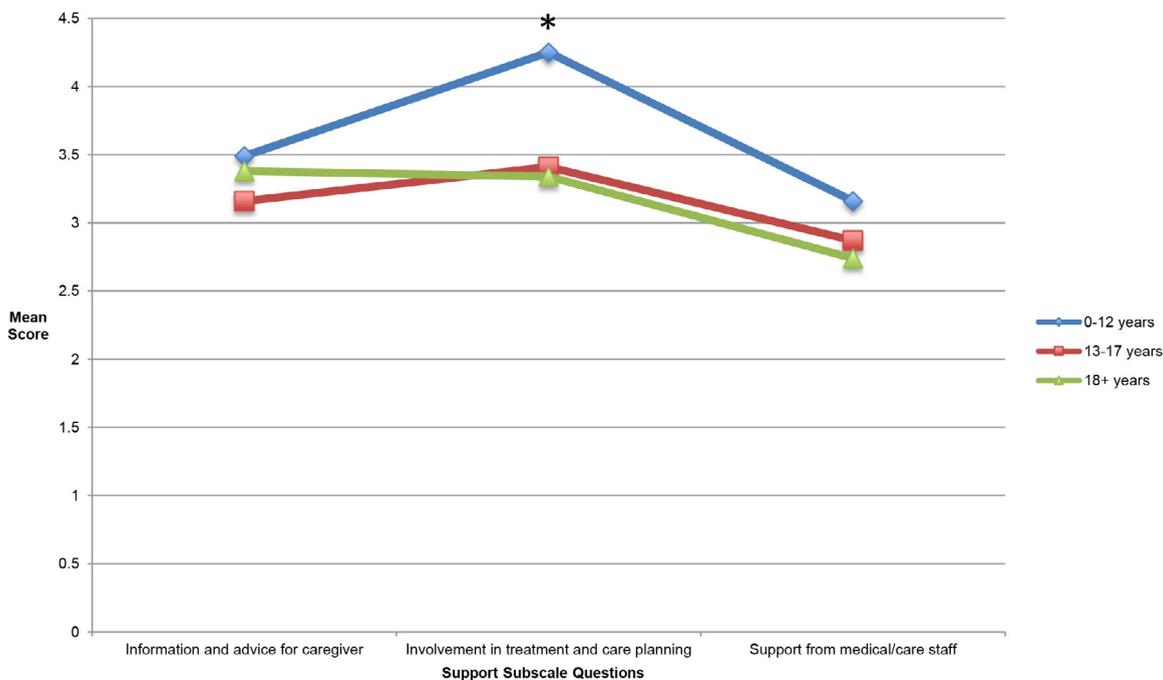


Fig. 3. Mean scores for "Support" subscale questions of FCS.

($M = 3.27$, $SD = 1.06$), and adoptive parents ($M = 3.25$, $SD = .81$). There were no significant effects of caregiver type on Support, or on caregiver stress, $ps > .05$.

There was no significant effect for the length of time the individual with FASD had been in the care of the caregiver on caregiver stress, $p > .05$. However, there was a significant effect on well-being $F(2, 122) = 7.72$, $p = .001$; caregivers who cared for the individual with FASD for longer periods of time reporting more Well-Being concerns than those who had cared for the individuals for shorter amount of times (0–5 years: $M = 2.57$, $SD = .85$; 6–10 years: $M = 3.13$, $SD = .79$; more than 10 years: $M = 3.38$, $SD = .82$). There was also a significant effect for the length of time the individual with FASD had been in the care of the caregiver on Support, $F(2, 122) = 3.22$, $p = .04$, and here there was a linear decreasing trend with caregivers who cared for the individual with FASD for longer periods of time reporting less satisfaction with the supports they were receiving (0–5 years: $M = 3.57$, $SD = .84$; 6–10 years: $M = 3.25$, $SD = .94$; more than 10 years: $M = 3.05$, $SD = .73$). However, "length of time cared for an individual with FASD" was highly correlated with age of the participant, $r(121) = .54$, $p < .001$. Thus, we next examined whether the effects of length of time in care remained significant after we included age category of the individual with FASD as a covariate; the effect of length in care remained significant for Well-Being ($p = .023$) but not for Support ($p = .212$). There were no significant effects of the number of children with FASD for whom the caregiver provided care (1, 2, or 3 or more) on Well-Being, Support, or caregiver stress, $ps > .05$.

In terms of reported income, there were no significant effects on Well-Being and Support, $ps > .13$. However, there was a significant effect of income on caregiver stress, $F(2, 101) = 4.15$, $p = .02$, as caregivers with the lowest income levels (\$0–49,999/year) reported the highest levels of stress ($M = 24.67$, $SD = 4.68$), compared to those with annual incomes ranging from \$50,000–99,999 ($M = 19.80$, $SD = 7.61$) and \$100,000 or higher ($M = 20.63$, $SD = 7.01$). Finally, there were no differences in Well-Being, Support, or stress level for caregivers who lived in urban vs rural settings, $ps > .51$.

3.6. Correlations between caregiver needs and stress

As evident in Table 5, there were many correlations between caregiver stress and needs related to Well-Being and Support.

4. Discussion

We examined the needs and stress of caregivers supporting individuals with FASD from infancy to adulthood (18+ years) and the effects of various demographic variables including: the age and gender of their child with FASD; caregiver type; caregiver income; the length of time they had cared for the individual; the number of other individual with FASD they cared for; and their current living location. Finally, we examined whether caregiver needs were associated with caregiver stress.

Caregivers generally reported many well-being concerns; however, they reported less concerns with their overall caregiving experience. Satisfaction with the supports they received varied across age. In general, caregivers of young individuals

Table 5
Correlations between Caregiver needs and stress.

	Correlation with Stress
Part B: Well being	
Role as caregiver	0.49**
Caregiver relationship with person you care for	0.63**
Caregiver relationship with family and friends	0.60**
Caregiver financial situation	0.36**
Caregiver physical health	0.60**
Caregiver emotional well being	0.72**
Caregiver stigma and discrimination	0.39**
Caregiver safety	0.35**
Safety of the person you care for	0.38**
Experience of caregiving	−0.14
Well being total score	0.67**
Part C: Support	
Information and advice for caregiver	0.39**
Involvement in treatment and care planning	0.23*
Support from medical and/or care staff	0.22*
Support total score	0.32**

* $p < .05$.

** $p < .01$.

(0–12 years) reported less concerns, than caregivers of adolescents. This may be due, in part, to the fact that some concerns can be supported through early identification and implementation of services and support both at home and at school, but provision of these resources are not always maintained as the child with FASD transitions to adolescence and adulthood, when issues of employability, independent living and funding supports arise. Additionally, the typical developmental processes of adolescence and adulthood, such as heightened awareness and concern about one's body, the onset of puberty, romantic relationships, and gradual emergence of independence may be complicated by impairments in learning, memory, executive functioning, attention, intelligence, language, and behavioral problems (Mattson & Riley, 2000; Paley et al., 2005). These deficits are commonly observed in individuals with FASD, leading to potentially more challenges as the child ages. Caregivers who provide care for individuals with FASD for longer periods of time (6–10+ years) reported more well-being concerns than those who cared for the individuals for shorter amounts of time (0–5 years). This remained significant after controlling for age of the individual with FASD. This finding may result from the fact that these caregivers have had more time to experience stressors related to the individual in their care and specific needs to manage daily life.

Previous research indicates that adoptive and foster parents of children with FASD often report higher levels of child-related parenting stress than biological parents, but that biological parents report higher levels of parent-related stress (Paley et al., 2006). Adoptive and foster parents may report high levels of child-related stress secondary to being unprepared to cope with the extent of their child's difficulties. In contrast, increased levels of parent-related stress in biological parents may be related to guilt for having a child with FASD, or an underlying vulnerability to stress leading to alcohol use during pregnancy (Paley et al., 2006). We found that biological parents and adoptive parents reported significantly more concerns on the overall Well-Being score of the FCS than foster parents; however, there were no significant effects of caregiver type on the Support summary score or on reported stress, $ps > .05$. Interestingly, there were no significant gender effects on any of the subscales or summary scores on the FCS or PSS in our study, except on the "safety of the individual being cared for" subscale on the FCS, where caregivers of adolescent males tended to have more concerns than females, a pattern that was not observed in the 0–12 or 18+ age groups. Lastly, there were no significant effects of urban vs. rural settings or the number of children with FASD for whom the caregiver provided care on overall Well-Being, Support, or caregiver stress, $ps > .05$. Although it was expected that caregivers with more than one child with FASD would have more needs and stress, the lack of significance found may be due to the fact that caregivers were asked to report only on the most challenging child in their care.

Caregivers in this study reported high levels of stress, with a mean stress score of 29.5 (out of 40), which is disconcertingly higher than average mean stress scores of 12.1–16.1 reported by Cohen and Janicki-Deverts, (2012) in numerous sample representatives of the general American population. Caregivers reporting a lower income also reported high levels of stress, which was not surprising as prior research demonstrates an association between lower socioeconomic status and higher stress (Baum, Garofalo, & Yali, 1999), and specifically on the PSS (Cohen & Janicki-Deverts, 2012).

There are several limitations to this study that should be considered. First, given that the data was anonymous, there was no way to medically verify the diagnosis of FASD, so we had to rely on caregiver report. However, we only recruited through FASD-specific agencies, groups, and websites in an attempt to only communicate to those caring for individuals with FASD and not the general public. Second, as with any survey research, we acknowledge that our sample may be slightly biased, as those with the most needs may be more inclined to complete the survey. Third, although this is a large sample, it is not representative of all of Canada, and respondent numbers varied by geographic location which limited our ability to analyze province by province where services and supports for FASD may vary drastically, and the higher percentage of adoptive parents, post secondary education and income levels in this sample may not be reflective of all caregivers of individuals with

FASD. Additionally, participants had to have access to the Internet to complete the survey, which may mean that potential respondents who reside in remote and rural communities were missed. Fourth, the FCS questionnaire was developed for a different population that is typically older at diagnosis and very medical in management. It does not include questions regarding items such as education system, which may be another area of stress for those caring for individuals with FASD and thus would be an important for future research. Fifth, we did not include the age of the caregiver in the demographics section, and stress and needs may vary as the caregiver ages, which is important to consider as well in future research. Finally, respondents were asked to report on the child with FASD that had the most needs, so results may not generalize to all individuals with FASD. That being said, the data is reflective of the overall/average experience of caregivers as each was commenting on the usual amount of stress experienced over the last month and their general needs.

5. Conclusion

Caregivers of individuals with FASD have multiple areas of concern (particularly as the individual ages), experience high levels of stress, and have a significant number of needs. These findings have important implications for policy and practice regarding supports and services available to caregivers of individuals with FASD. Clinicians and allied health care providers who help support individuals with FASD should be aware of the impact, stress and needs of the caregivers in developing appropriate management plans for their patients/clients. These efforts may be particularly necessary for those caring for adolescents and adults, and those with lower socioeconomic status.

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