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ORIGINAL PAPER

Caregivers of Youth with a Fetal Alcohol Spectrum Disorder: Hopes for Them as Adults

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Abstract Caregivers of youth with a fetal alcohol spectrum disorder participated in telephone interviews about their hopes for their youths as adults. Interviews with 16 birth, adoptive, and foster parents, as well as with aunts and grandparents of children over the age of 10 years, were conducted. A total of 54 unique responses were made to the question "What do you want for your child as an adult?". Participants independently grouped all responses into themes. The groupings were analyzed using multidimensional scaling and cluster analysis using the concept system and resulted in four concepts. The concepts included the following: (a) education and employment, (b) positive relationships, (c) community integration, and (d) support services. The main differences between the participants' experiences and the literature centered on different emphases on feelings relative to skills and on strengths relative to deficits.

Keywords Alcohol · Fetal alcohol syndrome · Birth defects

Introduction

Alcohol is a significant and frequently identified environmental cause of birth defects. Global prevalence rates suggest that 2.9 and 22.8 of every 1000 births were to a child who met the full set of criteria (i.e., fetal alcohol syndrome) or a subset of the criteria (i.e., fetal alcohol spectrum disorder), respectively (Roozen et al. 2016). In 2016, the rates in the United States were 0.7 and 33.5, respectively, and in Canada, 37.9 and 30.5 but with considerable geographic and ethnic variability (Thanh et al. 2014). A substantial number of cases of FASD remain undiagnosed (Thanh et al. 2011). Despite increasing diagnostic capacity (Onoye and Thompson 2017), demand often exceeds supply (Watkins et al. 2014), and interventions have focused primarily on affected children. However, adults with FASD are an increasingly recognized group (Tsang et al. 2016) with their caregivers as those most likely to provide a stabilizing influence through long-term residential and personal support (Boland et al. 2002).

Caregivers recognize and appreciate that the needs of their children with FASD are lifelong (Petrenko et al. 2014). The challenges faced during childhood and adolescence may change in response to physical maturation, but as they age, others' expectations of them also change. Often, the social (e.g., interpersonal), intellectual (e.g., decision-making), behavioral (e.g., impulsivity), and emotional (e.g., arousal) challenges that exist during childhood persist into adulthood, but manifest differently and have significantly different outcomes such as legal consequences (DeJoseph 2011). The needs of adults with FASD are understudied. Caregivers of children with FASD are well-positioned to anticipate their needs. This knowledge can be used to inform the development of FASD interventions and services for adults.

There is a growing body of literature concerning the development of youth with FASD. The transition from adolescent to young adult has been noted as a challenging time with risk factors for negative outcomes receiving attention (e.g., Coriale et al. 2013). A typical profile of an 18-year old with FASD reflects stronger social skills with less advanced problem-solving and emotional regulation abilities (Malbin 2002).

Recent efforts have included improved attention to the issues affecting young adults with FASD (e.g., Temple et al. 2015). In general, extensive and diffuse alcohol effects result

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in significant disabilities that require intensive and longer-term support (Fagerlund et al. 2011). It has been noted, for example, that memory problems persist from childhood into young adulthood (Coles et al. 2010) and that children with FASD will have elevated rates of mental health problems as young adults (Denys et al. 2011; O'Connor and Paley 2009). Anecdotally, however, as reflected in several case accounts, a high quality of life is possible (e.g., Boyle Street Education Centre 2007; Community Living British Columbia 2011; Erb 2015).

When caregivers are consistently involved, positive outcomes for individuals affected by prenatal alcohol exposure are more likely. It has been noted that a child's risk of developing secondary disabilities in adulthood such as mental health concerns, trouble with the law, and drug and alcohol use can be reduced by two to four times when there is a consistent and supportive living arrangement (Streissguth et al. 2004). Life chances are substantially improved for young adults who have been diagnosed early and live with the same caregiver, whether it be an adoptive, foster, or birth parent, in a highly structured and consistent home environment (Clark et al. 2004).

It is important to note that major functions of caregivers during young adulthood are to facilitate relationships within the community, such as professionals and peers, as well as enhance adaptive functioning. Caregivers typically remain very involved in their adult children's lives (Olson et al. 2009). They act as advocates with educational, health care, social services, and legal systems as necessary (Streissguth et al. 1996) and are connected to other caregivers facing similar challenges (Olson et al. 2009; Rowbottom et al. 2010).

Less developed conceptual abilities and associated skill deficits in youth with FASD compared to typically developing youth, such as managing time and money, expressing complicated ideas, future planning, emotion, and behavioral impulse control are particularly challenging for caregivers (Temple et al. 2011). The presence of a trusted and reliable caregiver (Gomos 2015) who functions as a coordinator, organizer, and planner goes a long way toward not only the personal well-being of an individual with FASD, but also to optimal community integration (Erb 2015; Rangmar et al. 2015). Indeed, young adults with FASD who had a consistent caregiver and in-home support described themselves as "normal," and by their early twenties, developed a growing awareness of self and what it meant to live with FASD (McGregor 2009).

There is considerable evidence that while challenges associated with prenatal alcohol exposure may change, they do not necessarily abate with age. Caregivers are fundamentally important, function in a variety of roles, and make important contributions to their children's lives. Caregivers also recognize their child's needs as lifelong and appreciate their own limitations to providing lifelong care. They want good lives for their grown children. Their hopes for children with FASD may be more likely realized when there is professional and community support for them as adults. The purpose of the present study was to identify areas of overlap between caregiver hopes and relevant interventions that appear in the literature. Consistency provides evidence in support of particularly credible ways to move forward in service development for adults with FASD.

There are relatively few interventions for adults with FASD. Health Canada published a document identifying best practices for FASD prevention, identification, and intervention which concluded that "while there is no evidence to date, there is a consensus among experts supporting continuing advocacy or case management to help the adult affected by prenatal alcohol exposure to adequately deal with the many challenges of adult life" (Health Canada 2000, p. 81). The evidence base has since grown, and there are four types of programs that have been studied including (a) community-based, (b) family-centered, (c) adaptive functioning, as well as (d) cognitive interventions (Wheeler et al. 2013). While some of these have been used successfully with adults, others show promise for working with adults.

Community-based interventions emphasize empowerment of families to access local supports. Parent-child assistance assists women with FASD at risk of giving birth to an alcohol-affected child (Grant et al. 2004). This program uses a case management approach. The step-by-step program also works with mothers who have a suspected or confirmed FASD diagnosis (Denys et al. 2011). In each program, participants set goals and identify needs. Results include improvements to housing situation, decreased alcohol and drug dependency, increased use of contraceptives, as well as access of community resources such as treatment for medical and mental health needs.

Family-centered interventions focus on helping caregivers raise their children who have FASD. Coaching families connected parents of children with FASD with mentors who assist them with education about FASD and links to resources (Leenaars et al. 2012). Participants in this program have fewer support needs in relation to the child, improved personal skills, and community integration (Leenaars et al. 2012). Another program, neurocognitive habilitation, teaches caregivers ways to recognize cues from their child that indicate changes in arousal levels and ways to respond (Wells et al. 2012). Increases in emotional problem solving ability are an outcome (Wells et al. 2012).

Adaptive skills are necessary to achieve independence and increase social abilities (Wheeler et al. 2013); however, there are currently no experimental adaptive skills interventions for adults. Some adaptive skills training for children include computer instruction for fire safety (Padgett et al. 2006), a virtual reality computer program for safety skills (Coles et al. 2007), and Children's Friendship Training for social skills (Frankel et al. (2006); O'connor et al. 2006).

Although rehearsal training is effective for children with FASD, cognitive interventions have not yet been developed for adults specifically (Loomes et al. 2008). Computerized Progressive Attention Training has been shown to enhance a variety of cognitive and learning skills such as working memory, sustained and selective attention, academic tasks, math, and reading fluency (Kerns et al. 2010).

Connections within the community, such as social activities, are a protective factor against secondary disabilities (Olson and Montague 2011; Wodehouse and McGill 2009). Lockhart (2001) noted that connections to psychopharmacological treatment, behavior therapy, education placement, speech and language services, family education, and vocational services are helpful for individuals with FASD. Assisted living supports are also of fundamental importance for adaptive functioning and daily living skills (Streissguth et al. 1996, 2004). Additionally, relationships and friendships from childhood and adolescence, when positive and consistent, can be very valuable connections for adults with FASD to maintain (Copeland 2002). In a study of caregiver perceptions of community integration for adults with FASD, there is strong evidence for medical, dental, and housing needs being met, but deficits in productive daily activities and social opportunities were found (Clark et al. 2008).

While there is a growing literature concerning the community and family support issues and interventions as well as methods to enhance personal skill development for children with FASD, there is limited data on the hopes of caregivers for their youth with FASD as adults. In the present study, we asked caregivers of youth with FASD about what they want for their children when they grow into adults.

Method

Participants

The research team collaborated with a diagnostic clinic and local community networking organization for health, social services, justice, and education professionals working with individuals affected by prenatal alcohol exposure. Advertisements were sent via the organization's email address database, and professionals were asked to share the advertisement with families caring for a child over the age of 10 years who had a suspected or confirmed FASD diagnosis. Caregivers contacted the researchers directly, by telephone, in person, or email.

A total of 16 telephone interviews were conducted with caregivers of a youth over the age of 10 years who had a suspected or confirmed diagnosis in the fetal alcohol spectrum. All but one of the participants was female. They included foster parents, adoptive parents, as well as birth parents, aunts, or grandparents. Half of the participants had a gross annual family income under $50,000 and none had household annual incomes above $100,000.

Procedure

Potential participants were provided with an overview of the study, description of their participation, and if they provided oral consent, a telephone interview was conducted. All responses were hand recorded by the researchers during telephone interviews. The responses to the question were independently reviewed by three members of the research team. Each was asked to review all responses and identify any that were unclear or redundant. The group met and discussed each response that had been identified by two or three reviewers. A decision was made about each response. Unclear responses were edited for clarity and redundant responses were removed from the analysis.

Each participant who had indicated interest during the interview was contacted a second time by telephone. Those who were willing to participate in this phase were sent a complete set of unique responses to the research question. Each response was printed on a separate card. Participants were asked to review all responses made and group them together in whatever way made sense. A member of the research team followed up with each participant to ensure the package arrived, and again after a few days to answer any questions. A date was set for a call to obtain the groupings by telephone.

Measures

The Neurodevelopmental Screening Tool (NST) (Nash et al. 2006, 2009) was developed to identify a behavioral phenotype of FASD based on caregivers' perceptions of children's behavior over the 6 months prior. In the present study, it was used to identify potential participants who cared for a youth with a suspected but unconfirmed diagnosis in the fetal alcohol spectrum. The NST was used to determine the likelihood of a positive diagnosis in the child, and that if the result was negative, the participant was deemed ineligible.

The interview included demographic questions as well as several open-ended questions including the focal question for this study "What do you want for your child as an adult?" If the caregiver had obtained an FASD diagnosis for a youth in their care, it was recorded. If the caregiver had not obtained a formal diagnosis for a youth in their care but such a diagnosis was suspected, the NST was administered. Four potential participants were found ineligible out of the 10 times the NST was administered.

Data Analyses

Concept mapping is a procedure for the collection and quantitative analysis of qualitative data (Trochim and McLinden

2017). The primary benefit of concept mapping relative to other qualitative approaches is that participants determine the underlying conceptual structure of the qualitative data. This approach has been used with patients in treatment for chronic pain (Beurskens et al. 2016), counselors providing mental health services (Tangen and Cashwell 2016), as well as community residents and service providers in high-risk communities (Stack-Cutler et al. 2017). There are five steps to the concept mapping process including (a) preparation, (b) generation, (c) structuring, (d) representation, and (e) interpretation.

In the preparation step, the population and sample parameters are identified. In the present study, local diagnostic and networking services for families and professionals were asked to forward email advertisements to potential participants. In the generation step, the focal question is asked of the participants. In the present study, this step was performed by graduate student research assistants via telephone interviews. In the structuring step, responses made by participants are reviewed by the researchers for clarity and to remove redundant responses. In the present study, the responses were mailed to interested participants for them to group together into concepts. In the representation step, the grouping data is analyzed using multidimensional scaling and cluster analysis to create a map of the concepts. In the present study, these analyses were performed by Concept System Global MAX software (Concept Systems 2017). In the interpretation step, maps with different numbers of clusters are reviewed to identify the best fit with the data. Those clusters are labeled. In the present study, researchers reviewed a range of maps generated from the analyses, identified the best map for the data, and gave each of the concepts a descriptive label for the responses contained within it.

The structuring data were analyzed using two procedures in the Concept System Global MAX software (Concept Systems 2017). These procedures included multidimensional scaling and cluster analysis (Kane and Trochim 2007). Multidimensional scaling placed each response on an *x-y* matrix with the distance between each reflecting the frequency with which they were grouped together by participants (Kruskal and Wish 1978). Responses near each other had been grouped together frequently by participants. Responses far from each other indicated that the responses had not been grouped together often by participants.

Cluster analysis used the multidimensional scaling values to identify the underlying conceptual structure (Anderberg 1973). At the beginning of this analysis, each response was its own concept, and at each stage of the analysis, concepts were combined until all responses were within one concept (Everitt 1980). The bridging index was a value between 0 and 1 that reflected the degree to which each response was grouped together by participants with other responses nearby on the map. A high bridging index value (i.e., 0.75 or greater) indicated that the response was frequently grouped together by participants with other responses in other areas of the map. A low bridging index (i.e., 0.25 or lower) indicated that the response was frequently grouped only with responses nearby on the map.

Two members of the research team determined the most appropriate number of concepts for the map and generated labels for each. The decision about the most appropriate number of concepts was made by reviewing different concept solutions from 10 to 3. The 10-concept solution was fragmented, but reviewing solutions with 9, 7, 5, 4, and 3 concepts, the similarities of responses within the concepts and differences of responses between concepts emerged. Average concept bridging indices were also used to inform which solution to select. Specifically, higher average bridging indices indicated that the responses within it were grouped by participants with responses in other concepts while a low average bridging index indicated that the responses within the concept were rarely grouped together with responses in other concepts. It was decided that the 4-concept solution provided the best interpretability.

Decisions about the labels for the concepts were made by two members of the research team. It was optional for participants to provide descriptive labels for their groups of responses, and these were provided by 8 participants. These labels were consulted. Responses within each concept were reviewed and individual bridging indices were used to identify those most central (i.e., smallest bridging indices) to the main idea represented by each.

Results

The 16 participants generated a total of 53 unique responses for the analysis (see Table 1). All but one participant independently grouped all the responses. The stress value of the final map was 0.31, which is within an acceptable range (Trochim 1993), and the 4-concept solution was selected by the research team (see Fig. 1). The concepts included (a) education and employment, (b) positive relationships, (c) community integration, and (d) support services.

Education and Employment

Responses in this concept centered on the caregivers' desires for their adult children in school and work activities. They ranged from more modest hopes, such as "further education", to include post-secondary options such as "go to college" and "go to university." The nature of employment also ranged a great deal. Caregivers noted that they wanted their youth to have a "career" or the potential to "run her own business," such as a "computer business," and thereby achieving "independent employment." A more supportive work

Table 1 Unique responses for the analysis

Concept	Statement	Bridging Index
Education and employment		*0.23*
	45. Run her own business	0.13
	17. Career	0.13
	12. Amazing job	0.13
	36. Independent employment	0.17
	27. Further education	0.21
	19. Computer business	0.21
	28. Go to college	0.21
	1. A job that uses his skills	0.23
	24. Employed at least sometimes	0.33
	53. Work place co-op	0.34
	34. Hold a job	0.35
	29. Go to university	0.38
Positive relationships		*0.17*
	50. To be happy	0
	49. To be a good person	0
	5. A wife who understands	0.07
	3. A social life	0.08
	32. Have positive relationships	0.08
	31. Have children	0.09
	30. Have a family	0.09
	15. Be successful	0.1
	20. Content	0.13
	13. Be in a relationship with someone	0.13
	21. Contribute to society	0.14
	8. Achieve to the best of their ability	0.14
	41. Normal healthy life	0.14
	7. Able to survive in society	0.26
	18. Community involvement	0.3
	9. Advocate for himself	0.37
	23. Feel like he can manage his disorder	0.46
	26. Finish school	0.51
Community integration		*0.6*
	40. Live with someone who understands her needs	0.33
	38. Keep her alive	0.4
	52. Whatever she wants with support	0.4
	5. Able to recognize when needs to calm down	0.47
	2. A place where they fit	0.54
	51. To understand what his issues are	0.55
	44. Push them to the point they are at their best	0.57
	43. People to be aware of the disability	0.64
	16. Bring awareness to the community about FASD	0.75
	42. Not everyone gets married and has babies	0.91
	22. Cultural transitioning to become a man, through ceremony	1
Support services		*0.31*
	23. Do own shopping	0.22
	46. Slowly increase his responsibilities	0.24
	33. Supervision his whole life	0.24
	35. Housing	0.26

Table 1 (continued)

Concept	Statement	Bridging Index
	37. Inter-dependence with me	0.27
	10. Always have 24-h support	0.28
	4. A special home that allows him a family environment	0.28
	14. Be semi-independent	0.29
	11. Always live with me	0.32
	48. Supportive situation	0.36
	47. Special services	0.36
	39. Legal help	0.57

environment identified by participants included a “work place co-op.” Qualities of the job were important to participants as well, who reported that having “a job that uses his skills” could be enough to make a job an “amazing job.” They also noted that being “employed at least sometimes” and having the ability to “hold a job” were hopes they had for their children as adults.

Positive Relationships

In this concept, responses centered on the desire for good relationships for adults with FASD. Caregivers wanted their children as adults to have a “normal healthy life” and to “have positive relationships.” They also described the desire they had for their children “to be happy” and “content” as well as “be successful” and “to be a good person.” It was important for their children as adults to “advocate for himself” and “achieve to the best of their ability.” Confidence to “feel like he can manage his disorder” or “finish school” was also identified. Caregivers also spoke about their hope for their children to “have a family” or “be in a relationship with someone,” have “a wife who understands” or themselves to “have children.” They also described it as important that the children would be “able to survive in society” as adults, hoping that they would experience “community involvement” as well as have “a social life” and “contribute to society.”

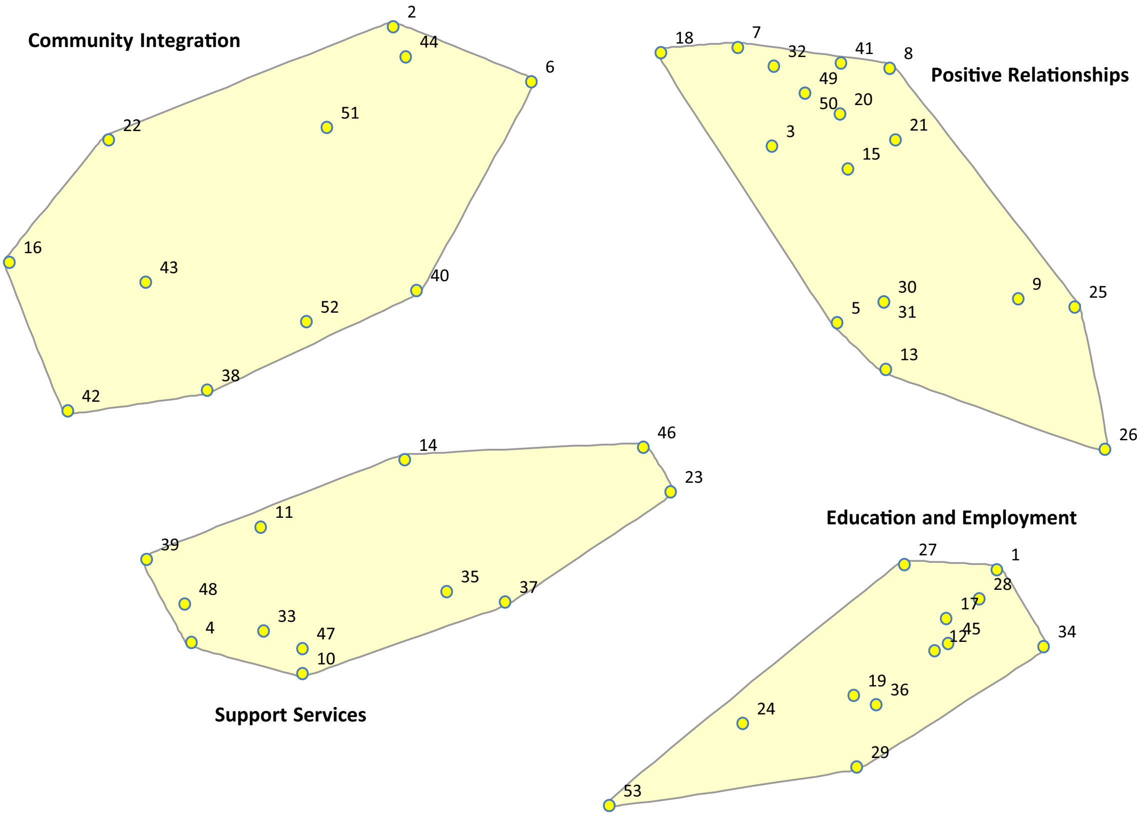

Fig. 1 Concept map of responses to “What do you want for your youth with FASD as adults?”

Community Integration

In this concept, responses centered on the need for their grown children to feel included and supported, by having "a place where they fit" and receiving "whatever she wants with support." Participants also described the need for improved public knowledge about FASD and so that "people to be aware of the disability" and that perhaps their own children could "bring awareness to the community about FASD." Such awareness would include a range of possibilities for adults with FASD and being open to differences, such as recognition that "not everyone gets married and has babies." Caregivers also noted that supportive people would be needed by their own children in basic ways, such as to "keep her alive," but also to "live with someone who understands her needs." These support people would be able "to understand what his issues are" and be "able to recognize when needs to calm down." They would also "push them to the point they are at their best" and assist them with "cultural transitioning to become a man, through ceremony."

Support Services

The long-term, likely lifetime connection between caregiver and child was described through responses in this concept. In addition to the basic need for "housing," it would need to be a "supportive situation" where there is "always have 24-h support" because the youth would need "supervision his whole life." They also described the family support they would provide themselves, including the child's "inter-dependence with me" and "a special home that allows him a family environment." Caregivers noted that it was possible that the child would "always live with me." Improvement over time was suggested in response to supports such as "special services" and "legal help," which would "slowly increase his responsibilities." Basic skills and greater independence were indicated by the responses "do own shopping" and "be semi-independent."

Discussion

While there was little attention in the literature on post-secondary education specifically, participants' responses implied that their child with FASD had a level of functioning that would make post-secondary education achievable. Case accounts of individuals with FASD have shown that post-secondary education and consistent employment outcomes are possible (e.g., Boyle Street Education Centre 2007; Community Living British Columbia 2011; Erb 2015). However, the literature is generally reflective of lower expectations of adult development for youth with FASD, noting that memory challenges and social challenges contribute to learning and health difficulties for many (Coles et al. 2010; Denys et al. 2011; O'Connor and Paley 2009). However, educational and occupational opportunities can be facilitated through community-based initiatives that inform adults and their caregivers about appropriate programs (Grant et al. 2004; Denys et al. 2011).

There is little attention in the literature on healthy development for young adults with FASD (Moore and Riley 2015)—most of the attention is largely focused on health and legal problems as well as skill deficits. However, interventions for children with FASD have been found to improve social skills and facilitate greater independence (Coles et al. 2007; Frankel et al. 2006; O'connor et al. 2006; Padgett et al. 2006; Wheeler et al. 2013), but there is little in the literature on what adults with FASD require in order to achieve healthy development, well-being, success, and community participation.

Processes and effects of inclusion within a community that understands and accepts adults with FASD are generally absent from the literature. There is, however, substantial attention to family qualities and processes as well as their protective effects. There is considerable evidence about the importance of consistent caregiving and its positive effect among individuals with FASD (Olson and Montague 2011; Wodehouse and McGill 2009). A stable home environment, which would include meeting basic needs as well as recognizing cues that indicate readiness and resistance to change by a knowledgeable caregiver, is well supported (Lutke 2004). The absence of such stability increases the chance of negative outcomes such as homelessness and substance abuse (Clark et al. 2008).

As evidenced in the literature, and reported by participants in the present study, youth and adults with FASD often benefit from having long-term, in-home support (Fagerlund et al. 2011; Streissguth et al. 2004). In the present study, participants' desire for caregivers who not only provide support and encouragement at home but who also promote connections with others in the community, especially service providers and professionals, are concerns that are also supported by the literature (Olson et al. 2009; Streissguth et al. 1996). However, participants did not comment on the benefits of supportive peers and friends to provide a sense of normalcy and mutual support (McGregor 2009; Olson et al. 2009; Rowbottom et al. 2010).

There was overlap between the issues identified by participants in the present study and the literature. While interventions for adults with FASD have not been the subject of considerable research to date, the underlying causes of challenges experienced during childhood and adolescence do persist into adulthood. Caregivers are acutely aware of the persistence of neurological and physiological challenges, and given the results of the present study, thinking ahead for their children and their futures as adults. However, neither they nor the literature reflect a substantive interest in adult interventions for FASD.

The topics where there was difference between the literature and the present study centered on educational expectations, healthy development, community involvement, and friendships in adulthood. Participants in the present study described their hope for possibilities beyond primary and secondary school education. The literature centered on the educational and learning challenges experienced as well as interventions and supports that will be helpful (Kalberg and Buckley 2007). The idea of healthy development, such as having a sense of self-worth, capacity, achievement, and inclusion, was identified by participants as hope for their children and youth with FASD. With some exceptions (e.g., DeJoseph 2011), research concerns the "problem" or "deficits" associated with FASD and the lack of opportunities for promoting healthy adjustment throughout adolescence and into adulthood. The hope for healthy development as their children age was evident in the desire to have them feel included within a community of others who understand and accept them. This community of support was not evident in the literature. However, the presence of friends and the support that healthy peers can provide were reflected in the research that focused on children (McGregor 2009; Olson et al. 2009; Rowbottom et al. 2010).

In this study, a fundamental difference was noted between participants' comments about what they hope for their adolescents with FASD as adults and the literature. While caregivers are preparing to adjust to their children becoming youth and adults with FASD, there has been little attention to the possibilities for their development in the literature. Caregivers described hopes for a good future that included both internal (e.g., self-esteem) and external (e.g., inclusion) qualities for their children. They emphasized healthy development, including relationships with family members, peers, and others in their communities. They described a hope for their youth to achieve their fullest potential, to be included, and to feel good about themselves. The literature, in contrast, placed emphasis on deficits (e.g., Kully-Martens et al. 2012) and skill development (e.g., Kalberg and Buckley 2007), potential social and legal problems (e.g., Mela and Luther 2013), and interventions (e.g., Paley and O'connor 2009) for children and youth. While this difference in perspectives can be viewed as inconsistent and potentially in conflict, it also offers an opportunity to view these contrasting views as complementary.

One implication of these findings is that differing perspectives about capacities and potential be viewed both practically as well as hopefully, recognizing both challenges and strengths, at personal and community levels. The research possibilities that extend from such an approach could include the nature and extent of adaptive functioning, the extent to which it compensates for functional deficits, emotional resilience and its relationship to mental wellness, personal adjustment, and family demographics, social network breadth, and strength in relationship to belonging and inclusion. There is a need for further research into what healthy development for adolescents and adults with FASD consists of and the ways that families, services, and professionals as well as communities can promote it.

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Author Contributions JB: designed and executed study, assisted with data analysis, and drafted the manuscript. AK: managed data collection, assisted with literature review, collaborated on final drafting of manuscript. EN: assisted with data analysis and interpretation of results of multidimensional scaling and cluster analysis, and performed final editing of manuscript. KC: assisted with data collection. AS: assisted with data collection.

Compliance with Ethical Standards

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Ethical Approval All procedures performed in the study were in accordance with the ethics protocol approved by the Non-Medical Ethics Board at the University of Western Ontario.

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