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Motives and Motivations for Peer Mentors of Caregivers with Children who have Fetal Alcohol Spectrum Disorder

" Motifs et motivations des pairs mentors auprès de proches aidants d'enfants ayant un trouble du spectre de l'alcoolisation fœtale

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Abstract

Fetal alcohol spectrum disorder (FASD) refers to a spectrum of neurodevelopmental conditions that significantly impact an individual's physical appearance, learning, and behaviour. A consistent caregiver and home life are known to reduce the occurrence or severity of adverse outcomes. Peer mentors can be important sources of support to caregivers with children who have FASD. The purpose of this study was to identify the motives[1] and motivations[2] of peer mentors to caregivers of children and youth with FASD. Ten mentors with lived experience raising a dependent with FASD participated in in-person or telephone interviews that included the focal question: "Why do you want to be a peer mentor?" Responses were analyzed with a qualitative content analysis procedure. Four themes were generated from the responses. Mentors wanted to provide emotional support as a means of improving mentee wellbeing through therapeutic means and relationship development. They wanted to share lived experience as a means of educating mentees through the provision of personal knowledge, strategies, and skills. Mentors also chose to become involved for personal or mutual benefit, including fulfilling a call to give back or for personal growth and development. Finally, mentors participated to alter the perceptions and expectations held by mentees regarding caring for a child with FASD by sharing personal values and opinion statements. The themes were compared and contrasted with existing literature.

[1] *Motives: Reasons for doing something*
[2] *Motivation: The process that initiates, guides, and maintains goal-oriented behaviours*

Résumé

Le trouble du spectre de l’alcoolisation fœtale (TSAF) réfère à un éventail de troubles neurodéveloppementaux qui ont un impact significatif sur l’apparence physique, l’apprentissage et le comportement d’un individu. Il est connu qu’un proche aidant et une vie familiale stables réduisent l’apparition ou la sévérité de résultats défavorables. Des pairs mentors peuvent être d’importantes sources de soutien pour les proches aidants d’enfants ayant un TSAF. Le but de cette étude était d'identifier les motifs[1] et les motivations[2] de pairs mentors auprès des proches aidants d'enfants et de jeunes ayant un TSAF. Dix mentors ayant une expérience vécue dans l’éducation d’une personne à charge ayant un TSAF ont participé à des entretiens en personne ou par téléphone qui comportaient la question centrale : « Pourquoi voulez-vous être un pair mentor ? » Une procédure d’analyse qualitative du contenu effectuée sur ces réponses a fait ressortir quatre thèmes. Les mentors souhaitaient fournir un soutien émotionnel afin d'améliorer le bien-être des mentorés grâce à des moyens thérapeutiques et au développement de relations. Ils voulaient partager leur expérience vécue afin d'éduquer les mentorés en leur fournissant des connaissances, des stratégies et des compétences personnelles. Les mentors ont également choisi de s'impliquer pour un bénéfice personnel ou mutuel, notamment pour répondre à l’appel de redonner ou à des fins de croissance et de développement personnels. Finalement, les mentors ont contribué à modifier les perceptions et les attentes des mentorés concernant les soins à donner à un enfant ayant un TSAF en partageant leurs valeurs personnelles et leurs opinions. Les thèmes ont été comparés avec les écrits scientifiques existants.

1 Motifs : raisons de faire quelque chose
2 Motivation : le processus qui initie, guide et maintient des comportements centrés sur un objectif

Mots-clés : mentorat, proches aidants, trouble du spectre de l'alcoolisation fœtale, expérience vécue

Introduction

Fetal alcohol spectrum disorder (FASD) is one cause of developmental disability in Canada (Stade et al., 2019) and internationally (Carpenter, 2011). FASD refers to a spectrum of neurodevelopmental conditions that significantly impact an individual’s physical appearance, learning, and behaviour as a result of their mother’s consumption of alcohol during pregnancy (Millar et al., 2017). A consistent caregiver and home life are known to reduce the occurrence or severity of adverse outcomes such as school or work issues, as well as justice system involvement (Petrenko et al., 2014; Petrenko et al., 2019).

The lived experience of mentors plays a vital role in the credibility and impact of the assistance they provide to other caregivers (Magnacca et al., 2022). One-on-one peer mentorship for caregivers raising children with FASD holds great promise as a means to provide caregivers with connections and encouragement as well as strategies and advice to help their child at home and in the community. The purpose of the present study is to describe mentors’ motives and motivations for becoming a mentor. Mentors in the study were involved in a FASD mentorship program. This program, called FASD Connect, was created to connect caregivers of individuals with FASD with experienced mentors. The mentors had lived experience as a caregiver of a child or youth diagnosed with FASD.

Literature Review

Background

In Canada, the diagnosis of FASD involves a multidisciplinary assessment that considers confirmation of prenatal alcohol exposure, the presence of sentinel facial features, and an impairment in at least three areas of development. The categories of at risk for neurodevelopmental disorder and FASD associated with prenatal alcohol exposure were created to include individuals with confirmed prenatal alcohol exposure that do not meet the central nervous system impairment criteria but exhibit some indication of neurodevelopmental disorder (Cook et al., 2015).

A global review of the prevalence rates of FASD among children and youth was found to be 7.7 of 1000 births, ranging from 0.1 in the Eastern Mediterranean to 19.8 in Europe (Lange et al., 2017). The most recent Canadian research indicates that the rate of FASD ranges between 2% and 3% (Popova et al., 2018). Prevalence rates have been suggested to be higher in northern communities (Popova et al., 2017), among children in care (Fuchs & Burnside, 2014) and youth correctional populations (Murphy et al., 2005). Due to variability in definitions, care is necessary to ensure that frequencies and comparisons are consistent (Brown et al., 2019).

Caregiver support is crucial to improving the lives of children and youth with FASD (Olson et al., 2007). For children with FASD, the odds of negative life outcomes decrease by two to four times with an early diagnosis and consistent environment (Streissguth et al., 2004). Among caregivers, high parental stress and reduced psychological well-being are associated with increased child behaviour problems (Neece et al., 2012) as well as reduced effectiveness of therapeutic interventions for the child (Osborne et al., 2008). Despite the importance of caregivers in creating positive outcomes for children with FASD, caregivers are provided with limited community support (Brown, 2015; Clark et al., 2008; Naumann et al., 2013).

Adoptive, biological, and foster parents of children with FASD experience a number of similar difficulties associated with their caregiving roles. Each group has expressed feeling burdens such as stress and isolation (Michaud & Temple, 2013; Mukherjee et al., 2013; Whitehurst, 2012), the need to adapt parenting strategies to meet their child's specific needs (Gardner, 2000; Ryan & Ferguson, 2006; Sanders & Buck, 2010), and concern for their child's future (Chamberlain et al., 2017; Watson et al., 2013a). Caregivers also report the need to be an advocate for their child (Chamberlain et al., 2017; Mukherjee et al., 2013) and respond to the lack of knowledge about FASD among many professionals with whom they come into contact. They also report feeling blamed for a child's behaviour because of their presumed "bad parenting" (Coons et al., 2016; Domeij et al., 2018; Ryan & Ferguson, 2006; Whitehurst, 2012).

Caregiver Needs

Because FASD is often described as "preventable," there is a considerable amount of blame directed toward mothers (Corrigan et al., 2017). Caregivers have identified the stigma attributed to them as difficult to cope with (Salmon 2008). Birth mothers feel particularly responsible and many feel oppressed by others (Salmon, 2008). Additionally, caregivers may struggle with the daily realities of caring for a child with FASD. According to Gardner (2000), foster parents described difficulty coping with the need to provide consistency and fears about their child's future (e.g., prospects as adults). Caregivers may also benefit from learning healthy coping strategies in response to stress (Astley et al., 2000). Self-care strategies used by caregivers can be helpful for reducing distress and promoting parenting confidence (Kautz et al., 2020).

Parenting stress is high among caregivers of children with FASD (Hill & Rose, 2009). Reports of stress by caregivers of children with disabilities indicate that relative to other disabilities, such as autism spectrum disorder, caregivers of children with FASD experience greater levels (Watson et al., 2013a). Importantly, caring for an individual with FASD has been identified as stressful regardless of the severity of the disorder (Paley et al., 2006). Importantly, there is literature referencing positive aspects of caregiving children with disabilities (Scorgie et al., 2004) and children with FASD (Coons et al., 2016).

Caregivers have identified the need for information and strategies. For some, such as foster parents, information about the child's challenges is not available or provided (Brown et al., 2007). Even when it is known that a child has FASD, many caregivers feel unprepared. Some behaviours associated with FASD may be distressing (author 3). In particular, caregivers report that managing illegal behaviour, resulting from poor judgment in choosing appropriate friends, was particularly distressing (Watson et al., 2013). Information about navigating the system may promote confidence and better care (Doig et al., 2009; Weinner & Morse, 1994).

Sources of stress for caregivers include community perceptions, blame directed at them, and limited information and support for what works. Difficulty obtaining a diagnosis adds to the stress a caregiver experiences (Caley et al., 2009; May et al., 2018). While recommendations have been made for mental health professionals to be sensitized to possible indications of FASD (Brown et al., 2017), practitioners are not confident about making diagnoses. Between half and two-thirds of American pediatricians who are in a position to diagnose are not comfortable doing so (Gahagan et al., 2006). Surveys of Canadian family physicians and midwives between 2002 and 2017 showed a decrease in endorsement of the statement that FASD was an "identifiable syndrome" (Green et al., 2021).

A support system is necessary for caregivers (Brown, 2015; Bailey, 2007; Streissguth, 1997). This support system should include those from education and health as well as social services and justice, as appropriate (Brown, 2015). Caregivers benefit considerably from supportive others who understand. This occurs formally from FASD support groups (Weinmann et al., 2021) and professionals who understand their caregiving needs and challenges (Brown, 2015). Such support also occurs informally with friends and family as well as other community members such as neighbours, who know what they are going through (Balcaen et al., 2021). Despite the clear need for the support of professional and systems, caregivers are provided relatively little assistance. In a study of caregiver perceptions of the community support and integration of adults living with FASD, caregivers expressed low community integration of adults and noted that areas of high integration were due to the caregivers' efforts rather than community supports (Clark et al., 2008).

Peer Mentorship

The disability services system needs restructuring to become more partnership oriented and client-centred (Matthews et al., 2021). In addition, the bureaucratized and individualized nature of most current programs rarely recognizes the community and family strengths that are present (Reynolds et al., 2018). One form of community-based support involves participation in specialized peer mentorship programs. While research has sought to establish the experience of caregiver mentees, minimal research has examined the experience and motivations of caregivers serving as mentors. Moreover, the experiences of FASD caregivers in peer mentorship positions are understudied. In this section, literature on peer mentorship by caregivers of children with health challenges is presented.

In a systematic review of studies of peer support for children with chronic health conditions Shilling and colleagues (2013) noted four benefits to mentees that occurred across qualitative studies. These benefits included shared social identity, learning from others' experiences, personal growth, and providing support. Among caregivers of children with intellectual disabilities it was found that the source of support was less important than the way it was offered – if the support was offered by someone who treated them with respect and interested in what they needed (Strnadová et al., 2019).

Peers have been used to provide a range of services for caregivers including information about illness and treatment, emotional support, advocacy, and connecting with services (Hoagwood et al., 2010). A review of peer delivered models for caregivers of children with health conditions indicated that the models resulted in reductions of caregiver stress, a greater quality of life, and enhanced social support (Acri et al., 2017).

The experience of peer mentors has already been explored by others. One theme generated from responses is the helper therapy principle, in which mentors gain a number of benefits from helping others (Proudfoot et al., 2012). Mentors may experience an improvement in communication skills, self-confidence, a greater sense of interpersonal competence, an enriched sense of self and personal value, and personalized feedback from their work with others (Beutel & Spooner-Lane, 2009; Irby et al., 2020; Mowbray et al., 1996; Sourk et al., 2019).

While there is a considerable literature on the experiences of caregivers with children who have FASD, the emphasis tends to be toward the struggles and challenges. Peer support has received limited attention on the FASD literature. Studies with caregivers of children with disabilities and health challenges reflect the benefits of mentorship from those with similar lived experience. However, there is little known about the motives of peer mentors for caregivers of children and youth with FASD. The purpose of the present study is to describe the motives and motivations of peer mentors seeking to be matched with another caregiver of a child with FASD.

Methods

Overview

A peer mentorship program (FASD Connect) in a medium-sized south central human services agency recruited experienced caregivers to provide mentorship. The purpose of the FASD Connect was to connect isolated parents/caregivers to trained mentors with shared experience, thereby increasing social connection through a mutual support network. The program officially started in January of 2017. A project coordinator was hired to oversee the matching process. The first author of the present article was the research assistant hired to collect data for the evaluation of the FASD Connect program under the supervision of the second and third authors. The present study focused on the initial group of mentors who joined the program during the first year and a half of its operation. All interviews were conducted individually by the first author in person following a program orientation with the coordinator. Participants were asked "Why do you want to be a peer mentor?" Follow-up probes included asking participants about their own personal mentorship experience, relevant life experience, what they see as important about mentoring and what they have learned as a caregiver that could help others.

The primary goal of FASD Connect was to improve quality of life and well-being through reduced social isolation for parents and caregivers by increasing mutual support network, parental confidence and awareness of strengths, feelings of self-worth, positive coping strategies and personal growth, and strategies for connecting with school and social services. The coordinator recruited program participants by contacting schools, Children's Aid Societies, community agencies and hosting presentations about FASD in the community. Mentors were parents or caregivers of a child with suspected or diagnosed FASD with the capacity to commit to two meetings per month for six months.

Procedure

All mentors were required to attend a 2-hour training with the coordinator of the program. The training covered several topics including, basics about the program, basics about peer mentoring, the neurobehavioural model, the determinants of health, parenting, advocacy, self-care, and evaluation. Data for the present study was collected as part of a formal intake interview that included a demographic questionnaire as well as address and contact information. All participants had been interviewed by the coordinator to ensure they met program participation requirements prior to the training. The study was approved by the third author's institutional ethics board.

All but one participant met with the interviewer in person. One participant did the interview later via telephone. Interviews were performed by the first author who took handwritten notes. Overlapping questions included: Why do you want to be a peer mentor? Have you had personal mentorship experience? Do you have life experiences that will help others? What are the most important things about mentoring? What have you learned as a caregiver that you want to pass along to others? The interviewer prompted participants to expand upon each of these questions. In accordance with the institutionally approved ethics protocol, individuals were invited to share their intake questionnaire results with the evaluation team. We achieved saturation, defined as two consecutive interviews with no novel responses, after interviewing 10 participants.

All 10 program participants allowed their intake questionnaire data to be used for the present study. Research participants included one birth parent, one grandparent, one foster parent, and seven adoptive parents. All participants were white females with an average age of 49 (ranging from 28-60). Three of the participants were single, two separated/divorced, and five married. Two had annual family incomes in the $30,000s, one in the $40,000s and seven with more than $50,000. (Incomes are reported in Canadian dollars.) Eight owned their homes and two rented. One participant had some high school, one some college, three graduated from college, one graduated from trade school, three completed an undergraduate university degree and one completed a graduate university degree.

All participants had a child with suspected FASD while only three families had received a formal diagnosis. Five had one caregiver in the home and five had two caregivers in the home. Five worked full-time, three part-time, and two were not employed. Five families had one child, two had two children, and two had three children. Eight families had one child with FASD and two had two children with FASD.

Data Analysis

Responses were analyzed by the first author through qualitative content analysis in accordance with Creswell's (2003) procedures. This analysis procedure involved (1) arrangement of data into types, (2) reading the data to acquire general meaning, (3) initial coding of data into chunks and labeling into categories, (4) a detailed description regarding the people, places, and events, and creation of codes for use with a small number of categories, (5) discussion of themes and (6) interpretation of the data.

Trustworthiness, through credibility, dependability and confirmability, was promoted at each step of the analysis through the use of several strategies (Nowell et al., 2017). To become familiar with the data the first author reviewed all notes made during interviews and notes kept of their process during the collection and analysis. In these notes, they documented thoughts about codes and themes. During the generation of codes, the first author consulted with the second and third co-authors regarding thoughts about notes from reflexive journaling. As themes were generated, the first author constructed a visual map of connections between responses in the data. The authors met to discuss themes, considered the coverage of responses by themes, cohesion within the themes and distinctions between the themes.

Results

Four themes were generated from the responses. The first theme highlighted motivation to provide emotional support as a means of improving mentee wellbeing through therapeutic means and relationship development. The second theme involved motivation to participate by sharing lived experiences as a means of educating mentees through the provision of personal knowledge, strategies, and skills. The third theme illustrated motivation to engage for personal or mutual benefit, including fulfilling a call to give back, engaging in personal growth, and development. The fourth theme highlighted the mentor's motivation to alter perceptions and expectations held by mentees based on personal opinions and values.

Provide Emotional Support to Improve Mentee Wellbeing

This theme highlighted the provision of emotional support to mentees as a motivating factor for program participation. Emotional support was provided through the mentor's desire to instill hope in the lives of mentees, provide mentees with supportive listening, be empathetic to mentee experience, encourage enjoyment, create a nonjudgmental relationship, help mentees process their feelings, and decrease mentee's feelings of isolation.

Instilling Hope

Instilling hope in their mentees was a motive to become a mentor. Mentors wanted to send positive messages to other caregivers (their mentees) that could uplift them through difficult times. Participant 01 explained that they wanted to share with their mentee that, "it gets better." Participant 02 wanted to share a similar sentiment with their mentee that, "it is not necessarily going to be easier, but it will get better," and share that the future, "is not as scary as you think when first diagnosed." Participant 05 aimed to instill hope in their mentee as they expressed the desire, "to give hope amidst the struggles." Participant 05 further emphasized wanting to help their mentee by instilling hope when they expressed the importance of, "not fall into the feeling that my life is awful, not falling into the awful, but giving hope" to their mentee, and sharing, "it is not hopeless, there can be good days."

Listening

This term indicates a desire to emotionally support mentees by providing listening to their experience. For caregivers, listening provides a sense of understanding, connection, and was identified as an important element to provide within the mentorship relationship. Participant 05 expressed the desire as a mentor to, "be a good listener," for their mentee. Further, Participant 01 identified, "listening to my mentee," and Participant 08 noted the need, "to be listening to my mentee" as an important element of their mentorship.

Empathy

Mentors identified the importance of being empathetic to mentee experience. The mentors wanted their mentees to feel understood, Participant 02 wanted to be, "empathetic," with their mentee and share, "I know where you are, I get it." Further participant 010 expressed wanting to be "empathetic, not out there saying it's going to get better because it doesn't always but ask how you are doing or managing." Some variation about degree of hopefulness was apparent. This may be due to the wide differences in effects and impact on functioning in children, leaving some to be more optimistic than others.

Encourage Enjoyment

Despite the challenges experienced by caregivers of children with FASD, mentors were motivated to improve mentee wellbeing by encouraging enjoyment in the lives of mentees to help foster positive emotions. Participant 01 wanted to share with their mentee the importance of having a, "sense of humour," and that, "having fun is important." Participant 04 wanted to share the importance of, "being relaxed," given the many stressors they faced as caregivers. Participant 05 wanted to help, "families find ways to have fun together and enjoy family life amidst the challenges." Similarly, Participant 07 wanted to foster this enjoyment by encouraging, "living in the moment."

Nonjudgmental Support

Mentors identified a desire to provide mentees with nonjudgmental support. Since mentors shared lived experiences, they understood the challenges faced by their mentees and the importance of addressing these experiences in a nonjudgmental manner. Participant 04 emphasized the need to strive to engage their mentee with, “no judgments, leave the judgments somewhere else even though we all have them.” Further, Participant 07 noted that as a mentor, they want to be, “open minded to what the person is going through,” rather than engaging in a close-minded and judgmental way.

Processing Difficult Emotions

Mentors understood and often experienced the difficult emotions associated with being the caregiver of a child with FASD. There was some variation on the timing of different reactions with guilt being more prominent in the earlier points in relationship between child and caregiver. Participant 04 identified grief as a challenging emotion that they wanted to help mentees process. The same participant was motivated to help their mentee, “process through hopelessness and frustration without guilt,” and noting that, “it is important for parents to express how they are feeling, and not feel guilty for expressing that.”

Decrease Isolation

Based on their lived experiences, mentors expressed feeling alone and isolated throughout their time as caregivers. In order to prevent future caregivers from experiencing similar isolation, mentors expressed motivation to decrease isolation for their mentees. Participant 06 echoed this sentiment by expressing, “I know how alone I felt in the trenches,” as a caregiver. Further noting that, “it is not fair that parents have to battle through by themselves.” Similarly, Participant 02 wanted to decrease mentee isolation as a mentor by providing, “someone that walks the journey with you.”

Share Lived Experience to Educate Mentees

This theme highlights the sharing of lived experiences as a means of educating mentees to be a motivating factor for mentor participation in the FASD mentorship program. The education is provided through the mentor’s desire to utilize their wisdom to educate mentees, share strategies and information, and specific lived experience that may help others in similar circumstances.

Wisdom

Mentors with extensive lived experience as caregivers of children with FASD have a wealth of knowledge associated with navigating their lives in the caregiving role. Mentors expressed a desire to share their wisdom as a means of educating mentees. Participant 04 discussed their aim to educate mentees by, “sharing knowledge I have through my lived experience.” Participant 01 explained that their longevity and experience as caregivers has made them important sources of knowledge for other caregivers. Participant 10 said that they want to be a mentor because of, “everyday life with my son, having so many years of raising him,” has provided insight and knowledge that can be passed on to mentees.

Information Sharing

Mentors identified the need to educate mentees through information sharing, including resources and strategies, to be an important component of their role. A fundamental source of information held by mentors was based in their own lived experiences as a caregiver. Participant 04 expressed a desire to “support through sharing experiential information,” and, “offer beneficial insights,” noting that the, “sharing of information is important,” for mentees. Participant 01 also acknowledged the importance of sharing information, specifically aimed to, “help mentees to problem solve,” given the ongoing challenges they experience. The need to provide resources was also identified as a motivating factor for mentors to educate mentees. Participant 05 expressed a desire to provide, “tools, give ideas, and resources,” to their mentee. Participant 06 sought to engage in “information sharing, providing what is out there, where they can find things, providing resources,” to help educate mentees to navigate everyday experiences.

Mentoring for Personal or Mutual Benefit

This theme highlights the participant’s motivation to engage as mentors in the FASD mentorship program for personal or mutual benefit. This includes being motivated to give back to their caregiving communities and fulfilling a duty or call to action. Mentors were also motivated to participate as a means of personal enjoyment, or for personal development purposes.

Giving Back

Mentors identified a personal call to give back as a motive for their participation in the program. Given the lack of resources available to caregivers of FASD in the community, caregivers have had to create their own networks of support for one another. Participant 01 cited that, “others have helped me,” and, “to give back,” to their community as a motivating factor for participation. Participant 05 expressed gratitude for having mentors in the past and explained that this experience has called them to become mentors themselves noting, “adults who live with FASD have mentored me and given me feedback, they have been mentors for our family,” and felt they could similarly give back to others based on the support they were given.

Mutual Enrichment

In addition to the mentors giving back to their communities through the sharing of information from others with lived FASD experience, mentors expressed their motivation to participate in the program for mutual enrichment. Participant 04 echoed this sentiment saying, “we have to learn from each other,” highlighting their desire to engage in a mutually beneficial learning experience with the caregiver they were mentoring. Further, Participant 08 noted in reference to the mentorship relationship that mentors must, “have an openness to learn from them and never stop learning," highlighting that the mentorship relationship is not just beneficial for the caregiver's growth, but also for the mentor.

Personal Development

The mentor's desire to benefit from program participation was highlighted through their responses. Mentors emphasized personal enjoyment, learning, goals, and growth as reasons for participation. Participant 09 expressed that mentoring, "is helpful for me to learn to be a better person," and through, "meeting people you become a better person." Participant 08 similarly spoke of the desire to mentor for personal development stating that they were mentoring, "for my own learning." They also spoke to their personal experience as a mentor in the past being a rewarding experience noting that, "I was a mentor for the Children's Aid Society for young moms and helped a couple moms not lose their kids."

Altered Perceptions and Expectations Held by Mentees

This theme highlights the mentor's motivation to participate in the program in order to share their values and opinions to alter mentee expectations and modify their parenting approaches. Mentors emphasize the importance of changing expectations held by mentees that have been imposed by society. Further, mentors share values and opinions aimed at changing the mentee's approaches to parenting.

Changing Expectations

Since children with FASD learn and develop differently than typically developing children, often they do not meet social expectations for development and behaviour. Mentors aimed to challenge these expectations as they expressed the desire to help mentees ignore and let go of personal and societal expectations for their children. Further, mentors aimed to encourage mentees to reframe expectations to be more realistic, while Participant 10 shared that mentees, "must have realistic expectations," and specifically regarding education mentioned that through, "dealing with the school I learned to have realistic expectations for everyone involved."

Modifying Parenting

Mentors expressed a desire to assist in educating the mentees about different parenting approaches. Participants emphasized the importance of recognizing that children with FASD require an unconventional approach to parenting that must take the child's brain impairments into account. Participant 04 expressed that the "parent has to be the one to make modifications to meet the child's needs, there is no other option," while Participant 10 aimed to teach mentees, "how to look through a different lens," at their child so that they can adapt their parenting styles appropriately. Similarly, Participant 09 echoed the need to make a parenting shift because, "not all traditional methods work," when parenting a child with FASD. According to Participant 01 this shift involved sharing with mentees the importance of the neurodevelopmental model, which takes into account the impact of the brain injury on their child's behaviour.

Discussion

The results of this study highlighted similarities in the study's findings and in previous literature, including motivation to provide nonjudgmental support, process difficult emotions, decrease isolation, share information, personally develop, modify parenting and change expectations. Moreover, present in this study's results and limited or absent in the literature was motivation to instill hope, listening, empathy, encouraging enjoyment, sharing wisdom, giving back, and for mutual enrichment.

Similarities

Within the first theme, providing emotional support as a means of improving mentee wellbeing, providing nonjudgmental support, decreasing isolation, and processing difficult emotions were consistent with existing research. The motivation of mentors to provide nonjudgmental support and decrease isolation is consistent with previous research that highlights the blame, guilt, and judgment that caregivers of FASD experience (Salmon, 2008; Sanders & Buck, 2010; Whitehurst, 2012; Zabotka, 2012). It is likely that caregivers experiencing judgment, in combination with a lack of available support (Naumann et al., 2013), would become more isolated and therefore mentors in this study are seeking to help other caregivers by decreasing this isolation. Similarly, the motivation to help mentees process difficult emotions is consistent with previous research that speaks to the emotional challenges of caring for a child with FASD. In addition to experiencing judgment, caregivers have expressed feeling guilt (Michaud & Temple, 2013), frustration (Gransitas, 2004), and fear (Salmon, 2008). These emotional experiences are consistent with the mentor's motivation in the present study to help mentees "process through hopelessness and frustration without guilt".

Within the second theme, sharing lived experiences to educate mentees through the sharing of personal knowledge, strategies, and skills was similar to previous research. The findings in this study are consistent with previous research that highlights the need to adapt parenting to meet the unique needs of a child with FASD (Sanders & Buck, 2010), a lack of adequate knowledge of professionals (Coons et al., 2016), and lack of information regarding their child's diagnosis (Gransitas, 2004; McGlone et al., 2002). It is possible that mentors in this study cited a need to provide information and strategies given this lack of available and accurate information noted in existing literature. For example, information about available resources that a diagnosis will provide access to will help mentees receive supports for their children.

Moreover, within the third theme, the component of participating for personal development is similar to previous peer mentorship research findings. Past literature has highlighted benefits that mentors may experience through their mentorship positions (Mowbray et al., 1996; Proudfoot et al., 2012; Skovholt, 1974). It is possible that mentors in this study felt holding mentorship positions would benefit their growth and knowledge, like other peer mentors in the literature.

Finally, within the fourth theme, motivation to alter perceptions and expectations held by mentees as well as modifying parenting and changing expectations were consistent with previous research. Previous literature highlights that raising a child with FASD does not fit conventional parenting techniques (Michaud & Temple, 2013), and that there is a need to adapt parenting strategies to meet the child's specific needs (Gardner, 2000; Ryan & Ferguson, 2006; Sanders &

Buck, 2010). It is evident that mentors in this study recognize that consistent with previous literature, conventional parenting strategies do not work for their children and modifications must be made. Along with making these modifications, it is important to parents to change unrealistic expectations. In addition to the similarities between this study's results and the literature, several findings in this study were not prominent or present in previous research.

Differences

Emotional support to improve mentee wellbeing through therapeutic means and relationship development, instilling hope, listening, and encouraging enjoyment were not prominent in previous research. However, hope has been mentioned within the body of literature pertaining to caregivers of FASD (Watson et al., 2013b). Hope has been identified as a key element for caregivers to manage and deal with their caregiving experiences (Borneman et al., 2002; Herth, 1993; Holtslander et al., 2005). It is likely that given the benefits of hope for other caregiving populations, instilling hope may also be beneficial for caregivers of FASD. The limited attention to hope in FASD coincides with existing FASD literature that remains focused on the deficits of individuals with FASD (and subsequently their families) and has not provided caregivers with enough space to talk about their strengths and successes.

Further, the component of encouraging enjoyment has not been referenced in previous research. The apparent lack of focus on strengths and positives is evident throughout disability research, with a clear focus on deficiencies, problems, and limitations (Dinishak, 2016). In addition to the historical deficit-based approach to disability in the literature, the lack of reference to the enjoyment of caring for a child with FASD may be attributed to the etiology of FASD. Given that FASD is caused by maternal consumption of alcohol, considerable stigma has arisen regarding the caregivers of children with FASD (Corrigan et al., 2017). The negative associations regarding the cause of FASD may contribute to a lack of focus on the positive experience of caregivers in the literature. The motivation of mentors to encourage enjoyment highlights that despite these negative perceptions existing, caregivers have many positive experiences that are important to share. The disabilities literature references transformational parenting (Scorgie et al., 2004) and there is a limited amount of research on the positive aspects of caring for a child with FASD (Brown et al., 2008; Coons et al., 2016).

Within the second theme, the component of wisdom is not evident in previous research. Wisdom may have arisen in this study specifically because the study is exploring caregivers in mentorship roles. It is possible that the mentors in this study are different from those studied in the existing literature, because they are seeking out a role that requires them to be knowledgeable as well as possess the time and energy to devote to this position. As a result, it is possible that mentors who sought out a position in this program feel they have wisdom to share.

Wisdom may also be absent from prior research because of the stigma caregivers of children with FASD experience. Given this stigma, it is possible that caregiver knowledge is ignored and that there is a perception that caregivers of children with FASD do not have valuable insights to offer. In addition to the stigma, caregiver wisdom may also be ignored or disregarded if others simplify the role of caregiver to basic survival tasks. In reality, caregivers of children with FASD are responsible for shaping the values and behaviours of their children while supporting and facilitating their child's goals for the future. The acknowledgment of wisdom in this study highlights the need for caregiver knowledge to be taken seriously and respected as a valuable source of support for others.

Within the third theme, the components of giving back and mutual enrichment are not present in previous research. Although giving back has not been mentioned in previous research pertaining to caregivers of children with FASD, research has examined the experience of foster parents and has identified giving back to their communities as a reason for fostering (Sebba, 2012). Given the large proportion of FASD caregivers who are foster or adoptive parents in the community and who participated in this study, it is possible that these individuals are intrinsically motivated to give back through mentorship in the same ways they were motivated to care for their children. Their desire to give back and support other caregivers speaks to the generosity and selflessness of caregivers of children with FASD. In addition to giving back, mutual enrichment has not been mentioned in previous research pertaining to caregivers of children with FASD. This discrepancy may exist because mentorship research largely focuses on the benefits and the experience for mentees. It may be assumed that since mentors are perceived to be the knowledgeable individual, then the mentors do not have to learn themselves. However, given the unique nature of this population and the lack of information they receive in comparison to other caregiving populations, it is possible that mentors engaged in this program to learn while also helping their mentee to learn.

Implications

There was significant overlap with the existing caregiver literature pertaining to FASD and peer mentorship. This supports the credibility and transferability of findings to different geographical areas where the work has taken place. Importantly, the limited presence of positive aspects of caregiving in the FASD literature is evident. Mentors with lived experience caring for children with FASD have had positive experiences. However, there is little attention to this. Positive aspects of caregiving including what makes the experience rewarding to themselves as well as their families and children need to be explored more thoroughly. Mentors in the present study spoke to a more holistic experience of parenting – beyond skills and strategies, information, and advocacy – to include qualities of wisdom and spirituality which have not yet been explored in FASD research.

Professionals will likely benefit from a strengths-based approach with caregivers of children with FASD. It is noteworthy that experiences with professionals reported by caregivers are often found to be challenging. To be helpful, professionals would do well to recognize what caregivers' strengths are, what they find rewarding, how they view their children considering their positive qualities and how they can be helpful to that person about that child and in particular circumstances. It would also be important for professionals to appreciate the challenges caregivers experience due to stigma about FASD and the difficulties that follow from others' attribution of a child's behaviour to the quality of parenting. A flexible and non-stigmatizing approach seems warranted.

Caregivers continue to struggle with a lack of and sometimes conflicting information about FASD. While it appears that one-on-one mentoring for caregivers is needed, there is little attention to the qualifications bestowed by lived experience. Unfortunately, caregiving, in its many forms, is underappreciated. The role of lived experience and the expertise it creates could be capitalized upon for its learning value. Caregivers should be recognized as experts, valued for their important role in the children's lives, appreciated for their flexibility and adaptability to what children with FASD need.

Future Direction

A key limitation in the current FASD caregiving literature is the absence of the perspectives of children and youth with FASD. Formally, little is known about their perceptions of what constitutes good caregiving and relationships with adults, what they experience as positive and difficult in their day-to-day lives at school, home and community, as well as what they identify as needs they have that, if adequately met, will help them achieve success.

Limitations

Regarding limitations in this study, the participants were selected based on their positions as mentors. As a mentor, the caregivers had to have resources including time available to devote to the position, knowledge, and community connections to share with mentees. It is likely that these caregivers were particularly experienced and connected to the FASD community. As a result, this group may differ from other families affected by FASD. There may also be a bias that exists regarding the voluntary nature of the position and participation in the research. The study also explored the experience of 10 mentors. Given this small sample and specific geographical location, it may be difficult to generalize results more broadly. Moreover, the interviews were conducted in person or over the phone depending on mentor availability. The nature of a telephone interview and the responses gathered might differ from an in-person interview, as telephone responses may be more difficult to interpret than in person responses.

Key Messages from this Article

People with Disabilities: Parents of children who have disabilities help other parents. These parents listen to and teach others about parenting.

Professionals: Caregivers want to adapt their parenting but lack information and support to do so. It is important to view their child's behaviour through the lens of a brain injury.

Policymakers: It may be beneficial to create future policies that aim to dispel the stigma caregivers of children with FASD experience. Such policies may improve awareness and understanding so that caregivers can begin to receive adequate supports.

Messages clés de cet article

Personnes ayant une incapacité : Les parents d'enfants ayant une incapacité aident d'autres parents. Ces parents écoutent et enseignent aux autres au sujet de la parentalité.

***Professionnels** :* Les proches aidants souhaitent adapter leur parentalité mais manquent d'informations et de soutien pour ce faire. Il est important d'envisager le comportement de leur enfant selon la perspective d'une lésion cérébrale.

***Décideurs politiques** :* Il pourrait être bénéfique de créer de futures politiques visant à dissiper la stigmatisation des personnes qui s'occupent des enfants ayant un TSAF. De telles politiques pourraient accroître la sensibilisation et la compréhension afin que les donneurs de soins puissent commencer à recevoir un soutien adéquat.

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References

Acri, M., Zhang, S., Adler, J. G., & Gopalan, G. (2017). Peer-delivered models for caregivers of children and adults with health conditions: A review. *Journal of Child and Family Studies, 26*(2), 337-344. https://doi.org/10.1007/s10826-016-0616-1

Astley, S. J., Bailey, D., Talbot, C., & Clarren, S. K. (2000). Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: I. Identification of high-risk birth mothers through the diagnosis of their children. *Alcohol and Alcoholism, 35*(5), 499-508. https://doi.org/10.1093/alcalc/35.5.499

Bailey, D. B., Jr. (2007). Introduction: Family adaptation to intellectual and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 291-292. https://doi.org/10.1002/mrdd.20168

Balcaen, L., Santos, R., Roger, K., & Mignone, J. (2021). Families with fetal alcohol spectrum disorders: Exploring adoptive parents' experiences of family well-being. *Adoption & Fostering, 45*(3), 283-299. https://doi.org/10.1177/03085759211050044

Beutel, D., & Spooner-Lane, R. (2009). Building mentoring capacities in experienced teachers. *International Journal of Learning, 16*(1), 1-10. https://eprints.qut.edu.au/26869/

Borneman, T., Stahl, C., Ferrell, B. R., & Smith, D. (2002). The concept of hope in family caregivers of cancer patients at home. *Journal of Hospice & Palliative Nursing, 4*(1), 21-33. *Psychology and Psychiatry, 1*, 1-3. https://doi.org/10.15761/JPP.1000105

Brown, J. (2015). The challenges of caring for a child with FASD. *Adoption & Fostering*, *39*(3), 247-255. https://doi.org/10.1177/0308575915599096

Brown, J., Bednar, L. M., & Sigvaldason, N. (2007). Causes of placement breakdown for foster children affected by alcohol. *Child and Adolescent Social Work Journal*, *24*, 313-332. https://doi.org/10.1007/s10560-007-0086-9

Brown, J., Harr, D., Morgan, S., Varga, S., & Fenrich, A. (2017). Fetal alcohol spectrum disorder (FASD): A call on mental health treatment professionals to become informed. *Journal of*

Brown, J. D., Rodger, S., George, N., Arnault, D. S., & Sintzel, J. (2008). Rewards of parenting a child with a fetal alcohol spectrum disorder. *The Open Family Studies Journal, 1(*1), 23-30. https://doi.org/10.2174/1874922400801010023

Brown, J. M., Bland, R., Jonsson, E., & Greenshaw, A. J. (2019). The standardization of diagnostic criteria for fetal alcohol spectrum disorder (FASD): Implications for research, clinical practice and population health. *Canadian Journal of Psychiatry, 64*(3), 169-176. https://doi.org/10.1177/0706743718777398

Caley, L., Winkelman, T., & Mariano, K. (2009). Problems expressed by caregivers of children with fetal alcohol spectrum disorder. *International Journal of Nursing Knowledge, 20*(4), 181-188. https://doi.org/10.1111/j.1744-618X.2009.01133.x

Carpenter, B. (2011). Pedagogically bereft! Improving learning outcomes for children with foetal alcohol spectrum disorders. *British Journal of Special Education*, *38*(1), 37-43. https://doi.org/10.1111/j.1467-8578.2011.00495.x

Chamberlain, K., Reid, N., Warner, J., Shelton, D., & Dawe, S. (2017). A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD. *Research in Developmental Disabilities, 63*, 99-106. https://doi.org/10.1016/j.ridd.2016.06.007

Clark, E., Minnes, P., Lutke, J., & Ouellette-Kuntz, H. (2008). Caregiver perceptions of the community integration of adults with foetal alcohol spectrum disorder in British Columbia. *Journal of Applied Research in Intellectual Disabilities, 21*(5), 446-456. https://doi.org/10.1111/j.1468-3148.2007.00414.x

Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M.E., Chudley, A. E., Conry, J. L., LeBlanc, N., Loock, C. A., Lutke, J., Mallon, B. F., McFarlane, A. A., Temple, V. K., Rosales, T.; Canada Fetal Alcohol Spectrum Disorder Research Network. (2015). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal, 188*(3), 191-197. https://doi.org/10.1503/cmaj.141593

Coons, K., Watson, S., Schinke, R., & Yantzi, N. (2016). Adaptation in families raising children with fetal alcohol spectrum disorder. Part I: What has helped. *Journal of Intellectual and Developmental Disability, 41*(2), 150-165. https://doi.org/10.3109/13668250.2016.1156659

Corrigan, P. W., Lara, J. L., Shah, B. B., Mitchell, K. T., Simmes, D., & Jones, K. L. (2017). The public stigma of birth mothers of children with fetal alcohol spectrum disorders. *Alcoholism, Clinical and Experimental Research, 41*(6), 1166-1173. https://doi.org/10.1111/acer.13381

Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches* (2nd ed.). Sage Publications.

Dinishak, J. (2016). The deficit view and its critics. *Disability Studies Quarterly, 36*(4). https://dsq-sds.org/index.php/dsq/article/view/5236/4475

Doig, J. L., McLennan, J. D., & Urichuk, L. (2009). 'Jumping through hoops': Parents' experiences with seeking respite care for children with special needs. *Child: Care, Health and Development, 35*(2), 234-242. https://doi.org/10.1111/j.1365-2214.2008.00922.x

Domeij, H., Fahlström, G., Bertilsson, G., Hultcrantz, M., Munthe-Kaas, H., Gordh, C. N., & Helgesson, G. (2018). Experiences of living with fetal alcohol spectrum disorders: A systematic review and synthesis of qualitative data. *Developmental Medicine & Child Neurology, 60*(8), 741-752. https://doi.org/10.1111/dmcn.13696

Fuchs, D. & Burnside, L. (2014). *Study on the prevalence of FASD in Canadian child welfare settings:* Final report. Centre of Excellence for Child Welfare.

Gahagan, S., Telfair Sharpe, T., Brimacombe, M., Fry-Johnson, Y., Levine, R., Mengel, M., O'Connor, M., Paley, B., Adubato, S., & Brenneman, G. (2006). Pediatricans' knowledge, training, and experience in the care of children with fetal alcohol syndrome. *Pediatrics, 118*(3), 657-668. https://doi.org/10.1542/peds.2005-0516

Gardner, J. (2000). Living with a child with fetal alcohol syndrome. MCN: *American Journal of Maternal/Child Nursing, 25*(5), 252-257. doi: 10.1097/00005721-200009000-00007

Granitsas, J. (2004). Experiences of adoptive parents of children with fetal alcohol syndrome. *Clinical Excellence for Nurse Practitioners, 8*(1), 22-28.

Green, C. R., Kaminsky, K.J ., Tough, S., Roberts, N., Nagpal, T. S., & Cook, J. L. (2021). Perspectives of Canadian health care providers on fetal alcohol spectrum disorder: Has anything changed in 15 years? A Brief Report. *Journal of Obstetrics and Gynaecology Canada, 43*(9), 1086-1089. https://doi.org/10.1016/j.jogc.2021.01.015

Herth, K. (1993). Hope in the family caregiver of terminally ill people. *Journal of Advanced Nursing*, *18*(4), 538-548. https://doi.org/10.1046/j.1365-2648.1993.18040538.x

Hill, C., & Rose, J. (2009). Parenting stress in mothers of adults with an intellectual disability: Parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 53*(12), 969-980. http://doi.org/10.1111/j.1365-2788.2009.01207.x

Hoagwood, K. E., Cavaleri, M. A., Serene Olin, S., Burns, B. J., Slaton, E., Gruttadaro, D., & Hughes, R. (2010). Family support in children's mental health: A review and synthesis. *Clinical Child and Family Psychology Review, 13*(1), 1-45. https://doi.org/10.1007/s10567-009-0060-5

Holtslander, L. F., Duggleby, W., Williams, A. M., & Wright, K. E. (2005). The experience of hope for informal caregivers of palliative patients. *Journal of Palliative Care, 21*(4), 285-291.

Irby, B., Boswell, J., Searby, L., Kochan, F., & Garza, R. (2020). *The Wiley international handbook of mentoring*. Wiley-Blackwell.

Kautz, C., Parr, J., & Petrenko, C. L. (2020). Self-care in caregivers of children with FASD: How do caregivers care for themselves, and what are the benefits and obstacles for doing so? *Research in Developmental Disabilities, 99*, 103578. https://doi.org/10.1016/j.ridd.2020.103578

Lange, S.M., Probst, C., Gmel, G., Rehm, J., Burd, L., & Popova, S. (2017). Global prevalence of fetal alcohol spectrum disorder among children and youth: A systematic review and meta-analysis. *JAMA Pediatrics, 171* (10), 948-956. https://doi.org/10.1001/jamapediatrics.2017.1919

Magnacca, C., Thomson, K., Marcinkiewicz, A., Davis, S., Steel, L., Lunsky, Y., Fung, K., Vause, T., & Redquest, B. (2022). A telecommunication model to teach facilitators to deliver acceptance and commitment training. *Behavior Analysis in Practice, 15*, 730-751. https://doi.org/10.1007/s40617-021-00628-x

Matthews, E. J., Gelech, J., Graumans, R., Desjardins, M., & Gélinas, I. (2021). Mediating a fragmented system: Partnership experiences of parents of children with neurodevelopmental and neuromuscular disabilities. *Journal of Developmental and Physical Disabilities, 33*(2), 311-330. https://doi.org/10.1007/s10882-020-09750-0

May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, D., Hoyme, H. E. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. JAMA: *Journal of the American Medical Association, 319*(5), 474-482. https://doi.org/10.1001/jama.2017.21896

McGlone, K., Santos, L., Kazama, L., Fong, R., & Mueller, C. (2002). Psychological stress in adoptive parents of special-needs children. *Child Welfare: Journal of Policy, Practice, and Program, 81*(2), 151-171.

Michaud, D., & Temple, V. (2013). The complexities of caring for individuals with fetal alcohol spectrum disorder: The perspective of mothers. *Journal on Developmental Disabilities, 19(*3), 94-101.

Millar, J. A., Thompson, J., Schwab, D., Hanlon-Dearman, A., Goodman, D., Koren, G., & Masotti, P. (2017). Educating students with FASD: linking policy, research and practice. *Journal of Research in Special Educational Needs*, *17*(1), 3-17. https://doi.org/10.1111/1471-3802.12090

Mowbray, C. T., Moxley, D. P., Thrasher, S., Bybee, D., & Harris, S. (1996). Consumers as community support providers: Issues created by role innovation. *Community Mental Health Journal*, *32*, 47-67. https://doi.org/10.1007/bf02249367

Mukherjee, R., Wray, E., Commers, M., Hollins, S., & Curfs, L. (2013). The impact of raising a child with FASD upon carers: Findings from a mixed methodology study in the UK. *Adoption & Fostering, 37*(1), 43-56. https://doi.org/10.1177/0308575913477331

Murphy, A., Chittenden, M., & McCreary Centre Society. (2005). *Time out II: A profile of BC youth in custody*. McCreary Centre Society.

Naumann, D. N., Reynolds, J. N., McColl, M. A., & Smith, H. D. (2013). Environmental scan of programs for fetal alcohol spectrum disorder in eastern Ontario. *Journal on Developmental Disabilities*, *19*(3), 29-50. https://doi.org/10.1036/1097-8542.255300

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: A transactional relationship across time. *American Journal on Developmental and Intellectual Disabilities, 117*(1), 48-66. http;//doi.org/10.1352/1944-7558-117.1.48

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods, 16*(1). https://doi.org/10.1177/1609406917733847

Olson, H. C., Jirikowic, T., Kartin, D., & Astley, S. (2007). Responding to the challenge of early intervention for fetal alcohol spectrum disorders. *Infants & Young Children, 20*(2), 172-189. https://doi.org/10.1097/01.IYC.0000264484.73688.4a

Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, *38*, 1092-1103. https://doi.org/10.1007/s10803-007-0497-7

Paley, B., O'Connor, M. J., Frankel, F., & Marquardt, R. (2006). Predictors of stress in parents of children with fetal alcohol spectrum disorders. *Journal of Developmental and Behavioral Pediatrics, 27*(5), 396-404. https://doi.org/10.1097/00004703-200610000-00005

Petrenko, C. L., Alto, M. E., Hart, A. R., Freeze, S. M., & Cole, L. L. (2019). "I'm doing my part, I just need help from the community": Intervention implications of foster and adoptive parents' experiences raising children and young adults with FASD. *Journal of Family Nursing, 25*(2), 314-347. https://doi.org/10.1177/1074840719847185

Petrenko, C. L., Tahir, N., Mahoney, E. C., & Chin, N. P. (2014). Prevention of secondary conditions in fetal alcohol spectrum disorders: Identification of systems-level barriers. *Maternal and Child Health Journal, 18*(6), 1496-1505. https://doi.org/10.1007/s10995-013-1390-y

Popova, S., Lange, S., Probst, C. & Rehm, J. (2017). Prevalence of alcohol consumption during pregnancy and fetal alcohol spectrum disorders among the general and Aboriginal populations in Canada and the United States. *European Journal of Medical Genetics, 60*(1), 32-48. https://doi.org/10.1016/j.ejmg.2016.09.010

Proudfoot, J. G., Jayawant, A., Whitton, A. E., Parker, G., Manicavasagar, V., Smith, M., & Nicholas, J. (2012). Mechanisms underpinning effective peer support: A qualitative analysis of interactions between expert peers and patients newly-diagnosed with bipolar disorder. *BMC Psychiatry, 12*, 11. https://doi.org/10.1186/1471-244X-12-196

Reynolds, M. C., Palmer, S. B., & Gotto, G. S. (2018). Reconceptualizing natural supports for people with disabilities and their families. *International Review of Research in Developmental Disabilities, 54*, 177-209. https://doi.org/10.1016/bs.irrdd.2018.07.006

Ryan S, & Ferguson, D. (2006). On, yet under, the radar: Students with fetal alcohol syndrome disorder. *Exceptional Children, 72*(3), 363-379. https://doi.org/10.1177/001440290607200307

Salmon, J. (2008). Fetal alcohol spectrum disorder: New Zealand birth mothers' experiences. *Canadian Journal of Clinical Pharmacology, 15*(2), e191-e213.

Sanders, J., & Buck, G. (2010). A long journey: Biological and non-biological parents' experiences raising children with FASD. *Journal of Population Therapeutics and Clinical Pharmacology, 17*(2), e308-e322. https://www.jptcp.com/index.php/jptcp/article/view/524

Scorgie, K., Wilgosh, L., & Sobsey, D. (2004). The experience of transformation in parents of children with disabilities: Theoretical considerations. *Developmental Disabilities Bulletin, 32*(1), 84-110.

Sebba, J. (2012). Why do people become foster carers? An international literature review on the motivation to foster. Rees Centre for Research and Fostering, University of Oxford.

Shilling, V., Morris, C., Thompson-Coon, J., Ukoumunne, O., Rogers, M., & Logan, S. (2013). Peer support for parents of children with chronic disabling conditions: A systematic review of quantitative and qualitative studies. *Developmental Medicine & Child Neurology, 55*(7), 602-609. https://doi.org/10.1111/dmcn.12091

Skovholt, T. M. (1974). The client as helper: A means to promote psychological growth. *Counseling Psychologist, 43*(3), 58-64. https://doi.org/10.1177/001100007400400308

Sourk, M., Weiler, L. M., & Cavell, T. A. (2019). Risk, support, and reasons for wanting a mentor: Comparing parents of youth in community versus school-based matches. *Children and Youth Services Review, 99*, 156-164. https://doi.org/10.1016/j.childyouth.2019.01.046

Stade, B., Barco, A., Caccamo, B., Lewis, K., & Zefkic, V. (2019). Burden of prenatal exposure to alcohol: 2018 revised measurement of cost. *Paediatrics & Child Health, 24*(Supplement 2), e34-e35. https://doi.org/10.1093/pch/pxz066.088

Strnadová, I., Collings, S., Loblinzk, J., & Danker, J. (2019). Parents with intellectual disabilities and their perspective of peer support: "It depends on how they give it". *Journal of Applied Research in Intellectual Disabilities, 32*(4), 879-889. https://doi.org/10.1111/jar.12579

Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics, 25*(4), 228-238. https://doi.org/10.1097/00004703-200408000-00002

Watson, S. L., Hayes, S. A., Coons, K. D., & Radford-Paz, E. (2013a). Autism spectrum disorder and fetal alcohol spectrum disorder. Part II: A qualitative comparison of parenting stress. *Journal of Intellectual & Developmental Disability, 38*(2), 105-113. https://doi.org/10.3109/13668250.2013.788137

Watson, S., Hayes, S., Radford-Paz, E., & Coons, K. (2013b). "I'm hoping, I'm hoping..." Thoughts about the future from families of children with autism or fetal alcohol spectrum disorder in Ontario. *Journal on Developmental Disabilities, 19*(3), 76-93.

Weinmann. T., Moder, J.E., Ordenewitz, L.K., Schlueter, J., Jung, J., Kerber, K., Giese, R.M., Kusser, F., Hannibal, I., Heinen, F., & Landgraf, M.N. (2021). Assessing the needs of caregivers of children and adolescents with fetal alcohol spectrum disorders: Results from a survey among families and professionals in Germany. *European Journal of Paediatric Neurology, 33*, 1-8. https://doi.org/10.1016/j.ejpn.2021.04.008

Weinner, L., & Morse, B. A. (1994). Intervention and the child with FAS. *Alcohol Health & Research World, 18*(1), 67-72.

Whitehurst, T. (2012). Raising a child with foetal alcohol syndrome: Hearing the parent voice. *British Journal of Learning Disabilities, 40*(3), 187-193. https://doi.org/10.1111/j.1468-3156.2011.00692.x

Zabotka, J. M. (2012). "How could I have done this?" A qualitative study of birth mothers who have children diagnosed with fetal alcohol syndrome. *Journal of Social Work Practice in the Addictions, 17*(3), 258-274. https://doi.org/10.1080/1533256X.2016.1243123.