

Electronic Thesis and Dissertation Repository

3-4-2020 9:00 AM

Motives of Caregivers for Children with FASD to Become Peer Mentors

Lydia Murray
The University of Western Ontario

Graduate Program in Education

A thesis submitted in partial fulfillment of the requirements for the degree in Master of Arts

© Lydia Murray 2020

Follow this and additional works at: <https://ir.lib.uwo.ca/etd>

Recommended Citation

Murray, Lydia, "Motives of Caregivers for Children with FASD to Become Peer Mentors" (2020). *Electronic Thesis and Dissertation Repository*. 6902.

<https://ir.lib.uwo.ca/etd/6902>

This Dissertation/Thesis is brought to you for free and open access by Scholarship@Western. It has been accepted for inclusion in Electronic Thesis and Dissertation Repository by an authorized administrator of Scholarship@Western. For more information, please contact wlsadmin@uwo.ca.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Abstract

The purpose of this study was to identify the motives of peer mentors to caregivers of children and youth with Fetal Alcohol Spectrum Disorder (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 emerged 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. The themes were compared and contrasted with existing literature.

Keywords: FASD, caregivers, youth, peer mentorship, mentors

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Lay Summary

Fetal Alcohol Spectrum Disorder (FASD) is a developmental disability characterized as a permanent neurological disorder that can significantly impact an affected individual's physical appearance, learning, and behaviour as a result of maternal consumption of alcohol during pregnancy. Research outlining the best practices in FASD intervention has identified providing caregivers with support as a crucial element toward improving outcomes for the disorder, yet minimal research has explored the most effective ways to support caregivers. Peer delivered models of support have resulted in positive outcomes for caregivers. However, marginal research has examined the experience and motivations of caregivers to seek social support. More specifically, no research has explored FASD caregiver motivation to participate in mentorship. Therefore, the aim of this study is to explore the motives of caregivers of FASD for participating in a mentorship program as peer mentors. The mentors were interviewed using open ended questions to explore their motives for participation and responses were grouped into four themes using qualitative content analysis. The themes included that 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. The themes explored in this study provide a first-hand account of the strengths, challenges, and needs identified by caregivers with this lived experience. Moreover, by identifying motives for seeking social support, professionals and policy makers can develop a deeper understanding of the experiences of caregivers of FASD to more effectively support them and inform appropriate policies and practices.

Table of Contents

Abstract.....ii

Lay Summary.....iii

Chapter 1: Introduction.....1

Chapter 2: Literature Review.....7

Chapter 3: Methodology.....18

Chapter 4: Results.....24

Chapter 5: Discussion.....34

References.....54

Appendix.....70

CV.....76

Chapter 1: Introduction

Fetal Alcohol Spectrum Disorder (FASD) is the leading cause of preventable developmental disability in Canada (Stade et al., 2009) and internationally (Carpenter, 2011). FASD refers to a spectrum of neurological conditions that significantly impact an affected 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 prevent the occurrence or severity of secondary disabilities such as mental health problems, school or work issues, as well as justice system involvement. Caregivers face a variety of challenges to raising a child who is alcohol-affected. The potential for social exclusion and isolation are very high. Peer mentorship holds great promise as a means to provide caregivers with encouragement as well as strategies and advice to help their child at home and in the community.

In this chapter, the profile of children with FASD is outlined, the evolution of the diagnostic criteria for FASD is reviewed and benefits and drawbacks of diagnosis are explored. Moreover, the prevalence of FASD is highlighted internationally, within Canada, and within special populations. Finally, the cost of raising a child with FASD is outlined.

Children with FASD

As a result of their brain injury, children with FASD often behave and develop skills differently than neurotypical children. Children with FASD experience challenges developing adaptive skills, that limit their ability to function independently over the lifespan (Kable, Taddeo, Strickland, Claire, & Coles, 2016). They also exhibit difficulties with self-regulation, impulse control, and executive functioning skills which causes difficulty for individuals to engage in higher order planning and organization (Connor, Sampson, Bookstein, Barr, & Streissguth, 2000).

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Diagnosis of FASD

FASD is an umbrella term for a varying spectrum of FASD diagnoses. Although the medical and scientific community recognizes FASD as a clinical disorder, no internationally standardized diagnostic tool exists (Brown, Bland, Jonsson, & Greenshaw, 2018). Numerous diagnostic criteria and guidelines for FASD have been proposed and while most are similar for the severest form of FASD, fetal alcohol syndrome (FAS), the guidelines remain inconsistent for less severe forms.

The Institute of Medicine (IOM) created the first diagnostic guidelines in 1996. According to Stratton et al. (1996), the IOM identified four subtypes of FASD including: FAS, partial FAS (pFAS), alcohol related neurodevelopmental disorder (ARND), and alcohol related birth defects (ARBD). To meet the criteria for FAS, individuals must have presented with growth deficiency below the 10th percentile, facial characteristics, and central nervous system damage. For pFAS qualification, individuals must have presented with some but not all of the FAS symptoms. Individuals with ARND presented with symptoms of CNS damage but do not exhibit facial characteristics of FAS. Finally, individuals with ARBD presented with physical defects impacting their heart, bone, kidney, vision, or hearing. The IOM guidelines were criticized for lacking the proper diagnostic criteria and definition for ARND and ARBD, as well as potentially harming those diagnosed with pFAS that do not have brain damage but are assumed to have CNS impairments when given the pFAS diagnostic label.

A more precise diagnostic tool than the IOM, the 4-Digit Diagnostic Code also known as the Washington Criteria, was created for improved accuracy in FASD diagnoses. According to Astley (2004), the criteria assesses growth deficiency, the FAS facial phenotype, CNS damage, and prenatal exposure to alcohol on a 4-point Likert scale. The 4-Digit Diagnostic Code has been criticized for

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

being impractical in real-world application and failing to control for variations in diagnoses along the FASD spectrum.

In order to address the limitations of the IOM and the 4-Digit Diagnostic Code, Hoyme et al. (2005) operationalized the IOM subtypes for their application in clinical practice. The IOM revision included diagnostic criteria for FAS with confirmed maternal alcohol exposure, FAS without confirmed maternal alcohol exposure, pFAS with confirmed maternal alcohol exposure, pFAS without confirmed maternal alcohol exposure, ARBD, and ARND. The revised criteria also included greater clarification of the neurological and behavioural criteria for FAS, pFAS, and ARND, as well as revisions for the ARBD diagnostic criteria.

In pursuance of an agreed upon Canadian standard for diagnosis, the Public Health Agency of Canada's National Advisory Committee on FASD combined IOM terminology and the 4-Digit Diagnostic Code's description, assessment, and measurement features. The resulting diagnostic subtypes included Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), and Alcohol-Related Neurodevelopmental Disorder (ARND) (Chudley et al., 2005). The update of these guidelines by Cook et al., (2015) included the use of FASD as a diagnostic term. According to these guidelines, individuals are diagnosed based on their display of facial features characteristic of FASD. These include diagnoses of FASD with sentinel facial features and FASD without sentinel facial features. Furthermore, a new category, at risk for neurodevelopmental disorder and FASD associated with prenatal alcohol exposure, was created to include individuals with confirmed prenatal alcohol exposure that do not meet the CNS impairment criteria but exhibit some indication of neurodevelopmental disorder. Once a diagnosis is obtained, individuals with FASD and their caregivers may experience benefits and drawbacks of their diagnosis.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Benefits and Drawbacks of Diagnosis

Caregivers have expressed a number of benefits to receiving an accurate FASD diagnosis. Birth mothers expressed relief after receiving the diagnosis and noted that the diagnosis helped to make sense of their children's problematic behaviour that was once believed to be a consequence of poor parenting skills (Salmon, 2008). Sanders and Buck (2010) also concluded that both biological and non-biological parents expressed feeling relief and validation by helping the parents to understand their child's challenges more clearly. These parents also noted that it is helpful for other family members to be informed of the child's diagnosis in order for others to understand the child's behaviour. Furthermore, obtaining a correct diagnosis of FASD meant that the child can begin to receive appropriate supports in school, health, and family settings (Chamberlain et al., 2017). Finally, by providing parents with the FASD diagnosis, parents may be more likely to avoid consuming alcohol during pregnancy in the future to avoid future risk of FASD (Helgesson et al., 2018).

Although a FASD diagnosis may be beneficial, there are also drawbacks. Most notably, parents of children diagnosed have expressed feeling grief and guilt for their role in the etiology of the disorder (Sanders & Buck, 2010). The diagnosis may also cause problems amongst family members due to the belief that the child's mother is to blame, as well as experiencing blame from professionals (Mukherjee et al., 2013). Concern also exists that receiving an FASD diagnosis may result in stigmatization and reduce an individual's confidence and ability to achieve future goals (Helgesson et al., 2018).

Prevalence of FASD

A global review of the prevalence rates of FASD among children and youth was conducted by Lange et al. (2017). The researchers reported the global prevalence of FASD to be 7.7 of 1000

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

births. The European region yielded the highest overall prevalence of 19.8 of 1000 births. Whereas the Eastern Mediterranean region yielded the lowest prevalence of 0.1 of 1000 births. The researchers also examined prevalence in special populations and reported that prevalence in these populations was higher than the general population. Among the special populations, prevalence was 5.2 to 67.6 higher among children in care, 30.3 times higher among correctional populations, 23.7 times higher in low socioeconomic populations, and 18.5 times higher in psychiatric populations.

It is estimated that 1% of the Canadian population have met the criteria for a FASD diagnosis (Millar et al., 2017). However, more recent Canadian research indicates that this may be an underestimation, with rates of FASD ranging between 2% and 3% (Popova et al., 2018). The prevalence rates in Canada are also higher in special populations. Specifically, northern communities have prevalence rates 16 times higher than the general population (Popova, Lange, Probst, & Rehm, 2017). Similarly rates of FASD for children in care are 13.1 to 15.5 times higher than the general Canadian population, with rates of 103.3 of 1000 in Alberta, 122.7 of 1000 in Manitoba, and 105.1 of 1000 in Ontario (Fuchs & Burnside, 2014). Moreover, it is estimated that 32.6 of 1000 foster children in Ontario have FASD (Burge, 2007). Finally, prevalence rates are higher for youth correctional populations, with rates of 116.8 of 1000 youth in juvenile detention in British Columbia (Murphy et al., 2005).

Cost of FASD

According to their systemic review and analysis of the economic impact Greenmyer and colleagues (2018) calculated, an annual per-person cost of care. The costs were estimated at \$24,308 for adults with FASD and \$22,810 for children with FASD. The mean cost per-person yearly ranged from \$3691 to 19,787 in Canada. The annual cost of care for FASD also exceeded other serious conditions including autism by 26%, asthma by 87%, diabetes by 13%, and epilepsy by 56%.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Summary

This chapter introduced Fetal Alcohol Spectrum Disorder (FASD) and the need for a stable caregiver to improve outcomes of the disorder. The evolution of the diagnostic criteria for FASD was reviewed, and the benefits and drawbacks of diagnosis outlined. Moreover, the prevalence of FASD was presented, as was the cost of raising a child with FASD. Given the high prevalence of FASD, costs associated with child rearing, and challenges associated with diagnosis, it is important to understand how to most effectively support individuals with FASD and their caregivers to improve outcomes. Community-based mentorship programs are an important source of support for caregivers. Little is known about the motives of those who take on the mentor role. The purpose of the present study is to explore the motives of FASD caregivers to participate in community support programs.

Chapter 2: Literature Review

Caregiver support is crucial to improving the lives of children and youth with FASD (Olsen, Jirikowic, Kartin, & Astley, 2007). A stable home is as a protective factor for children (Streissguth, 1997). 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, Green, & Baker, 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, caretakers are provided limited community support (Brown & Bednar, 2003; Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008; Naumann, Reynolds, McColl, & Smith, 2013).

In this chapter the status of caregivers as adoptive, biological, and foster parents is explored. Similarities and differences between these groups are presented. Research on caregiver needs and interventions to assist are outlined. Peer mentorship is explored, including benefits of peer mentorship and a review of existing data on the experiences of peer mentors.

Status of Caregivers

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; Whitehurst, 2012; Mukherjee et al., 2013), 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 and successful lifelong parenting (Chamberlain et al., 2017; Watson, Hayes, Coons, & Radford-Paz, 2013). 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

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

into contact. They also report feeling blamed for a child's behaviour because of their presumed, "bad parenting" (Coons, Watson, Schinke, & Yantzi, 2016; Ryan & Ferguson, 2006; Whitehurst, 2012).

Despite these similarities, custodial status also influences the unique experiences of each caregiver.

Adoptive Parents. By the time of diagnosis, approximately 70% of individuals with FASD are no longer under the care of their birth parents (Astley, 2010). According to Habbick et al. (1996) of 207 FASD cases examined in Saskatoon, Canada 18.4% of the children were adopted. In an adoption study from Eastern Europe, half of the 71 children were diagnosed with FASD (Landgren, Svensson, Stomland, & Andersson Gronlund, 2010).

The adoptive parents of children with disabilities experience a lack of adequate information regarding their child's medical condition prior to adoption. McGlone et al. (2002) provided 25 sets of adoptive parents with a semi-structured interview exploring their experience of adopting a child with special needs. The adoptive parents reported inadequate information about the child. They also emphasized the need for agencies to conduct more thorough evaluations of children before placement including the effects of prenatal substance exposure and severity of their condition. Interviews with four adoptive parents of children with FASD pointed to the common experience of insufficient information about their child's diagnosis (Granitsas, 2004). They were also frustrated by unanticipated challenges associated with raising a child with FASD.

Adoptive and biological parents differ on the type of stress they experience. Paley et al. (2006) administered the Parenting Stress Index (PSI) to the parents of 100 children with prenatal alcohol exposure in the United States. Of the parents, 71% were adoptive, 23% were biological, and 6% were foster parents. Adoptive and foster parents reported higher levels of child-related stress than the biological parents. One possible explanation for these findings is that the adoptive parents may not have been properly prepared for their child's condition.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Biological Parents. Many biological parents do not maintain custody of their children (Astley, 2010). Streissguth et al. (2004) found that among over 400 individuals with FASD, only 1/5 of the group were raised by a biological parent. According to a review of characteristics associated with having a child with FASD, birth mothers are most likely to be older, have low educational attainment, a lower socioeconomic status, be unmarried, unemployed, have suboptimal nutrition, use contraceptives less frequently, and have mental health related issues (Montag, 2016).

Biological mothers face unique challenges. Not only do they experience the daily stressors associated with parenting a child with FASD, but they also feel responsible for the challenges their children face. Unique to FASD biological parents is the guilt and shame associated with maternal consumption of alcohol (Salmon 2008; Sanders & Buck, 2010). Guilt regarding the cause of their child's FAS was found to persist despite time since diagnosis and age of child (Zabotka, 2012).

Foster Parents. The estimated number of children in Canadian foster care with FASD ranges from 2,225 to 7,620, indicating that 3% to 11% of children in foster care has FASD (Popova, Lange, Burd, & Rehm, 2014). However, researchers note that this prevalence may be an underestimate. Astley (2010) examined the profiles of 1,400 individuals with confirmed prenatal alcohol exposure from the Washington State FASD electronic database. The true prevalence of prenatal alcohol exposure in foster populations was between 15% and 48%, 15 to 47 times greater than the FAS prevalence estimate often cited for the general United States population. Furthermore, the children diagnosed with FAS were 28 times more likely to be placed in foster care and children with pFAS were five times more likely to be placed in foster care. Stade et al. (2009) examined 250 families of children with FASD across Canada and concluded that foster parents headed 25% of the families.

Similar to adoptive parents, foster parents are seldom made aware of the circumstances

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

surrounding their child's removal from their biological parents or informed about the possibility of alcohol exposure (Spohr & Steinhausen, 2008). According to Sanders and Buck (2010), seven out of eight foster and adoptive parents brought their child home without the knowledge that their child had FASD.

Caregiver Needs

Caregivers of dependents with FASD have identified areas of need. These include coping strategies, parenting skills and knowledge, stress management, and a solid support system. Such needs may underlie community support seeking.

Coping Strategies. Because FASD is preventable, there is a considerable amount of blame directed toward the etiology of the disorder (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 worry about their child's future. Caregivers may also benefit from learning healthy coping strategies in response to stress (Astley, Bailey, Talbot, & Clarren, 2000).

Parenting Skills and Knowledge. 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, Bednar, & Sigvaldson, 2005). Even when it is known that a child has FASD, many caregivers feel unprepared. Some behaviours associated with FASD may be distressing (Brown & Bednar, 2004). In particular, caregivers report that managing illegal behaviour, resulting from poor judgment in choosing appropriate friends, was particularly distressing (Watson, Hayes,

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Coons, & Radford-Paz, 2013). Information and skills may promote confidence and better care as well as ease the feeling of guilt over struggles encountered in caregiving (Weinner & Morse, 1994).

Stress Management. Parenting stress is high among caregivers of children with FASD (Hill & Rose, 2009). Stress reported by caregivers of children with disabilities finds that relative to other disabilities, such as autism spectrum disorder, caregivers of children with FASD experience greater levels (Watson et al., 2013). Importantly, caring for an individual with FASD has been identified as stressful regardless of the severity of the disorder (Paley, O'Connor, Frankel, & Marquardt, 2006).

Sources of stress for caregivers include community perceptions, blame directed at them, and limited information and support for what works. In addition, the cost associated with FASD is a contributing factor to the stress experienced by caregivers (Caley, Winkleman, & Mariano, 2009). It is estimated that the annual cost associated with raising a single child with FASD is approximately \$21,000 (Stade et al., 2009). Finally, difficulty obtaining a diagnosis adds to the stress a caregiver experiences (Caley et al., 2009; May et al., 2014). Between half and two-thirds of American pediatricians who in a position to diagnose are not comfortable doing so (Gahagan et al., 2006).

Community Support. A support system is necessary for caregivers (Bailey 2007; Brown, et al., 2005; Streissguth 1997). This support system should include those from education and health as well as social services and justice, as appropriate (Brown & Bednar, 2003). Despite the clear need for the support of professionals and systems, caregivers are provided relatively little assistance. For example, a recent review of FASD programs in Eastern Ontario concluded that there is a lack of professional services for FASD populations (Naumann et al., 2013). 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 caregiver's efforts rather than community supports. (Clark et al., 2008). In order to inform and

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

support caregivers, it is important to understand what interventions and resources have contributed to improved outcomes.

Interventions that Benefit Caregivers

A variety of programs and services have been developed and implemented to support caregivers of children with FASD. These are broadly grouped into categories of prevention and social service. Prevention efforts center on the needs of birth families. Social service models are strong in the areas of professional capacity building and advocacy as well as peer support and mentoring.

Prevention Models. Limited research has assessed the experiences of parents with FASD raising children (Rutman & Bibber, 2010) despite literature indicating that approximately half will become parents (Lange, Shield, Rehm, & Popova, 2013). O'Malley (2014) asserted that FASD interventions must be from a transgenerational perspective to break the cycle of FASD. One such method is the incorporation of prevention models for adults at risk of substance use.

Parent Child Assistance Program (PCAP). The PCAP was developed in the USA in 1991 by Ernst, Grant, Streissguth, and Sampson (1999) and has been reproduced in Canada since 1998. The program involves intensive three-year case management aiming to prevent further births within families with a history of alcohol or drug use. The case managers acting as mentors work with clients to establish personalized goals of reducing or eliminating substance use through bimonthly meetings. Further, case managers aim to empower the women to build and maintain healthy and independent lives while also ensuring that their children are in stable homes. Most recently, PCAP's have been implemented and evaluated by Pei, Tremblay, Carlson, and Poth (2017). Using a participatory approach, evaluators reported that participating clients expressed feeling strong relationships with mentors and held high perceptions of their quality of support. Further, clients reported that mentors

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

helped to build on their strengths and develop a more positive outlook. Regarding their addictions and mental health, the women accessed health and addictions services, with some completing addictions treatment. The women participating also had healthy births, regained custody of children, and demonstrated an improvement in parenting practices.

Social Service Models. Three models that utilize social service frameworks are currently employed in Canada. The frameworks outlined by Gibbs, Bagley, Badry, and Gollner (2018) involve the developmental or brain-based framework, which informs interventions and understand FASD as a complex disability that is not readily visible or evident. Further, the ecosystems framework emphasizes the impacts of social disadvantage and marginalization arguing for interventions that foster resilience while acknowledging systemic exclusion and trauma. Finally, the right-based framework was developed from disability activism and stresses working toward equity, equality, antidiscrimination, and social justice for those impacted by FASD. From these frameworks three models intervention have been developed including the key worker model, communities of practice, as well as advocacy and mentoring.

The Key Worker Model. The Canadian Key Worker model outlined by Rutman, Hubberstey, and Hume (2011) was the first comprehensive evidence informed casework model for FASD. The model is based in the ecosystem framework employing an empathetic and nonjudgmental approach that is family centered. The model is further grounded in the developmental framework emphasizing FASD as a brain-based disability requiring appropriate accommodations. The Key Worker provides support, education, and intervention services to those impacted by FASD, as well as networking and capacity building. The Key Worker has specialist training in FASD practice and provides FASD consultancy and training to professionals in other services. In a review of the model, professionals receiving consultancy from Key Workers cited an increase in their understanding of FASD as well as

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

the ability to appropriately modify their practices. Further, the review demonstrated an improvement in knowledge and services for families impacted by FASD (Rutman et al., 2011).

Communities of Practice. A Community of Practice (CoP) is a group in which common interests, practices, or professions are shared (Lave & Wenger, 1991). Group members learn from each other and develop personally and professionally through the process of sharing information and experiences. According to Gibbs et al. (2018), the FASD CoP was created as an innovation in child welfare practice in Alberta. The project initially focused on the unique needs to children with FASD and included training for foster parents and caseworkers of FASD. The FASD CoP was identified as instrumental in identifying and bridging practice gaps through advanced training and education. Most recently, the FASD CoP has expanded to advanced FASD training through Workforce Development in Human Services. This training involved courses for caseworkers and their supervisors to assure consistency in knowledge regarding the needs of children with FASD. This education has specifically emphasized FASD as a disability due to neurological damage in order to shift negative perceptions of those with FASD. Furthermore, the training acknowledges the need to adapt the environment based on the needs of the child (Gibbs et al., 2018).

Advocacy and Mentoring. The two aforementioned models incorporate advocacy but do not highlight the importance of both advocacy and mentoring. The following models follow the rights-based framework aimed at helping those impacted by FASD live successful lives and maintain community connections (Good et al., 2017).

The Wellness, Resilience, and Partnership (WRaP) Scheme. According to Tremblay (2017) the WRaP Scheme employs trained social workers as Success Coaches. The role of a Success Coach includes providing supports for students with FASD and training teachers to increase their awareness of FASD. They also engage in peer support whereby experienced success coaches act as mentors for

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

less experienced coaches. The WRaP Scheme has successfully helped students with FASD complete academic courses and increased staff and student awareness of FASD (Tremblay, 2017).

Coaching Families (CF). In the CF program, caregivers are paired with trained mentors that play an educational role by supporting families in learning about FASD and facilitate the caregiver's integration of knowledge regarding their child's abilities and disabilities. Mentors also support caregivers through advocacy support and locating community resources. Qualifying mentors did not have lived experience as a FASD caregiver but must have obtained two years of post-secondary education and completed training required by the program. Among caregivers, there was a significant decrease in needs and an increase in goal attainment from pre to post program. There was also a significant decrease in caregiver stress and increases in overall satisfaction with the CF program (Leenaars, Denys, Henneveld, & Rasmussen, 2012).

Parent-to-Parent Support Course. The parent-to-parent support course was a 7-week course created based on the best practices in FASD support. The course aimed to assist caregivers to develop greater resilience and strategies to help their families live successfully. Professionally trained caregivers of children with FASD facilitated the two-hour weekly group over seven weeks. The groups included talks, exercises, and case study discussions aimed at increasing knowledge of FASD, increasing knowledge of successful strategies and interventions for families, and providing an opportunity to develop peer-support relationships. Following an evaluation of the course, caregivers identified the course's strength to be the inclusion of trained caregivers as facilitators. Furthermore, the caregivers acknowledged valuing the opportunity to connect with peers that understood their lived experiences (Gibbs, 2018).

Peer Mentorship

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 as peer mentorship positions are understudied. In this section, literature on peer mentorship by caregivers of children with health challenges is presented.

Benefits of Peer Mentorship. 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, Zhang, Adler, & Gopalan, 2017). Preyde and Ardal (2003) evaluated the Parent Buddy Program, a peer mentorship program for parents of children born prematurely in the neonatal ICU. Mothers in the intervention group were paired with trained mentors who previously had a preterm infant in the NICU. The mentors provided support via telephone communication. Participation reduced caregiver depression, state anxiety, and provided an increase in social support.

In other work Sullivan-Boyai et al. (2004) examined the outcomes of a post diagnosis parent-mentoring program for mothers of children newly diagnosed with Type 1 Diabetes. The parent mentors previously raised young children with Type 1 Diabetes and were trained to provide support. Support was provided via home visits and telephone communication over the course of six months. The control group did not receive mentor support. Mothers received emotional support, practical information, and reassurance. They also reported fewer concerns, greater confidence, identified

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

greater resources, and held a less negative perception of the impact diabetes has on their families compared participants who did not receive peer mentorship.

Experience of Peer Mentors. The experience of peer mentors has been marginally explored in research. One theme that has emerged 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 (Mowbray et al., 1996; Skovholt, 1974). In addition, peer mentors may be motivated to help others based on receiving minimal help themselves. Vandal et al. (2018) examined the experiences of eight peer mentors participating in a nursing student peer mentorship program. The mentors participated in a semi-structured interview and responses were examined through inductive thematic content analysis. Researchers identified the theme, “doing what I wish someone had done for me,” as a reason for becoming a peer mentor.

Purpose of the Current Study

To date, no research has examined the experience of caregivers as mentors, nor explored the motives of caregiver peer mentors. The present study is an exploration of mentors’ motives. Mentors in the study are involved in the FASD mentorship program. The program is a peer-mentorship based program created to connect caregivers of individuals with FASD. The mentees entering the program are paired with a trained peer mentor, with lived experience as a caregiver of someone diagnosed with FASD.

Chapter 3: Methodology

The topic of mentor motives was explored with a qualitative lens to advance understanding of caregiver experiences with children who have FASD. This is an under-researched area in the peer mentoring and FASD literature. Specifically, I was interested in the motives that mentors had for becoming involved. In this chapter I begin with a statement about my own position within the research as a member of the research team and graduate student with experience in the disabilities field. The participants, questions and analyses performed follow.

Positionality

As the youngest of three siblings growing up in a white upper middle-class family, I reflect on a childhood free of stressors and what I now have the fortune to reflect on as a childhood abundant with privilege. Both of my parents began their careers as teachers and moved into the role of principals. My parent's extensive experience with children, and their ability to identify developmental and academic challenges led to the start of my interest in developmental disability.

Early in my elementary school education, my parents noticed my challenges with anxiety in the classroom and apparent difficulties with attention. They immediately advocated for assessments that could help to identify my academic challenges and the ways I learn best. Following psychological assessment, I was provided with an Individualized Education Plan that I continued to be accommodated by through my high school education. I remember being told that despite requiring accommodation in certain areas, there were areas of strength that naturally develop to compensate for difficulties. This notion caused me to become more reflective regarding societies perceptions of the term, "disability," and the lack of emphasis on the strengths that also develop alongside areas of need. During this time, I also became more aware of the privilege I had experienced with parents in a position to advocate for me and emphasized my strengths rather than weaknesses as the term,

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

“disability” would imply. I became more motivated to pursue a career that would allow me to help others that were not afforded the same privilege.

In order to increase my understanding of the strengths exhibited and challenges experienced by vulnerable populations, I pursued university education studying Psychology. My degree allowed me to learn from the experiences of those living in poverty, abuse and sexual assault survivors, persons with disabilities, individuals with mental health challenges and persons experiencing suicide crises. I engaged in volunteering as a childcare worker at a shelter for abused women, a crisis outreach worker for individuals experiencing homelessness, a crisis line operator for abuse and sexual assault survivors and began employment as a disability support worker. Working with diverse populations afforded me opportunities to learn about the role of systemic and personal barriers that affect the lives of those I have worked alongside, and the impact of privilege. Specifically, my current employment as a disability support worker has required close contact with the parents of my clients to ensure client goals and needs are being supported. Through my engagement with individuals with developmental disabilities and their caregivers, I have gained a greater understanding and interest in exploring the strengths, needs and challenges experienced by caregivers.

Upon deciding to pursue the present research, I felt it was important to inform myself using the available literature with an aim to support a high needs caregiving population. Given the high prevalence of FASD, and lack of resources available for their caregivers, I felt it was imperative that they receive greater research exposure that could improve supports. I had the opportunity to engage for the present research in in-person interviews with the mentors entering the FASD mentorship program.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Prior to the interviews I had the opportunity to sit in on the mentor training sessions. These sessions were typically done with the mentors individually, or at most with two mentors together spanning approximately six hours. My observations in the mentor training sessions allowed me to orient myself to the unique personality of each mentor and the lived experiences that brought them to their role as mentors. Given the time required to dedicate to training, research participation, and mentorship itself, it was evident that the mentors participating in the program were highly motivated individuals with a desire to engage in prosocial behaviour. Many of the mentors explained that they are known advocates in the community of FASD and are highly experienced and knowledgeable regarding FASD. Several mentors held high status jobs in community agencies. The mentors typically obtained their knowledge through their professional work, personal advocacy experiences, and lived experiences as parents of now teenage and adult children with FASD.

Upon entering the interviews, I anticipated mentors to be fatigued and express anger toward the system that has failed to support them. However, my views quickly shifted when I was met with optimism and a genuine desire to make a positive impact in the lives of the mentees. It was evident that based on the mentor's lived experiences, professional work, and unpaid volunteerism that the mentors had a wealth of knowledge to share in the area of FASD. The mentor's extensive lived and professional experiences appeared to lead them to a place of acceptance, whereby the notion of changing their child with FASD was not an option. Rather, the mentors came to understand the need to change their perceptions and parenting styles to meet the needs of their child.

Perhaps most impactful in the interviews was not the impressive resumes that mentors brought to their roles, but the underlying desire to connect with mentees based on the universally shared experiences of isolation and hopelessness that caregivers of FASD are often faced with. These shared emotional experiences appeared to invoke the most impassioned responses from mentors as

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

they recalled the past and present barriers that have existed as caregivers of children with FASD. Although these barriers were emotionally expressed, overwhelmingly caregivers shared hopeful messages and felt their involvement could have a positive impact on the lives of their mentees.

Participants

This study explored the responses of 10 mentors, selected through purposive sampling. The mentors selected for inclusion were over the age of 18, had lived experience as a caregiver of a dependent with FASD, and were located in London Ontario. All of the participants identified as Female, White, and ranged in age from 28-60 years old. Regarding caregiving status, seven mentors identified as adoptive parents, one mentor identified as a foster parent, one mentor identified as a birth parent, and one mentor identified as a grandparent. The mentors were recruited from the FASD mentorship program and participated in the present study as a requirement of their completion of the program. They graciously, in accordance with the approved university ethics protocol, allowed their responses to be included in the present study.

The Mentorship Program

The participants obtained their role as mentors through a new peer mentorship program for caregivers of FASD. Mentors participating in the program received approximately six hours of mentorship training and were then connected with a mentee based on compatibility. The mentorship relationships were six months in length, with an option to extend the mentorship if the mentor and mentee desired to do so. The mentorship relationships were flexible and allowed the mentor and mentee to determine the frequency and nature of their contact.

Questions

Prior to the onset of the FASD mentorship program, the mentors received group training for their positions at a mutually agreed upon time. At this training session, participants were provided

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

with the Letter of Information (see Appendix A) for the present study. After reading the Letter of Information, participants were provided with written informed consent (see Appendix B).

Participants that signed the informed consent were asked to individually participate in a semi-structured interview. Each participant met privately with the interviewer and were asked the open-ended questions from the mentor motives questionnaire (see Appendix C) requiring verbal response. This interview took approximately one hour per participant. Following the questioning, the interviewer asked the participant if they have any questions about the interview.

If a mentor was unable to participate in the interview the day of the mentor training, the mentor was contacted via telephone for an interview. Of the 10 mentors in this study, one mentor was interviewed over the phone. In this case, the telephone script was read to the mentor (see Appendix D). Once the participant chose to complete the interview via telephone, the interviewer read the letter of information to the participant and offered to provide an email copy or a physical copy. After reading the Letter of Information, the verbal informed consent was read (see Appendix E). Once the verbal consent was obtained, the mentor was asked the open-ended questions from the mentor motives questionnaire requiring verbal response. The telephone interview took approximately one hour per participant. Following the telephone questioning, the mentor was asked if they have any questions about the interview.

Data Analysis

The mentor responses were analyzed 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

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

codes for use with a small number of categories, (5) discussion of themes, and (6) interpretation of the data. I arranged, coded and thematically organized the results of interviews using Word.

Chapter 4: Results

The interview responses of 10 mentors participating in the FASD mentorship program were reviewed. A qualitative content analysis procedure (Creswell, 2003) was performed on the data.

Motives for mentor participation in the FASD mentorship program emerged in the form of four themes. The first theme highlighted mentor motivation to provide emotional support as a means of improving mentee wellbeing through therapeutic means and relationship development. The second theme involved mentor 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 mentor motivation to engage for personal or mutual benefit, including fulfilling a call to give back, engaging in personal growth, and development. Lastly, the fourth theme highlighted the mentor's motivation to alter perceptions and expectations held by mentees.

Theme: To provide emotional support as a means of improving mentee wellbeing through therapeutic means and relationship development.

This theme highlights providing emotional support to mentees as a motivating factor for mentor participation in the FASD mentorship program. The emotional support is 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 to process their feelings, and decrease mentee's feelings of isolation.

Instilling hope. Mentors identified instilling hope in their mentees as motivation to become a mentor. Mentors wanted to send positive messages to their mentees that could uplift them through difficult times. Participant 001 explained that they wanted to share with their mentee that, "it get's better." Participant 002 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

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

think when first diagnosed.” Furthermore Participant 005 aimed to instill hope in their mentee as they expressed the desire, “to give hope amidst the struggles.” Participant 005 further emphasized wanting to help their mentee by instilling hope when they expressed the importance to, “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. Mentors expressed a desire to emotionally support mentees by providing listening to their mentee’s experience. For caregivers, listening provides a sense of understanding, connection, and was identified as an important element to provide within the mentorship relationship. Participant 005 expressed the desire as a mentor to, “be a good listener,” for their mentee. Further, Participant 001 identified, “listening to my mentee,” and Participant 008 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. Participant 006 identified providing, “empathy,” to their mentee as an important aspect of mentoring. The mentors wanted their mentees to feel understood, Participant 002 wanted to be, “empathetic,” with their mentee and share, “I know where you are, I get it.” Further Participant 011 expressed wanting to be “empathetic, not out there saying it’s going to get better because it doesn’t always but ask how are you doing or managing.”

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 in order to foster positive emotions. Participant 001 wanted to share with their mentee the importance of having a, “sense of humour,” and that, “having fun is important.” Participant 004 wanted to share the importance of, “being relaxed,” given the many stressors faced by the caregivers. Participant 005 wanted to help, “families find ways to have fun together and enjoy family life amidst

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

the challenges.” Similarly, Participant 007 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 have similar lived experiences, they understand the challenges faced by their mentee’s and the importance of addressing these experiences in a nonjudgmental manner. Participant 004 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 007 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. Participant 011 emphasized the importance for mentors to use their lived experience to help mentees feel understood because when they are, “talking to another parent with a child with FASD, they get it, you don’t have to feel like there is judgment.”

Processing difficult emotions. Mentors understand and have experienced the difficult emotions associated with being the caregiver of a child with FASD. Participant 004 identified grief as a challenging emotion that they would like to help mentees process. Participant 006 said, “in the early days I had extreme feelings of loss that our child may not be able to live a normal life.” Participant 004 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.” Similarly, Participant 008 wished to help alleviate the guilt and shame often experienced by biological mothers by expressing that as a, “biological mom, letting other moms know that it’s not their fault, taking away the shame.”

Decrease isolation. Based on their lived experiences, the mentors expressed feeling alone and isolated throughout their time as caregivers. In order to prevent future caregivers from

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

experiencing similar isolation, mentors expressed motivation to decrease isolation for their mentees. Participant 006 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 002 wanted to decrease mentee isolation as a mentor by providing, “someone that walks the journey with you.” Participant 008 also expressed the desire to “help others know they are not alone, there are people that have been there”, while Participant 010 aimed to decrease isolation because, “in the very beginning I was all alone I want to help others and do for others what I didn’t have.”

Theme: To share lived experience as a means of educating mentees through the provision of personal knowledge, strategies, and skills.

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 sharing strategies and information, and specific lived experience that may help others in similar circumstances.

Wisdom. Mentors with extensive lived experience as caregivers of 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 004 discussed their aim to educate mentees by, “sharing knowledge I have through my lived experience.” Participant 001 explained that their longevity and experience as caregivers has made them important sources of knowledge for other caregivers. They noted that, “in the community of FASD, people come to me for advice.” According to Participant 010, longevity and extensive experience also motivated their decision to become a mentor. Participant 010 said that they want to be a mentor because of,

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

“everyday life with my son, having so many years of raising him,” has provided insight and knowledge that can be passed on to mentees. Furthermore Participant 006 expressed a desire to share their extensive experience in order to educate mentees noting that, “I have years of parenting and grand parenting experience,” and having been a, “foster parent to over 200 children.” Similarly, Participant 009 was motivated to become a mentor in expressing that, “I’ve experienced just about everything,” and therefore can share these experiences so that others can learn from them.

Information sharing. Mentors identified the need to educate mentees through the provision of information sharing, including resources and strategies, to be an important component of their role as mentors. Participant 004 expressed a desire to “support through sharing experiential information,” and, “offer beneficial insights,” noting that the, “sharing of information is important,” for mentees. Participant 001 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 005 expressed a desire to provide, “tools, give ideas, and resources,” to their mentee. While Participant 006 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. Participant 006 also expressed that simply listening to their mentee is not enough because, “discussing and hearing others experience is one thing, but that can only go so far, they need other resources,” indicating that as a mentor they aim to provide these additional resources. Participant 008 expressed the need as mentors, “to give ideas or resources,” but also ensure that mentees are getting appropriate strategies because, “everyone gives me sticker charts and that works for conventional parenting, not these kids.” Given their experience parenting using unconventional methods, mentors can educate their mentees to adopt these strategies.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Theme: Mentoring for personal or mutual benefit, including fulfilling a call to give back or for personal growth and development.

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 created their own networks of support for one another. The mentors expressed a desire to fulfill this personal duty by giving back in the form of mentorship. Participant 001 cited that, "others have helped me," and, "to give back," to their community as a motivating factor for participation. Participant 010 similarly said they wanted to become a mentor because, "it is important to give back." Participant 005 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. Participant 011 cited an example of past mentorship that motivated them to give back, sharing the experience when their daughter was diagnosed with FASD saying, "I didn't find out until my daughter was nine, when I found out, I had a mentor to help me into the shift, what to read, and what to go on." While Participant 004 spoke to a duty felt to give back saying, "we don't know what we have to offer that may or may not be beneficial to them, so we need to share." The personal need to give back was also expressed by Participant 007 who stated that mentoring, "is a duty you have in the position I am in."

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

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 004 echoed this sentiment saying, “we have to learn from each other,” highlighting their desire to engage in a mutually beneficial learning experience with their mentee. Further, Participant 008 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 mentee 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. While discussing their past experience as a mentor, Participant 002 noted that they, “enjoyed this experience,” of being a mentor in the past and this personal enjoyment was a motivating factor to continue seeking mentorship opportunities. Participant 005 referred to mentorship as a means of staying focused to achieve goals noting that they became a mentor to, “keep on track, mentoring keeps me focused on my goals.” Mentors also cited motivation to become a better person through mentoring. Participant 009 expressed that mentoring, “is helpful for me to learn to be a better person,” and through, “meeting people you become a better person.” Participant 008 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 Children’s Aid Society for young moms and helped a couple moms not lose their kids,” and similarly would like to continue to engage in rewarding mentoring experiences.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Theme: To alter perceptions and expectations held by mentees regarding caring for a child with FASD.

This theme highlights the mentor's motivation to participate in the program in order 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.

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. Mentors emphasized passing on the message to ignore these expectations. Participant 007 supported this notion and expressed motivation to be a mentor in order to tell mentees to focus on, "letting go of your expectations." Further, Participant 006 wanted to share that, "if we strip away expectations of what a typical child would do, they are simply a child and a human." They also expressed that their daughter is, "in this big girl's body now, and people expect so much more from her, but you have to ignore this." Furthermore, mentors expressed a desire to encourage mentees to have realistic expectations for their children. Participant 009 aimed to tell parents to, "watch that your expectations aren't too high, you can't push them beyond their limitations." While Participant 011 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 modifying the mentee's 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 injury into

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

account. Participant 004 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 010 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 009 echoed the need to make a parenting shift because, “not all traditional methods work,” when parenting a child with FASD. According to Participant 001 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. Participant 001 wanted to share the neurodevelopmental model with their mentee because they expressed, “I believe the neurodevelopmental way of parenting is better than the other way.” Participant 011 also wanted to share the idea of, “always think brain, there is no such thing as bad kids, when you make that shift you realize that FASD is a brain injury, and you can understand what they are going through.” Mentors further sought to modify parenting approaches by emphasizing the notion that mentees should not take their child’s behaviours personally. Participant 005 wanted to share their personal theme with their mentee called, “QTIP, quit taking it personally.” Further expressing that kids with FASD, “don’t hold onto negative feelings so why should we?” Moreover, Participant 011 wanted to share with their mentee, “don’t take it personally, it’s their brain, always their brain, when you start understanding brain skills, and that our kids don’t have executive functioning skills, you become so much more empathetic to your child” rather than approaching the behaviours exhibited by their child in a punitive way.

Summary of Findings

The motives for mentor participation in the FASD mentorship program emerged in the form of four themes. The first theme highlighted mentor motivation to provide emotional support as a

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

means of improving mentee wellbeing through therapeutic means and relationship development.

This included: listening, empathy, encouraging enjoyment, providing nonjudgmental support, processing difficult emotions, and decreasing isolation. The second theme involved mentor motivation to participate by sharing lived experiences as a means of educating mentees through the provision of personal knowledge, strategies, and skills. This included: sharing wisdom and information sharing. The third theme illustrated mentor motivation to engage for personal or mutual benefit. This included: giving back, mutual enrichment, and personal development. Lastly, the fourth theme highlighted the mentor's motivation to alter perceptions and expectations held by mentees. This included: changing expectations and modifying parenting.

Chapter 5: Discussion

Given that FASD is the leading cause of developmental disability in Canada (Stade et al., 2009), and that a caregiver's environment protects against negative life outcomes (Streissguth 1997; Streissguth et al., 2004), it is crucial to explore the most beneficial ways to support caregivers of FASD. The motives identified by caregivers for seeking social support have not been explicitly explored in previous research. The findings also provide a first-hand account of the strengths, challenges, and needs identified by caretakers with this lived experience. Furthermore, a greater focus of caregiver experience in research may continue to legitimize caregivers as important voices alongside professionals in their child's treatment. By identifying motives for seeking social support, professionals and policy makers can develop a deeper understanding of an FASD caregiver's experience to more effectively support the caregivers. Finally, a greater understanding of caregiver motives can inform policies and practices aimed at effectively improving life outcomes for both caretakers and those with FASD.

Summary of Themes

The purpose of this study was to identify the motives for caregivers of children with FASD to participate as mentors in the FASD mentorship program. Participants were interviewed and asked: "Why do you want to be a peer mentor?" Followed by probing questions: "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 caregiver that you want to pass along to others?" Responses to the interview questions were explored through qualitative content analysis in accordance with Creswell's (2003) procedures.

In response to the interview questions, four themes emerged. The first theme was: participating in the program to provide emotional support as a means of improving mentee wellbeing

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

through therapeutic means and relationship development. The second theme was: participating in the program to share lived experience as a means of educating mentees through the provision of personal knowledge, strategies, and skills. The third theme was: mentoring for personal or mutual benefit, including fulfilling a call to give back or for personal growth and development. The fourth theme was: participating to alter the perceptions and expectations held by mentees regarding caring for a child with FASD.

The purpose of the discussion chapter is to compare and contrast the themes that have emerged in this study with evidence from the literature. This will allow for the interpretation of the findings in this study, in light of what has already been found in previous research exploring caregivers of FASD. By comparing this study's results with previous literature, consistencies can be used as supporting evidence for the importance of themes identified. Moreover, new insights and inconsistencies may warrant further discussion and exploration in future research.

Summary of the Literature

Research outlining the best practices in FASD intervention has identified providing caregivers with support as a crucial element toward improving outcomes for the disorder (Olsen, Jirikowic, Kartin, & Astley, 2007). Caregivers of children with FASD experience challenges associated with their caregiving roles and have unique needs. Most notably, caregivers may benefit from coping strategies (Astley et al., 2000; Corrigan et al., 2017; Gardner, 2000; Salmon, 2008), parenting skills and knowledge (Brown et al., 2005; Michaud & Temple, 2013), strategies for stress management (Brown & Bednar, 2004; Hill & Rose, 2009; Paley et al., 2006; Watson et al., 2013), and greater community support (Bailey 2007; Brown et al., 2005; Streissguth 1997). Historically, interventions for caregivers of FASD have been focused on prevention (Ernst et al., 1999; Pei et al., 2017) and through a developmental or a brain-based lens (Gibbs et al., 2018; Hubberstey & Hume,

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

2011). One type of intervention for caregivers includes peer-mentorship programs, which have helped caregivers to gain greater support, information, and a greater quality of life (Acri et al., 2017; Hoagwood et al., 2010). The experience or motivations for caregivers of children with FASD to become peer mentors has not been explored in previous research.

Theme: To provide emotional support as a means of improving mentee wellbeing through therapeutic means and relationship development.

This theme highlights providing emotional support to mentees as a motivating factor for mentor participation in the FASD mentorship program. The emotional support is provided through the mentor's desire to instill hope in the lives of mentees, provide mentees with supportive listening, provide empathy, encourage enjoyment, have a nonjudgmental relationship, assist mentees to process their feelings, and decrease mentee isolation.

Within this theme several components were consistent with previous literature including: providing nonjudgmental support, processing difficult emotions, and decreasing isolation. Previous research is consistent with the desire to provide nonjudgmental support given the disclosures by caregivers in the past who have shared experiencing stigma, shame, and feeling blamed (Salmon, 2008; Sanders & Buck, 2010; Zobotka, 2012). Further, the need to process difficult emotions is consistent with previous literature regarding caregiver experience of guilt (Zobotka, 2012) shame (Salmon, 2008), frustration (Gransitas, 2004), and fear (Gardner, 2000). Moreover, the motive of decreasing isolation was also consistent with previous literature citing the lack of support caregivers of FASD experience that contributes to their isolation (Naumann et al., 2013).

Additional components within this theme were not explicitly mentioned in previous research including instilling hope, listening, empathy, and encouraging enjoyment. Previous literature does address the unique challenges that caregivers of FASD experience including greater stress (Watson

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

et al., 2013), less support (Naumann et al., 2013), and stigmatization (Salmon, 2008). It is possible that based on these challenges, caregivers may benefit from the emotional support that the additional components seek to provide. Also notable is the absence of encouraging enjoyment from the literature. Previous research focuses heavily on a deficit-based approach to FASD, and little research explores positive experiences associated with being a caregiver of a child with FASD.

Instilling hope. Mentors identified instilling hope in their mentees as motivation to become a mentor. Instilling hope has not been explicitly mentioned as a need for caregivers of FASD in previous research. Previous literature has indicated that caregivers of FASD have concerns for their child's future and their ability to successfully parent (Michaud & Temple, 2013; Mukherjee et al., 2013; Whitehurst, 2012). It is possible that these concerns and self-doubt may cause caregivers to lose hope in anticipating a positive future for their child and themselves. Further, previous literature on caregivers of FASD focuses heavily on the negative experiences of caregivers. Research highlights greater stress (Watson et al., 2013) and a lack of support (Naumann et al., 2013) amongst caregivers of FASD. With greater stress and a lack of support, caregivers of FASD may feel hopelessness or lose hope overtime.

Listening. Mentors expressed a desire to emotionally support mentees by listening to their experiences and allowing them to feel heard. Listening has not been explicitly mentioned in the literature as a need for caregivers. In previous research, caregivers of FASD have expressed feeling judged or stigmatized (Salmon, 2008) largely due to the etiology of FASD. It is probable that caregivers, who are stigmatized and judged, are left feeling isolated and alone and have felt deterred from sharing their stories. Providing support in the form of listening may allow caregivers an opportunity to share their experiences.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Empathy. Mentors identified the importance of being empathetic to their mentee's experience. The need to experience empathy has not been explored in previous research for caregivers of FASD. The motivation to provide empathy and help mentees feel understood is consistent with previous literature that highlights the unique challenges that caregivers of FASD experience as compared to caregivers of other developmental disabilities. According to Watson et al. (2013) caregivers of FASD experience significantly more stress than caregivers of ASD. Moreover, medical professionals are less confident to diagnose and treat FASD (Gahagan et al., 2006), limited community support exists for caregivers of FASD and their children (Naumann et al., 2013), and this caregiving population experiences considerable stigma associated with the FASD label (Corrigan et al., 2017). Given these unique challenges faced by caregivers of FASD that other caregiving populations may not be able to relate to, it is understandable that mentors have highlighted the need to help their mentee's feel understood through the provision of empathy.

Encourage enjoyment. Mentors expressed motivation to improve mentee wellbeing through encouraging enjoyment by invoking humour, having fun, being relaxed, and enjoying time spent together. Although limited research in the area of FASD caregivers in mentoring exists, one study highlighted that participation in peer mentoring for caregivers of premature babies improved experiences of depression, anxiety, and increased social support (Preyde & Ardal, 2003). Limited research has sought to identify positive themes associated with being the caregiver of a child with FASD. One study of adoptive parents of FASD by Granitsas (2004) highlighted the positive themes of feeling pride in their children's accomplishments and feeling devoted to their children. Further, in one peer mentorship study of caregivers of children with Type 1 Diabetes, participation in the mentorship program resulted in a less negative perception of the impact of the disease on their families (Sullivan-Boyai et al., 2004).

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Nonjudgmental support. Mentors identified a desire to provide mentees with nonjudgmental support. Helping mentees to feel supported without judgment is consistent with previous literature that has highlighted caregiver experiences of feeling stigmatized, judged, and shamed. Most notably birth mothers experience shame given that maternal consumption of alcohol is the direct cause of FASD (Salmon, 2008; Sanders & Buck, 2010). Further, previous literature has shown that the guilt experienced by birth mothers of FASD is ongoing regardless of the child's age or length of time since diagnosis (Zabotka, 2012). Caregivers of FASD have also expressed feeling blamed for "bad parenting" due to the behaviours of their children (Whitehurst, 2012). Given the judgment that caregivers of FASD have expressed experiencing in previous literature, the mentor's desire to provide nonjudgmental support to their mentees is consistent with findings in previous literature.

Processing difficult emotions. Mentors identified a desire to help mentee's process difficult emotions including grief, frustration, guilt, and shame. In previous literature, caregivers of FASD have expressed experiencing challenging emotions consistent with the findings in this study. As previously discussed, guilt and shame experienced by birth mothers has been highlighted in previous literature (Salmon; 2008; Sanders & Buck, 2010; Zabotka, 2012). Caregivers of FASD have also expressed feeling guilty at being unable to meet the unique needs of their children (Michaud & Temple, 2013). In addition to guilt and shame, in an interview of adoptive parents of FASD, the theme of feeling frustrated given the challenges associated with raising a child with FASD was highlighted (Granitsas, 2004). Further, in a study of foster parents, the caregivers expressed difficulty coping and experiencing fear for the future caring for their child with FASD (Gardner, 2000).

Decrease isolation. Mentors expressed motivation to participate in the program to decrease isolation for their mentees. Participants specifically cited their experiences of isolation as motivation

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

to help others avoid feeling the way they did. This is consistent with previous peer mentorship literature that found, “doing what I wish someone had done for me,” as a reason for becoming a mentor (Vandal et al., 2018). The mentor’s desire to decrease isolation is also consistent with literature that highlights the need for greater support of caregivers of FASD. Research has demonstrated that having a support system is beneficial for caregivers of FASD (Bailey, 2007; Brown et al., 2005; Streissguth, 1997) and specifically peer delivered models for caregivers have resulted in greater emotional support (Acri et al., 2017; Hoagwood et al., 2010). However, a lack of community and professional services exist (Naumann et al., 2013). The lack of community support available in combination with the judgment and stigma caregivers experience, may contribute to their experience of isolation.

Theme: To share lived experience as a means of educating mentees through the provision of personal knowledge, strategies, and skills.

This theme highlights the desire of mentors to share their lived experiences as a means of educating mentees. The education is provided through the provision of the mentor’s wisdom based on their extensive experience with FASD. Moreover, mentors aimed to share strategies and information that may help mentee’s in their caregiving roles.

Within this theme, the component of information sharing was consistent with previous literature. Research has established that caregivers of FASD feel they lack adequate knowledge (Gransitas, 2004), and feel that professionals are also lacking adequate knowledge (Coons et al., 2016). In contrast, the component within this theme of wisdom has not been mentioned previously in research.

Wisdom. Mentors with extensive lived experience in the area of FASD expressed a desire to share their wisdom as a means of educating mentees. The provision of wisdom to help caregivers of

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

FASD has not been mentioned in previous research. The mentors that cited a desire to provide wisdom shared that this wisdom has been obtained through many years raising their children. The mentors did not mention wisdom gathered from the assistance of outside agencies, rather, the wisdom came from their experience parenting. This notion is consistent with previous literature whereby caregivers note that professionals lack knowledge regarding FASD (Coons et al., 2016; Gahagan et al., 2006). Given that professionals lack this adequate knowledge, caregivers are forced to learn through their years of experience and thus develop wisdom regarding caregiving and FASD.

Information sharing. Mentors identified the need to educate mentees through information sharing, including resources and strategies, as an important component of their role as mentors. The provision of accurate information has been identified as a need in previous literature. Caregivers of FASD have expressed needing to adapt parenting strategies to meet their child's unique needs but do not feel they have the adequate information to do so (Sanders & Buck, 2010). In addition to these challenges, parents that seek assistance from professionals have shared that the professionals lack adequate knowledge to provide proper information (Coons et al., 2016). Moreover, in the case of adoption, adoptive parents expressed having insufficient information about their child's diagnosis (Granitsas, 2004; McGlone et al., 2002). Peer mentorship programs in the past have successfully assisted to facilitate practical information sharing (Sullivan-Boyai et al., 2004) and information about illness and treatment (Hoagwood et al., 2000).

Theme: Mentoring for personal or mutual benefit, including fulfilling a call to give back or for personal growth and development.

This theme highlights the participant's motivation to obtain roles as mentors in the FASD mentorship program for personal or mutual benefit. This includes being motivated to give back to other caregivers facing challenges and fulfilling a duty or call to action to help others. Mentors were also

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

motivated to participate as a means of personal enjoyment or engaging in the program for personal development.

Within this theme, participation to give back and for mutual enrichment has not been mentioned in previous literature. However, both themes are consistent with research that highlights the lack of support and information caregivers receive (Brown & Bednar, 2003; Clark et al., 2008; Naumann et al., 2013). Such a lack of support may cause caregivers to obtain information from other caregivers and thus have a desire to give back this community as well as continue to learn from them. Further, personal enjoyment was consistent with previous literature that mentors gain a number of benefits from helping others (Proudfoot et al., 2012).

Giving back. Mentors identified a personal call to give back as a motive for their participation in the program. Giving back through mentorship has not been discussed in previous research. However, given the lack of resources available to caregivers of FASD in the community, it was evident through participant responses that mentors received support and information from other caregivers. The notion that there is little community support available has been supported in the literature (Brown & Bednar, 2003; Clark et al., 2008; Naumann et al., 2013). It is probable that such a lack of support has forced caregivers to create their own support networks and learn from other caregivers. Further, several mentors spoke to a duty they felt to give back. It is also logical that given the lack of resources available, mentors feel a duty to share the information that they have in order to provide support to caregivers that otherwise may not get support through community agencies. Their willingness to participate in this research also speaks to the desire to give back to their communities by furthering research in this area.

Mutual enrichment. In addition to the mentors giving back to their communities by sharing information from others with lived FASD experience, mentors expressed their motivation to

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

participate in the program for mutual enrichment. The motivation to participate for mutual enrichment has not been explored in previous literature. However, as previously mentioned, given the lack of community resources and information available to caregivers of FASD (Brown & Bednar, 2003; Clark et al., 2008; Naumann et al., 2013), it is probable that mentors are participating to further their own learning as well as their mentee. Furthermore, research has highlighted that parents believe raising a child with FASD does not fit conventional parenting techniques (Michaud & Temple, 2013), and as a result there is a need to adapt parenting strategies to meet their child's specific needs (Gardner, 2000; Ryan & Ferguson, 2006; Sanders & Buck, 2010). Given the unique parenting challenges experienced by caregivers of FASD, it is logical that mentors have not fully resolved daily parenting challenges. Therefore, mentors may have insights to share but may also still benefit from ongoing learning as they navigate new challenges while their children grow and change.

Personal development. Several mentors cited participating in the program for the purpose of personal development. Specifically, mentors acknowledged participating for personal enjoyment, learning, goals, and growth. Personal development has not been mentioned in previous research pertaining to caregivers of FASD but has been cited in previous literature regarding motivations to participate in peer mentoring. Specifically, Proudfoot et al. (2012) identified the helper therapy principle, in which mentors gain benefits from helping others. Mentors may experience improvements in communication skills, self-confidence, interpersonal competence, an enriched sense of self and personal value, and receive personalized feedback through with others (Mowbray et al., 1996; Skovholt, 1974).

Theme: To alter perceptions and expectations held by mentees regarding caring for a child with FASD.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

This theme highlights the mentor's motivation to participate in the program in order to alter mentee expectations and modify parenting approaches. Mentors note the importance of shifting expectations held by mentees that have been influenced by societal pressures.

Within this theme, the desire to change expectations and need to modify parenting is consistent with previous literature that highlights the need to adapt parenting strategies as parenting a child with FASD does not fit conventional parenting techniques (Gardner, 2000; Michaud & Temple, 2013; Ryan & Ferguson, 2006; Sanders & Buck, 2010).

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 expressed the desire to help mentees ignore and let go of personal and societal expectations for their children. The need to change or let go of expectations has been mentioned in previous literature as it pertains to the need to adapt parenting strategies to meet the unique needs of a child with FASD (Sanders & Buck, 2010). Moreover, in previous research, caregivers have expressed feeling blamed for their children's behaviour (Whitehurst, 2012). It is possible that feeling blamed as a bad parent for the behaviour of their child would cause caregivers to internalize these feelings and believe that their parenting is inadequate. It is understandable then, that mentors would seek to dispel the expectations that cause caregivers to feel as though they are failing or inadequate as parents.

Modifying parenting. Mentors expressed a desire to participate in the FASD mentorship program in order to modify approaches to parenting children with FASD. These modifications largely involved using a brain-based approach to parenting and that recognizing that their child's behaviour stems from a brain injury. The call to modify parenting is consistent with previous literature that highlights the need to adapt parenting strategies to meet their child's specific needs

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

(Gardner, 2000; Ryan & Ferguson, 2006; Sanders & Buck, 2010). Further, parents have shared that raising a child with FASD does not fit conventional parenting techniques (Michaud & Temple, 2013). Despite the acknowledgment that conventional parenting must be modified, little research has examined what modifications are most appropriate and effective. Moreover, no research has explored modifying parenting with a specific brain-based focus as the mentors in this study called for.

Discussion Summary

In response to the question: “Why do you want to be a peer mentor?” four themes emerged. The first theme highlighted mentor motivation to provide emotional support as a means of improving mentee wellbeing through therapeutic means and relationship development. This included: listening, empathy, encouraging enjoyment, providing nonjudgmental support, processing difficult emotions, and decreasing isolation. The second theme involved mentor motivation to participate by sharing lived experiences as a means of educating mentees through the provision of personal knowledge, strategies, and skills. This included: sharing wisdom and information sharing. The third theme highlighted mentor motivation to participate for personal or mutual benefit. This included: giving back, mutual enrichment, and personal development. Lastly, the fourth theme highlighted the mentor’s motivation to alter perceptions and expectations held by mentees. This included: changing expectations and modifying parenting.

Comparing the results and the literature. 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 not present in the literature was motivation to instill hope, listening, empathy, encouraging enjoyment, sharing

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

wisdom, giving back, and for mutual enrichment. Finally, within the literature and not present in this study's results is the stress associated with the cost of raising a child with FASD.

Similarities. Within the first theme, providing emotional support as a means of improving mentee wellbeing through therapeutic means and relationship development, the components of 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 probable that given these difficult emotional experiences, caregivers would be motivated to provide mentees with a nonjudgmental support. It is also likely that caregivers experiencing judgment, in combination with a lack of available support (Naumann et al., 2011), 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 these difficult emotions.

Within the second theme, participating to share lived experiences as a means of educating mentees through the provision of personal knowledge, strategies, and skills, the component of information sharing 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),

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

and lacking information regarding their child's diagnosis (Gransitas, 2004; McGlone et al., 2002). It is probable that mentors in this study cited a need to provide information and strategies given this lack of available and accurate information noted in previous literature.

Moreover, within the third theme, highlighting the mentor's motivation to participate for personal or mutual benefit, 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 probable that mentors in this study felt holding mentorship positions would benefit their growth and knowledge, similar other peer mentors in the literature.

Finally, within the fourth theme, motivation to alter perceptions and expectations held by mentees, the component of 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 the results and the literature, a number of findings in this study were not present in previous research.

Differences. Within the first theme, providing emotional support as a means of improving mentee wellbeing through therapeutic means and relationship development, the components of instilling hope, listening, empathy, and encouraging enjoyment were not present in previous research. Although hope has not been mentioned within the body of literature pertaining to

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

caregivers of FASD, hope has been identified as a key element for caregivers to manage and deal with their caregiving experiences (Borenman, Stahl, Ferrell, & Smith, 2002; Herth, 1993; Holstlander, Duggleby, Williams & Wright, 2005). It is likely that given the benefits of hope for other caregiving populations, that instilling hope may also be beneficial for caregivers of FASD. The lack of acknowledgment of hope in FASD research may be attributed to the fact that limited research has been conducted that allows caregivers to freely share their experiences. Moreover, the components of listening and empathy are not present in the literature. Similar to the component of instilling hope, listening and empathy may not be evident in previous research because limited studies have been conducted that allow caregivers to share their experiences. It is possible that if more studies with similar methodology to this present study were conducted, that caregivers may have an opportunity to more deeply express their personal needs.

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. 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 exist, caregivers have many positive experiences that are important to share.

Within the second theme, sharing lived experiences as a means of educating mentees through the provision of personal knowledge, strategies, and skills, the component of wisdom is not evident

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

in previous research. Wisdom may have arisen in this study specifically because the study is exploring caregivers in mentorship roles. It is probable that the mentors in this study are different from those studied in previous 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 FASD experience. Given this stigma, it is possible that caregiver knowledge is ignored and that there is a perception that caregivers of 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, participating for personal or mutual benefit, 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 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 for other caregivers speaks to the generosity and selflessness of caregivers of FASD. In addition to giving back, mutual enrichment has not been mentioned in previous research pertaining to caregivers of FASD. This discrepancy may

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

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.

One topic that has been identified in the literature but was not expressed by caregivers in this study was the stress associated with the cost of raising a child with FASD. Income has been previously identified as a problem area for a caregiver of FASD (Caley et al., 2009). In the present study, cost of raising their child or income was not mentioned. It is possible that given the unique nature of this mentor population, that they may be more financially stable as compared to other caregivers of FASD. In order to participate in the program, mentors had to have the time, energy, and knowledge to devote to the program. Several mentors in the program expressed a desire to help based on knowledge acquired in high-level community agency positions.

Implications

The results of this study add to the existing literature and presents new insights into the needs, strengths, and challenges experienced by peer mentors to caregivers of children with FASD. The responses from caregivers in this study may be used to assist in the development of counselling practices, policy, and research.

Counselling. The results of the study demonstrate the potential benefits for caregivers to engage in counselling. Most notably within the first theme, participants highlighted their motivation to support mentees by instilling hope, listening, providing empathy, encouraging enjoyment, having a nonjudgmental relationship, assisting mentees to process their feelings, and decreasing isolation. The components of this theme highlight the need for counsellors to uphold core aspects of

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

counselling when supporting caregivers of FASD. Most notably, allowing caregivers to feel heard, understood, and supported in a nonjudgmental manner. Moreover, caregivers highlighted experiencing grief and frustration, as well as experiences unique to a caregiver of FASD including feeling stigmatized, guilt, and shame. The participants mentioned the need to help process these difficult emotions. In light of these results, it would be beneficial for counsellors to focus on supporting caregivers to process these emotional experiences.

Finally, the results of this study highlight many strengths exhibited by the caregivers including altruism, optimism, initiative to seek out personal growth opportunities, and being sources of wisdom and having a wealth of knowledge to share. It is beneficial for counsellors to understand the strengths that caregivers of FASD possess in order to most effectively support them to achieve goals and process experiences.

Policy. The results of this study highlight the lack of services and information available to caregivers of FASD. As a result, the caregivers are forced to gather their own information and acknowledge becoming well versed in the needs of their children. In light of these results, policies in the future should be developed in consultation with caregivers and based on what caregivers have learned as the primary advocates and supports for their children. It would be beneficial to create future policies that aim to dispel the stigma caregivers of FASD experience. Such policies could improve awareness and understand so that caregivers can begin to receive adequate supports.

Research. Moving forward research must address the gaps in support and information highlighted by the caregivers. Most notably, caregivers expressed the need to modify parenting and change expectations. It is evident that caregivers recognize that there is a need to adapt their parenting approaches but lack information and support to do so. Specifically, caregivers in this study highlighted the need to view their child's behaviour through the lens of a brain injury, and parent

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

accordingly. Future research should explore the most effective approaches to parenting children with FASD, with a specific focus on the neurodevelopmental factors influencing behaviour and parenting. Such research will help parents learn and apply effective strategies at an early age, rather than having the burden of teaching themselves effective parenting techniques through a stressful trial and error process.

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 participants may also differ based on characteristics that influence their willingness to participate. 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.

Summary

The likelihood of achieving positive life outcomes for children with FASD improves when individuals are provided with a stable caregiving environment (Streissguth et al., 2004). Despite the importance of caregivers in creating positive outcomes for children with FASD, they are provided little community support (Naumann et al., 2013). As a result, it is crucial to understand the experience of caregivers and the most effective ways to support them. Peer mentorship programs have previously been employed to support caregiving populations. In this study, ten caregivers for individuals with

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

FASD acting as peer mentors were interviewed regarding their motivation to become mentors. Their responses were analyzed using qualitative content analysis and four themes emerged. These themes included mentors wanting to provide emotional support to improve mentee wellbeing, sharing lived experience as a means of educating mentees, participating for personal or mutual benefit, including fulfilling a call to give back or for personal growth, and to alter the perceptions and expectations held by mentees. The results highlight the first-hand account of the strengths, challenges, and needs identified by caretakers with this lived experience. It is important to recognize the strengths that caregivers of FASD exhibit in order to dispel the stigma that many caregivers still experience. The results of this study call for the continued inclusion of caregivers in policy and research development so that their knowledge and expertise can be used to further the understanding FASD.

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. doi: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. doi:10.1093/alcalc/35.5.499
- Astley, S. J. Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code. 3rd ed. Seattle WA: University of Washington Publication Services; 2004.
- Astley, S. J. (2010). Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Can J Clin Pharmacol, 17*(1), e132-164. Retrieved from <https://depts.washington.edu/fasdpn/pdfs/astley-profile-2010.pdf>
- Bailey, D. B., Jr. (2007). Introduction: Family adaptation to intellectual and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 291-292. doi:10.1002/mrdd.20168
- 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. doi:10.1097%2F00129191-200201000-00012
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*(7), 513-531. doi:10.1037/0003-066X.32.7.513
- Brown, J. D., & Bednar, L. M. (2003). Parenting children with fetal alcohol spectrum disorder: A

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

- concept map of needs. *Developmental Disabilities Bulletin*, 31(2), 130-154. Retrieved from <https://www-lib-uwo.ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/620828888?accountid=15115>
- Brown, J. D., & Bednar, L. M. (2004). Challenges of parenting children with a fetal alcohol spectrum disorder: A concept map. *Journal of Family Social Work*, 8(3), 1-18.
doi:10.1300/J039v08n03_01
- Brown, J.M., Bland, R.C., Jonsson, E., & Greenshaw, A.J. (2018). The standardization of diagnostic criteria for fetal alcohol spectrum disorder (FASD): Implications for research, clinical practice and population health. *Canadian Journal of Psychiatry*, 1-8.
doi: 10.1177/0706743718777398
- Brown, J. D., Sigvaldason, N., & Bednar, L. M. (2005). Foster parent perceptions of placement needs for children with a fetal alcohol spectrum disorder. *Children and Youth Services Review*, 27(3), 309-327.
doi:10.1016/j.chilyouth.2004.10.008
- Burge, P. (2007). Prevalence of mental disorders and associated service variables among Ontario children who are permanent wards. *Canadian Journal of Psychiatry*, 52, 305–314.
doi:10.1177/070674370705200505
- 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), 181-8. doi: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.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

doi: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.

doi: 10.1016/j.ridd.2016.06.007

Chudley, A. E., Conry, J., Cook, J. L., Looock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal, 172*, S1-S21.

doi: 10.1503/cmaj.1040302

Chudley, A. E., Kilgour, A. R., Cranston, M., & Edwards, M. (2007). Challenges of diagnosis in fetal alcohol syndrome and fetal alcohol spectrum disorder in the adult. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics, 145c(3)*, 261-272. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/68119730?accountid=15115>

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.

doi:10.1111/j.1468-3148.2007.00414.x

Connor, P. D., Sampson, P. D., Bookstein, F. L., Barr, H. M., & Streissguth, A. P. (2000). Direct and indirect effects of prenatal alcohol damage on executive function. *Developmental Neuropsychology, 18(3)*, 331-354. doi:10.1207/S1532694204Connor

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

- Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., Rosales, T. (2015). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, *188*(3), 191-197.
doi: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. doi: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.
doi:10.1111/acer.13381
- Creswell, J. W. (2003). Research design: Qualitative, quantitative, and mixed methods approaches (2nd ed.). Thousand Oaks, CA: Sage.
- Dinishak, J. (2016). The deficit view and its critics. *Disability Studies Quarterly*, *36*(4). Retrieved from <http://dsq-sds.org/article/view/5236/4475>
- Ernst, C. C., Grant, T. M., Streissguth, A. P., & Sampson, P. D. (1999). Intervention with high-risk alcohol- and drug-abusing mothers: II. 3-year findings from the Seattle model of paraprofessional advocacy. *Journal of Community Psychology*, *27*, 19–38.
doi:10.1016/j.ajog.2008.09.871
- Fuchs, D. & Burnside, L. (2014). *Study on the prevalence of FASD in Canadian child welfare settings: Final report*. Ottawa, ON: Centre of Excellence for Child Welfare. Retrieved from <http://fasdchildwelfare.ca/sites/default/files/research/Ap26%20O3b%20%20PHAC%20FAS>

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

D%20Prevalence%20Study%20Report%20FINAL%202014.pdf

Gahagan, S., Telfair Sharpe, T., Brimacombe, M., Fry-Johnson, Y., Levine, R., Mengel, M.,

O'Connor, M., Paley, B., Abudato, S., & Brenneman, G. (2006). Pediatricians' knowledge, training, and experience in the care of children with fetal alcohol syndrome. *Pediatrics*, *118*(3), 657-68. doi:10.1542/peds.2005-0516

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

doi:10.1097/00005721-200009000-00007

Gibbs, A. (2018). An evidence-based training and support course of caregivers of children with foetal alcohol spectrum disorder (FASD) in New Zealand. *Advances in Dual Diagnosis*.

doi: 10.1108/ADD-10-2018-0013

Gibbs, A., Bagley, K., Badry, D., & Gollner, V. (2018). Foetal alcohol spectrum disorder: Effective helping responses from social workers. *International Social Work*, 1-14.

doi: 10.1177/0020872818804032

Good, G., A. English, A. Attwell, et al. (2017) 'Social Model Mothers: Disability, Advocacy and Activism', *Counterfutures* 4. 107-36. Retrieved from

http://counterfutures.nz/4/Good_et_al.pdf

Granitsas, J. (2004). Experiences of adoptive parents of children with fetal alcohol

syndrome. *Clinical Excellence for Nurse Practitioners*, *8*(1), 22-28. Retrieved from

[https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-](https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/620364870?accountid=15115)

[bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/620364870?accountid=15115](https://www-lib-uwo-ca.proxy1.lib.uwo.ca/docview/620364870?accountid=15115)

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

- Greenmyer, J. R., Klug, M. G., Kambeitz, C., Popova, S., & Burd, L. (2018). A multicountry updated assessment of the economic impact of fetal alcohol spectrum disorder: costs for children and adults. *J Addict Med* 12(6), 466–473. doi: 10.1097/ADM.0000000000000438.
- Habbick, B. F., Nanson, J. L., Snyder, R. E., Casey, R. E., & Schulman, A. L. (1996). Foetal alcohol syndrome in Saskatchewan: unchanged incidence in 20-year period. *Canadian Journal of Public Health*, 87(3), 204-207.
- Helgesson, G., Bertilsson, G., Domeij, H., Fahlström, G., Heintz, E., Hjern, A., . . . Hultcrantz, M. (2018). Ethical aspects of diagnosis and interventions for children with fetal alcohol spectrum disorder (FASD) and their families. *BMC Medical Ethics*, 19(7). Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/2078692045?accountid=15115>
- Herth, K. (1993). Hope in the family caregiver of terminally ill people. *Journal of Advanced Nursing*, 18, 538-548. doi: 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. doi: 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. doi:10.1007/s10567-009-0060-5

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

- Holtzlander, 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. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/621062865?accountid=15115>
- Hoyme, H. E., May, P. A., Kalberg, W. O., Kodituwakku, P., Gossage, J. P., Trujillo, P. M., ... Robinson, L. K. (2005). A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: Clarification of the 1996 institute of medicine criteria. *Pediatrics*, 115(1), 39-47. doi: 10.1542/peds.2004-0259
- Kable, J. A., Taddeo, E., Strickland, D., & Coles, C. D. (2016). Improving FASD children's self-regulation: Piloting phase 1 of the GoFAR intervention. *Child & Family Behavior Therapy*, 38(2), 124-141. doi: 10.1080/07317107.2016.1172880
- Landgren, M., Svensson, L., Strömland, K., & Grönlund, M. A. (2010). Prenatal alcohol exposure and neurodevelopmental disorders in children adopted from eastern europe. *Pediatrics*, 125(5), e1178-e1185. doi:10.1542/peds.2009-0712
- 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. doi:10.1001/jamapediatrics.2017.1919
- Lange, S., Shield, K., Rehm, J., & Popova, S. (2013). Prevalence of fetal alcohol spectrum disorders in child care settings: A meta-analysis. *Pediatrics*, 132(4), e980-e995. doi:<http://dx.doi.org.proxy1.lib.uwo.ca/10.1542/peds.2013-0066>
- Lave, J. and E. Wenger (1991) *Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

- Leenaars, L., K. Denys, D. Henneveld, and Rasmussen, C. (2012) 'The Impact of Fetal Alcohol Spectrum Disorders on Families: Evaluation of a Family Intervention Program', *Community Mental Health* 48(4): 431–5. doi: 10.1007/s10597-011-9425-6
- 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.
doi: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. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/619796411?accountid=15115>
- 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. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/1528882333?accountid=15115>
- 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.
doi:10.1111/1471-3802.12090
- Montag, A. C. (2016). Fetal alcohol-spectrum disorders: Identifying at-risk mothers. *International Journal of Women's Health*, 8, 311-323. doi: 10.2147/IJWH.S85403

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

- Mowbray, C. T., Moxley, D. P., Thrasher, S., Bybee, D., McCrohan, N., Harris, S., & Clover, G. (1996). Consumers as community support providers: Issues created by role innovation. *Community Mental Health Journal, 32*(1), 47-67. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/78012948?accountid=15115>
- 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. doi: /10.1177/0308575913477331
- Murphy, A., Chittenden, M. & McCreary Centre Society. (2005). *Time out II: A pro le of BC youth in custody*. Vancouver, BC: McCreary Centre Society. Retrieved from www.mcs.bc.ca/pdf/time_out_2.pdf
- 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. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/1492201050?accountid=15115>
- 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. doi:10.1352/1944- 7558-117.1.48.
- 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. doi:10.1097/01.IYC.0000264484.73688.4a
- O'Malley, K. (2014). Developmental psychiatric disorder in children, adolescents and young adults

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

- with Fetal Alcohol Spectrum Disorders (FASD) A transgenerational approach to diagnosis and management in Fetal Alcohol Spectrum Disorders Interdisciplinary perspectives. London & New York, Routledge, Taylor & Francis Group.
- Osborne, L. S., 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(6), 1092-1103. doi:10.1007/s10803-007-04977
- 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. doi:10.1097/00004703- 200610000-00005
- Pei, J., Tremblay, M., Carlson, E., & Poth, C. (2017). PCAP in Alberta First Nation Communities: Evaluation Report. PolicyWise for Children & Families in collaboration with the University of Alberta. Retrieved from https://canfasd.ca/wp-content/uploads/sites/35/2018/02/PCAP-FN-Report_Revised_FINAL_10262017.pdf
- Petrenko, C. L., M., 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), 1496-505. doi:10.1007/s10995-013-1390-y
- Phung, M.H., Wallace, L., Alexander, J., Phung, J. (2011). Parenting Children with Fetal Alcohol Syndrome Disorders (FASD). *WebmedCentral PUBLIC HEALTH*, 2(2), 1–10.
- Popova, S., Lange, S., Bekmuradov, D., Mihic, A., & Rehm, J. (2011). Fetal alcohol spectrum disorder prevalence estimates in correctional systems: A systematic literature review. *Canadian Journal of Public Health*, 102(5), 336-40. Retrieved from <https://www-lib->

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/897665183?accountid=15115

Popova, S., Lange, S., Burd, L., & Rehm, J. (2014). Canadian children and youth in care: The cost of fetal alcohol spectrum disorder. *Child & Youth Care Forum, 43*(1), 83-96.
doi: 10.1007/s10566-013-9226-x

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. doi: 10.1016/j.ejmg.2016.09.010

Popova, S., Lange, S., Chudley, A., Reynolds, J., & Rehm, J. (2018). World health organization international study on the prevalence of fetal alcohol spectrum disorder (FASD) Canadian component. *Institute for Mental Health Policy Research*. Retrieved from <https://canfasd.ca/wp-content/uploads/sites/35/2018/05/2018-Popova-WHO-FASD-Prevalance-Report.pdf>

Preyde, M., & Ardal, F. (2003). Effectiveness of a parent "buddy" program for mothers of very preterm infants in a neonatal intensive care unit. *Canadian Medical Association Journal, 168*(8), 969-973. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/620153035?accountid=15115>

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

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

- disorder. *BMC Psychiatry*, 12, 11. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/1636820983?accountid=15115>
- Rutman, D., & Van Bibber, M. (2010). Parenting with fetal alcohol spectrum disorder. *International Journal of Mental Health and Addiction*, 8(2), 351-361.
doi:<http://dx.doi.org.proxy1.lib.uwo.ca/10.1007/s11469-009-9264-7>
- Rutman, D., Hubberstey, C., & Hume, S. (2011). British columbia's key worker and parent support program: Evaluation highlights and implications for practice and policy. In E. P. Riley, S. Clarren, J. Weinberg & E. Jonsson (Eds.), *Fetal alcohol spectrum disorder: Management and policy perspectives of FASD; fetal alcohol spectrum disorder: Management and policy perspectives of FASD* (pp. 297-316, Chapter xxiv, 458 Pages) Wiley-Blackwell. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/1782220367?accountid=15115>
- Ryan S, & Ferguson, D.,L. (2006). On, yet under, the radar: students with fetal alcohol syndrome disorder. *Exceptional Children*, 72(3), 363–79. doi: 10.1177/001440290607200307
- Salmon, J. (2008). Fetal alcohol spectrum disorder: New Zealand birth mothers' experiences. *The Canadian Journal of Clinical Pharmacology*, 15(2), e191-e213. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/71623582?accountid=15115>

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

- 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. Retrieved from https://www.researchgate.net/profile/James_Sanders7/publication/256486943_A_long_journey_Biological_and_nonbiological_parents'_experiences_raising_children_with_FASD/links/02e7e5230dc0eee2bd000000.pdf
- Sebba, J. (2012). Why do people become foster carers? An international literature review on the motivation to foster. Retrieved from https://ora.ox.ac.uk/objects/uuid:200c813e-3025-46b6-8ba760e52553fe42/download_file?file_format=pdf&safe_filename=ReesCentre_Motivation_ToFoster2013_web.pdf&type_of_work=Report
- Skovholt, T. M. (1974). The client as helper: A means to promote psychological growth. *Counseling Psychologist*, Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/64155926?accountid=15115>
- Spohr, H., & Steinhausen, H. (2008). Fetal alcohol spectrum disorders and their persisting sequelae in adult life. *Deutsches Ärzteblatt International*, 105(41), 693-698. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/900620524?accountid=15115>
- Stade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C., Koren, G. (2009). The burden of prenatal exposure to alcohol: Revised measurement of cost. *The Canadian Journal of Clinical Pharmacology*, 16(1), e91-102. Retrieved from <https://www-lib-uwo->

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/66852645?accountid=15115

Stratton, K., Howe, C., & Battaglia, F. C. (Eds.). (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment*. Washington, DC. National Academies Press.

Streissguth, A. P. (1997). *Fetal alcohol syndrome: A guide for families and communities*. Baltimore, MD, US: Paul H Brookes Publishing.

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.
doi:10.1097/00004703-200408000-00002

Sullivan-Bolyai, S., Bova, C., Leung, K., Trudeau, A., Lee, M., & Gruppuso, P. (2010). Social support to empower parents (STEP): An intervention for parents of young children newly diagnosed with type 1 diabetes. *The Diabetes Educator*, 36(1), 88-97.
doi:10.1177/0145721709352384

Temple, V. K., Ives, J., & Lindsay, A. (2015). Diagnosing FASD in adults: The development and operation of an adult FASD clinic in ontario, canada. *Journal of Population Therapeutics and Clinical Pharmacology*, 22(1), e96-e105. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/1661326472?accountid=15115>

Tremblay, M. (2017) 'Wellness, Resiliency, and Partnership (WRaP) Project', 2014–2017 Evaluation Report, WRaP Schools, St. Albert.

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

- Vandal, N., Leung, K., Sanzone, L., Fillion, F., Tsimicalis, A., Lang, A. (2018). Exploring the student peer mentor's experience in a nursing peer mentorship program. *J Nurs Educ*, (57)7, 422-425. doi:10.3928/01484834-20180618-07
- Watson, S. L., Coons, K. D., & Hayes, S. A. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. part I: A comparison of parenting stress. *Journal of Intellectual and Developmental Disability*, 38(2), 95-104.
doi: 10.3109/13668250.2013.788136
- Watson, S. L., Hayes, S. A., Coons, K. D., & Radford-Paz, E. (2013). 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.
doi:10.3109/13668250.2013.788137
- Weinner, L., & Morse, B. A. (1994). Intervention and the child with FAS. *Alcohol Health & Research World*, 18(1), 67-72. Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/618607742?accountid=15115>
- Whitehurst, T. (2012) Raising a child with foetal alcohol syndrome: hearing the parent voice. *British Journal of Learning Disabilities*, 40(3), 187–93. doi :10.1111/j.1468-3156.2011.00692.x

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Zabotka, J. M. (2012). *"How could I have done this?": A qualitative study of birth mothers who have children diagnosed with fetal alcohol syndrome* (Order No. 3541017). Available from ProQuest Dissertations & Theses Global: Social Sciences; Sociology Database. (1080532392). Retrieved from <https://www-lib-uwo-ca.proxy1.lib.uwo.ca/cgi-bin/ezpauthn.cgi?url=http://search.proquest.com.proxy1.lib.uwo.ca/docview/1080532392?accountid=15115>



**Mentorship for Caregivers
Letter of Information**

Dr. Kim Harris, Assistant Executive Director
London Family Court Clinic,

Dr. Jason Brown, Principal Investigator
Althouse, Faculty of Education,

1. Invitation to Participate

As part of a program requirements, all program participants are being invited to participate in a program evaluation consisting of questionnaires and interviews to evaluate the impact of FASD mentorship program.

2. Why is this study being done?

These program evaluation activities will be conducted by Dr. Harris and Dr. Brown to create a report for the agency and the program funder.

Additionally, participants are being invited to share their de-identified data (i.e. the scores from the questionnaires and answers to interview questions without any names attached) with the Western researchers to be used for their theses. Your name will never be associated with this data.

3. How long will you be in this study?

Interviews at the beginning and end of the program will take approximately 60 minutes each. They will take place at a mutually agreed time, date and location. Some of the interview can be done over the phone.

4. What are the study procedures?

We will ask you some open-ended questions about how you feel the program can help you as a caregiver. We will also ask you to complete questionnaires about your immediate family, your beliefs about caregiving, your confidence as well as what is stressful about caregiving.

5. What are the risks and harms of participating in this study?

There are no known risks to participating in the study.

6. What are the benefits of participating in this study?

You can share your experiences about the program with the agency and funder. The information will help them understand how well the program worked and what about it was most helpful as well as what could be changed to make improvements.

7. Can participants choose to leave the study?

Yes. You can choose to withdraw and data collected to that point will not be used.

8. How will participants information be kept confidential?

Only members of the research team will have access to your information. The members of the team will not share your identity with anyone outside of the team. Please note that we are required by law to share any

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

information concerning child maltreatment. The files will be held by the London Family Court Clinic in a secure location and in accordance with agency procedures to safeguard confidential information. In reports of results the views of all participants will be combined. At the end of the program the research team will compile all information gathered and prepare a report for the funder. De-identified data shared with the researchers will be stored at Western University for 7 years and will be accessible to the researchers.

9. Are participants compensated to be in the study?

No

10. What are the rights of participants?

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study at any time it will have no effect on your status with the LFCC. We will give you new information that is learned during the study that might affect your decision to stay in the study.

You may choose to participate in the program evaluation but not permit your de-identified data to be used for research purposes. Your decision to share this data for research purposes will not impact your relationship with the LFCC.

If you consent to sharing this information for research purposes, please complete the attached Consent Form. You do not waive any legal right by signing this consent form

11. Whom do participants contact for questions?

If you would like more information about the evaluation you can contact Dr. Kim Harris, Assistant Executive Director, London Family Court Clinic.

If you consent to sharing de-identified data for the research study and would like more information you can contact, Dr. Jason Brown, Principal Investigator, Faculty of Education.

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics. The Research Ethics Board is a group of people who oversee the ethical conduct of research studies. The Non-Medical Research Ethics Board is not part of the study team. Everything that you discuss will be kept confidential.

Representatives of The University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research.

This letter is yours to keep for future reference.

Appendix B



**Mentorship for Caregivers
Written Consent for Research Purposes**

Dr. Kim Harris, Assistant Executive Director
London Family Court Clinic,

Dr. Jason Brown, Principal Investigator

WRITTEN CONSENT

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Print Name of Participant

Signature

Date (DD-MMM-YYYY)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person
Obtaining Consent

Signature

Date (DD-MMM-YYYY)

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

Appendix C

Motives Questionnaire

MENTOR Motives Questionnaire (MentorQ)

1. Why do you want to be a peer mentor? (probes: 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 caregiver that you want to pass along to others?)



Mentorship for Caregivers

Telephone script for Program participants

Hello,

We have received your telephone number from the mentorship program administrators.

As a participant in the program we would like to meet to ask some questions that will help the agency find out how well the program is working. If you agree we will also use that information for research purposes.

The purpose of the evaluation is to describe how participants in the program, whether they are mentors or being mentored, feel about the program at the beginning and end of their involvement. This research will also be used by students as data for their theses which will be published, at minimum, on the Scholarship at Western repository.

There are questionnaires and some open-ended questions we will ask.

This will take approximately 60 minutes and would take place at a mutually agreed time, date and location. If it is more convenient for you some of the interview can be done over the phone.

At the end of the program the research team will compile all information gathered and prepare a report for the agency.

If you would like more information on this evaluation please contact Dr. Kim Harris. If you would like more information on the research study please contact Dr. Jason Brown.

Appendix E



**Mentorship for Caregivers
Consent Form**

Dr. Jason Brown, Principal Investigator
Althouse, Faculty of Education,

TELEPHONE INTERVIEW

You indicate your voluntary agreement to participate by responding to the interview.

I wish to be contacted by telephone _____ or email _____ in approximately one year for a post-program interview.

Curriculum Vitae

Lydia N. Murray

EDUCATION

Masters of Arts (*Counselling Psychology*) September 2018- April 2020
Western University – Faculty of Education
London, Ontario

- Graduate Student Assistantship Contract (2019)
- Social Sciences and Humanities Research Council Scholarship (2019)
- Ontario Graduate Scholarship (2018)

Bachelor of Arts September 2013-April 2018
(*Honours Specialization in Psychology*)
Western University - King's University College
London, Ontario

RELATED EXPERIENCE

Psychological Services Intern September 2019-Present
Thames Valley District School Board
London, Ontario

Group Co Facilitator July 2019- Present
Emily Murphy Centre
Stratford, ON

Crisis Line Operator December 2017- Present
ANOVA
London, ON

Disability Support Worker September 2018-Present
Private Contract
Mitchell, ON

Child Care Worker September 2016-October 2019
Emily Murphy Centre
Stratford, ON

Student Researcher February 2019-September 2019
London Family Court Clinic
London, ON

Crisis Outreach Student Intern September 2017-April 2018
Mission Services of London
London, ON

MOTIVES OF CAREGIVERS FOR CHILDREN WITH FASD

King's Academic Mentor
King's University College
London, ON

September 2015-April 2017

RESEARCH EXPERIENCE

Master Thesis

Supervisor: Dr. Jason Brown

Caregivers of Fetal Alcohol Spectrum Disorder: Motives for Peer Mentorship

Western University

London, Ontario

September 2018-Present

Undergraduate Thesis

Supervisor: Dr. Laura Melnyk Gribble

Pairing Visuals with Direct Questions: Can Children's Response Accuracy Be Improved?

Western University - King's University College

London, Ontario

September 2017-April 2018