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Motives for Caregivers of Children with FASD Who Connect with a Caregiver to Caregiver Mentor

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Abstract

This study was intended to determine the motives of caregivers of children and youth with Fetal Alcohol Spectrum Disorder (FASD) who accessed caregiver to caregiver mentors. Caregiver to caregiver mentorship is the term used in our study to describe the relationship, and this is the same as the term peer to peer mentorship which is often used as a broader description of the relationship in prior literature. Sixteen mentees engaged with caregiver to caregiver mentors who had lived experience in raising an individual with FASD and participated in telephone interviews to answer the question: “Why do you want to have a peer to peer mentor?” Participant responses were examined using a qualitative content analysis from which seven themes were derived. Mentees hoped that a caregiver to caregiver mentor would have comparable life experiences. According to mentees, a caregiver to caregiver mentor should also provide information and referral to resources. The gathered data also suggested mentees were in search of a mentor who displayed positive characteristics. The receipt of social and emotional support was expected by mentees who were navigating difficult emotions as well as a lack of assistance from family and friends. It was also clear that mentees’ needed clarity regarding FASD symptoms as well as comorbid diagnoses from caregiver to caregiver mentors. Characteristics demonstrated by mentees also led them to desire caregiver to caregiver mentorship due to their specific circumstances, traits, previous experiences, and referrals. Within the seventh theme, mentees were interested in gaining assistance with school and learning challenges including difficulties with teachers and the school system as well as cognitive issues. These themes were compared and contrasted with published research.

Keywords: Caregiver to caregiver mentorship, mentees, motives, FASD, caregivers, support.

Lay Audience Summary

This qualitative study explored motives of caregivers for children and youth with Fetal Alcohol Spectrum Disorder (FASD) who connected with caregiver to caregiver mentors. In this study, we use caregiver to caregiver mentorship to describe the relationship of focus, which is the same as the term peer to peer mentorship widely used in literature. Sixteen mentees who were in connection with caregiver to caregiver mentors who had experience caregiving for children and youth with FASD answered the question: “Why do you want to have a peer to peer mentor?” Seven themes about why mentees accessed caregiver to caregiver mentors emerged based on mentee interview responses. Themes included: (1) wanting to connect with someone with similar life experiences, (2) receiving information and referral to resources, (3) connecting with a mentor with positive characteristics, (4) obtaining social and emotional support, (5) gaining a clear picture of FASD symptoms and similar diagnoses, (6) mentee characteristics that made mentorship appealing including circumstances, traits, past experiences, and referral to the caregiver to caregiver mentorship program, and (7) help with school and learning challenges their child was facing. Discussion then centers around how these findings contribute to relevant fields of research as well as policy and counselling.

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Table of Contents

Chapter 1: Introduction

Fetal Alcohol Spectrum Disorder (FASD) refers to a range of diagnoses varying in severity and presentation related to consumption of alcohol during pregnancy (Chudley et al., 2005). Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), Alcohol-Related Neurodevelopmental Disability (ARND), and Alcohol-Related Birth Defects (ARBD) exist under the FASD umbrella, and these disabilities are permanent and invisible as well as physical, intellectual, and behavioural in nature (Rutman & Van Bibber, 2009). Variance in presentation and severity may be attributed to timing of alcohol exposure, consistency of consumption, and whether the pattern of use is occasional or frequent (Chudley et al., 2005).

Researchers have estimated that the Canadian prevalence of FASD is around 29.3 people with a diagnosable condition per 1000, which exceeds many other common and similar diagnoses including Down’s Syndrome and ASD (Popova et al., 2019). The importance of research and attention directed towards FASD is highlighted by increasingly high prevalence and worryingly low instances of diagnosis (Burd & Popova, 2019). Indeed, this is a very costly diagnosis in terms of the hours and expertise required to make a determination and the supports needed (Burd & Popova, 2019). In the face of these troubling statistics and phenomena, it is promising that in the presence of early screening and diagnosis, it is possible to limit and/or prevent the development and worsening of secondary conditions associated with FASD, thereby improving outcomes (Popova et al., 2013).

Symptoms of FASD can be classified into categories of primary effects and secondary behaviours (Rutman & Van Bibber, 2009). Primary effects are associated with the physical qualities and brain damage with which a person with FASD is born (Rutman & Van Bibber, 2009). Primary effects can manifest as problems with speech and language, short term memory, reasoning, social situations, analytical and judgement difficulties, and issues with many other sophisticated mental functions (Rutman & Van Bibber, 2009). While linked to primary effects, secondary behaviours can include substance abuse, difficulties engaging in academics and employment, and struggles with mental health (Rutman & Van Bibber, 2009). Severity and prevalence of secondary behaviours can be reduced with early diagnosis which confers access to support (Rutman & Van Bibber, 2009). As such, it is important to understand which programs assist caregivers, both biological and non-biological, in caring for their children with FASD and improving outcomes (Rutman & Van Bibber, 2009).

The focus on reducing prevalence and severity of secondary conditions suggests the necessity of an ecological systems approach for interventions as well as an understanding of how family and community systems play a role in outcomes for children with FASD (Bronfenbrenner 1974). Indeed, major protective factors against secondary conditions have been identified and include a high quality and secure home environment. Home environment is emphasized as fundamental to enhancing FASD outcomes for family and child (Streissguth et al., 2004). Researchers have suggested that future investigation in this area must examine the interaction between the individual with FASD and the context in which they exist, including their families (Reid at al., 2015).

Caregivers report that professionals often do not fully understand the experience of caring for a child with FASD (Caley et al., 2009). Meanwhile, parent support programs exist, but a chief concern outlined by caregivers of children with FASD was that support staff did not fully understand the experience of caring for a child with FASD, as they had not lived it (Flannigan et al., 2020). As such, the need to connect with and be understood by people with similar experiences suggests the potential utility of caregiver to caregiver mentoring programs for caregivers of children with FASD (Caley et al., 2009).

Peer to peer mentorship occurs when a person embarking on a new life experience, like having a child with a diagnosis, is connected with a mentor who has experienced similar events and can provide advice and support gained through lived experience (Saxena et al., 2019). While there is a gap in literature regarding mentorship programs with caregivers of children with FASD, there are many studies in support of this programming in comparable populations, including caregivers of children with other diagnoses and high needs. However, no literature published to date has represented the perspectives of mentees and families of children with FASD in caregiver to caregiver mentorship interventions. Caregiver to caregiver mentorship is the term used in our study to describe the mentoring relationship. Essentially, this is the same term as peer to peer mentorship which is often used as a broader description of the relationship in prior literature, the two will be used somewhat interchangeably when required by context.

The purpose of the present study is to determine the motives of mentees accessing a caregiver to caregiver mentoring program for caregivers of children with FASD and other developmental disabilities that are delivered by clinicians at a local partner agency. The research question is ‘What are the motives for parent mentees of caregivers with children who have FASD?’ Program participants include mentors who have extensive experience in raising children with high needs including FASD and mentees who are in search of support and knowledge regarding the experience of raising a child with high needs. The majority of research on FASD and caregiver to caregiver mentoring programs operate from a deficit-based understanding of the diagnosis and experience, which disregards insight, resilience, and positive outcomes in spite of challenges (Coons et al., 2016). The proposed research proceeds with a strengths-based perspective that addresses needs and challenges of caregivers of children with high needs while also examining benefits of raising a child with high needs and engaging with caregiver to caregiver mentoring. The literature demonstrates the relevance of the proposed research question as it addresses the, so far, limited empirical understanding of caregiver to caregiver mentorship programming for caregivers of children with FASD, specifically focusing on the seldom heard voices of mentees.

Chapter 2: Literature Review

Evidence suggests approximately 4% of Canadians live with FASD (Flannigan et al., 2018). Based on standardized instruments used to determine expense and utilization of services, the adjusted annual cost per child with FASD in Canada is $21,642 (Stade et al., 2009). An estimate of the population level cost is reportedly $5.3 billion annually (Stade et al., 2009) More recently, the cost of diagnosis in Canada has been estimated as somewhere within the range of $3.6 to $5.2 million at the low end and between $5.0 and $7.3 million at the upper end, which does not include all the services and healthcare required after diagnosis (Popova et al., 2013). Each of these estimates of cost demonstrates the seriousness of the situation and urgent need to investigate programs for people with FASD and their families to minimize both symptoms and costs (Stade et al., 2009; Popova et al., 2013).

The most recent diagnostic guidelines were developed in 2016 based on a literature review carried out by a 14-member committee of FASD experts from varied professional backgrounds, including one caregiver (Cook et al., 2016). This led to several recommendations for screening, referral, and support labelled from strong to weak and sorted by the quality of evidence (Cook et al., 2016). The recommendations suggest pregnant and postpartum women across Canada should always be screened for alcohol use and referred to a multidisciplinary team if FASD is suspected (Cook et al., 2016). In terms of FASD features, there must be evidence of unique and distinctive facial features, growth and central nervous system problems before and/or after being born, and disorders in the neurobehavioural realm, all leading to a range of physical and behavioural issues (Chudley et al., 2005). Due to the access to services it confers, obtaining a diagnosis is essential in mitigating difficulties linked with development of secondary behaviours through the increased support and improved environment associated with these services

(Chudley et al., 2005). Diagnosis and referral, while necessary, are insufficient as many caregivers' state that the limited supports and professionals available do not fully understand the experience of caring for a child with FASD (Whitehurst, 2011). Based on their evaluation of current FASD research, Warren et al. (2011) stated that interventions must be investigated in order to capitalize on the lifelong learning capabilities afforded by brain plasticity to improve the quality of life for people with FASD and their families.

Diagnosis requires a multidisciplinary team of professionals as well as numerous assessments, including physical and neurodevelopmental tests, self-report data from mothers regarding alcohol use during pregnancy as well as social and medical history (Cook et al., 2016). With such a complex process, there are barriers to receiving a diagnosis and the corresponding support including access which is hindered by living in remote areas, lack of awareness, and associated stigma (Caley et al., 2009). In an environmental scan of programming in Eastern Ontario, Nauman et al. (2013) determined that there are extreme gaps in service delivery including geographical distances between services and exclusion of non-community members. The caregiver to caregiver mentorship program delivered through the partner agency should be investigated as this service is cost effective and can be made more widely available through remote access, addressing concerns outlined by Nauman et al. (2013).

Ecological Context

FASD greatly impacts the individual with the diagnosis. It is also important to examine the systems in which the individual exists and the interpersonal relationships that influence their day-to-day existence and outcomes. In essence, the family and community systems in which an individual with FASD lives impacts how they will do in life. In turn, the individual with FASD will also affect the family and community, meaning the bidirectional influences and interrelations between the individual with FASD and their ecological context are important to understand. It has been suggested in a review of supportive interventions for people facing challenges due to a family member's complex medical needs that a family centered approach is the optimal model (Acri et al., 2017). For the purposes of this review, the primary caregivers of an individual with FASD are the main focus because they comprise the sample of mentees included in the partner agency caregiver to caregiver mentorship program.

Caregiver Challenges

Many challenges have been reported by caregivers of individuals with FASD which can impact the caregivers' themselves and the family system as a whole. One challenge is the increased parenting – related stress as a result of the child's reported behavioural problems, as determined through standardized measures of child related stress and behavioural ratings and checklists (Paley et al., 2006). Similarly, caregiver reported stress has been predicted by the severity of sensory problems displayed by a child with FASD based on caregiver interviews and questionnaires in addition to a neurodevelopmental assessment (Jirikowic et al., 2012). Behavioural and sensory processing problems are demonstrative of primary FASD symptoms which can be exacerbated by secondary conditions. As such, services designed to assist in reduction of secondary conditions may then reduce caregiver stress and increase harmony in the ecological context, all of which may enhance potential for positive outcomes.

Concern for the future is another challenge identified by caregivers of children with FASD. In comparison with parents of children with ASD, caregivers of children with FASD in interviews and questionnaires report less hope for children becoming independent (Watson et al., 2013). Caregivers of children with FASD also did not expect their children attend post-secondary education or maintain a stable career, and had less hope about their children's futures relative to the higher hope and lesser stress reported by parents of children with ASD (Watson et al., 2013). Similarly, in group sessions mothers discussed themes around raising a child with FASD, wherein a prevalent theme was worry for children's futures due to their ever-changing needs (Michaud & Temple, 2013). Interestingly, these mothers did have hope that with the correct supports in the community their children with FASD would experience more positive outcomes (Michaud & Temple, 2013).

Additional challenges associated with caregiving for a child with FASD include mental health struggles. Issues around mental health were described in a town hall forum on FASD, wherein caregivers and people with FASD reported that mental and emotional struggles were common due to having to respond to rapidly changing circumstances and maintaining social connections and interests (Caley et al., 2009). Similarly, emotional conflict was brought up by families who participated in interviews about living with a child with FASD (Whitehurst et al., 2011). Emotional issues identified included anxiety, fear, and guilt both in the present and in anticipation for future experiences, especially in the absence of support (Whitehurst et al., 2011). As has been widely reported, there is a complex interplay between the individual with FASD, their symptoms, and the family within which they exist. These reports suggest that the ecological systems can be influenced and have an influence on the child with FASD and their life outcomes.

Caregiver Strengths

While several challenges have been reported in the literature, it is also true that caregivers experiencing adversity are often able to draw on strengths to endure the situation and even attain positive outcomes. Adaptability is one such strength identified by mothers in a discussion session wherein they agreed that caring for their child with FASD became less of a struggle once they understood that the environment required modifications to fit the child rather than bending the child to the environment (Michaud & Temple, 2013). This ability to change parenting strategies was also reported by caregivers through concept mapping wherein caregivers stated that household functioning was enhanced by this ability and recognition of the child's unique needs, making the environment calmer and more predictable (Kapasi & Brown, 2016). Changing strategies to enhance quality of the environment positively impacts the child and their outcomes as well as the caregiver, as stress can be lessened through the reduction of difficult behaviours.

Strength can be observed in caregiver's abilities to engage in self-education and advocacy. Through interviews and focus groups, it was found that caregivers take protective actions to support their child with FASD and family as a whole at multiple levels including individual, family, and systems levels (Petrenko et al., 2019). Specific to the protective actions on the systems level, caregivers reported that they engaged in self-education about the diagnosis and engaged in advocacy on behalf of their child consistently (Petrenko et al., 2019). Likewise, qualitative interviews with caregivers of children with FASD identified a theme of advocacy, suggesting the importance of this action as well as understanding the diagnosis through self-education (Coons et al., 2019). While these are both important strengths, it is essential to note that many caregivers identify that these skills are not developed in isolation, instead, they are the result of motivation to seek support and learn (Coons et al., 2019).

Specific caregiver traits have also been identified as strengths in enhancing outcomes for families of children with FASD and the children themselves. Protective parenting attitudes were reported in interviews with caregivers which included understanding and acceptance of FASD and the desire to see the child happy and loved unconditionally (Petrenko et al., 2019). It is possible that these traits motivated parents to seek out and take advantage of any services available in the community, however, the relationship between these characteristics and seeking support were not investigated (Petrenko et al., 2019). Additionally, patience and understanding were identified as strengths through concept mapping, wherein these traits made it easier to cope with stressful behaviours and challenging circumstances (Kapasi & Brown, 2016). Self-care is another strength that has been explored more recently through measures carried out before and after a self-care intervention (Kautz et al., 2020). It was determined that caregivers who were more confident in their ability to engage in self-care were better able to meet family needs and derive satisfaction from the caregiving role (Kautz et al., 2020). The operational definition of self-care in this particular study included seeking resources like social support and respite to meaningfully reduce the burden of caregiving (Kautz et al., 2020). Self-care includes different activities when the caregiver thinks creatively and is able to access external support (Kautz et al., 2020).

The ability to locate, access, and maintain supports was highlighted as a strength in a number of investigations. Interviews in multiple studies suggested that parents identified seeking and experiencing formal and informal support as a strength (Whitehurst, 2011; Coons et al., 2016; Kapasi & Brown, 2016). Furthermore, the preferred source of support reported by families of children with FASD was from families in similar situations to both enhance support and reduce isolation as determined qualitatively (Petrenko et al., 2019). Expanding this strength may be achieved through the partner agency’s peer support group, enhancing positive outcomes for the child and the family system.

Multi-Level Impacts and Interventions

The impact of the caregiving environment on development has been examined in terms of outcomes for children with FASD engaged in child protective services (Koponen et al., 2009). Results based on health records suggested that caregiving environment in the early developmental years was strongly related to emotional, social, and neuropsychological functioning such that if the environment was volatile, the child's outcomes in these domains were more negative (Koponen et al., 2009). In spite of these findings, it is also true that caregivers are capable of taking protective actions (Petrenko et al., 2019). Protective actions can reduce the prevalence and impacts of secondary conditions associated with FASD (Petrenko et al., 2019). FASD is an individual diagnosis, however, multiple ecological systems levels influence outcomes which suggests the importance of multi-level interventions.

Regarding the interventions needed at multiple levels of the individual's ecology, multi-tiered interventions have been identified as preferred based on caregiver statements in town hall forums and interviews (Caley et al., 2009; Whitehurst, 2011; Brown et al., 2005). Additionally, ideal program traits suggested by parents in interviews and focus groups included that programs should be individualized, comprehensive, and coordinated throughout the lifespan (Petrenko et al., 2014). Parents indicated that a support group may assist in developing abilities to cope and advocate as well as decrease the feeling of being alone in challenging circumstances (Petrenko et al., 2014). Desire for programming is clear, however, motivation behind caregivers who act in ways to reduce the impacts of FASD, like participating in supportive multi-level interventions, remain unclear.

Social Support

Many studies, while not designed to assess peer support group outcomes, have, by virtue of their qualitative characteristics, described elements of social support groups that caregivers of children with FASD find most useful. Of particular interest are the types of support caregivers seek and receive through connection with more experienced caregivers. In examining strengths required to maintain optimal household functioning, it was suggested by caregivers that this goal could be achieved through interaction with practiced caregivers due to information sharing between families (Kapasi & Brown, 2016). Additionally, concept mapping with caregivers of children with FASD demonstrated that an understanding of FASD is a primary need for optimal caregiver functioning (Brown et al., 2005). Parent education was also highlighted by caregivers describing what a good intervention program would ideally provide in terms of assisting in the reduction of secondary conditions (Petrenko et al., 2014). Specifically, parent-to-parent support was highlighted as beneficial, and parents identified the need for education about advocacy and interfacing with systems like education and healthcare (Petrenko et al., 2014). These findings together suggest that caregiver to caregiver mentorship could provide the necessary pipeline of information sharing between veteran parents and those requiring additional support.

Caregivers have reported additional benefits of social support received from other caregivers raising children with FASD beyond sharing information. Indeed, reduced isolation has been identified as a reason to engage in supportive relationships with families experiencing similar circumstances (Petrenko et al., 2019). Another important benefit of interacting with practiced caregivers of children with FASD is the reduction of stress (Kapasi & Brown, 2016). Beyond the distribution of information, it is clear that social support from caregivers who have had similar experiences can contribute to wellbeing across levels of the ecological system and possibly assist in reducing secondary conditions, thereby improving outcomes for the family as a whole and the individual with FASD.

One final piece of the social support/peer to peer mentoring conversation is the benefit of social support in itself. Having peer support improves conditions for caregiver and the child with FASD. In interviews and questionnaires, it was described that participation in a support group was a supremely important activity (Coons et al., 2016). Support groups/peer to peer mentoring have been identified as potentially beneficial styles of programming based on interviews and focus groups wherein caregivers of children with FASD have stated that they would specifically seek support from people that have encountered similar circumstances (Petrenko et al., 2019). This sentiment was echoed by caregivers suggesting ways to enhance self-care abilities, who stated that seeking social support was a primary method for engaging in self-care to allow them to meet family needs and limit distress (Kautz et al., 2020).

Social support from caregivers who are in similar situations was also desired by parents as a method of reducing occurrence of secondary conditions, thereby improving outcomes (Petrenko et al., 2014). This style of social support was also identified as a way that parents would feel less alone and increase hope that they can rise to the challenge of caregiving for a child with FASD (Petrenko et al., 2014). Other foster parents with experience raising children with FASD were identified as an important resource for foster parents new to caring for a child with FASD as they could gain a positive relationship as well as understand how best to deal with challenges (Brown et al., 2005). While caregiver to caregiver mentorship has not yet been widely analyzed with caregivers of children with FASD, it is clear that this is a preferred intervention with anticipated benefits. It is possible that these anticipated benefits are part of the motivation for caregivers who do access peer support programming, which will be considered in the present research.

Caregiver to caregiver mentorship

Caregiver to caregiver mentorship designed to meet the needs of caregivers of children with FASD has not been widely examined at this time. However, similar populations - including caregivers of children with other developmental disabilities - have engaged in peer to peer mentorship and mentee outcomes have been reported. Within literature on peer to peer mentorship, mentors receive the most research attention. Indeed, empirical focus is often devoted to the motivations and characteristics of people who become mentors, while the majority of research on mentees centers on program outcomes. Recently, there has been increased interest in mentee characteristics and motives, however, participant samples are typically composed of individuals in academic and business contexts. The following section explores the benefits of peer to peer mentorship programs in populations similar to FASD caregivers. It is possible that the outlined benefits are commonly perceived as a reason and motivation to engage in caregiver to caregiver mentorship programs, which is what the present study seeks to determine. Additionally, mentee characteristics in their infantile development as a research area will be discussed.

Social/Emotional Support

Receipt of social and emotional support is one broad area of beneficial outcomes reported in peer to peer mentorship literature on caregivers of children with health-related problems. Caregivers self-reported emotional support by participating in caregiver to caregiver mentorship programming, with samples including parents of children with ASD, new foster parents, mothers of seriously ill/dying children, and mothers of preterm babies (Moody et al., 2018; Pope et al., 2020; Cohen Konrad, 2007; Preyde et al., 2003). Social and emotional support have also been reported as a positive outcome of peer support programs for people with newly diagnosed bipolar disorder and for high-risk probationers (Proudfoot et al., 2012; Taylor, 2020). Each of these populations confront distinctly challenging situations, so positive outcomes of peer to peer mentorship are promising when considering other populations facing challenges, like caregivers of children with FASD and other developmental disabilities. It is possible that some of the motivation behind mentee participation in caregiver to caregiver mentorship are their perceptions of beneficial outcomes.

While the broad domain of social and emotional support is promising, it is useful to examine elements that facilitate the creation of the supportive bond between mentor and mentee. One such characteristic of the positive relationship is perceived relatability/similarity. Following a caregiver to caregiver mentorship program, mothers of seriously ill or dying children stated that support included the benefit of perceived sameness, which led people to feel less isolated in their situation (Cohen Konrad, 2007). Similarly, feeling less isolated and regaining a sense of normalcy through social comparison was in evidence in qualitative measures following peer support programming for people newly diagnosed with bipolar disorder (Proudfoot et al., 2012). The same appreciation of relatability was reported by high-risk probationers who engaged in peer to peer mentoring and a feeling of relatability was also reported for a sample of caregivers looking after elder family members who had accessed caregiver to caregiver mentorship (Taylor, 2020; Bruening et al., 2019). Caregivers of elderly parents also described less isolation as a result of being connected to caregivers facing similar circumstances (Bruening et al., 2019). In terms of relatability, mentees reported that engaging in social comparison and seeing that others have overcome similar challenges provided hope and motivation to engage in interventions for people diagnosed with bipolar disorder (Proudfoot et al., 2012). The benefits of normalizing and relatability, elements of social and emotional support obtained through peer to peer mentoring, may be a perceived benefit to becoming a mentee for caregivers of children with developmental disabilities and/or FASD.

Additional benefits associated with social and emotional support includes feelings of empowerment as reported by caregivers of children with ASD who had participated in caregiver to caregiver mentorship (Moody et al., 2019). Emotional health and wellbeing for parents of children with health problems as well as wellbeing more generally for mothers of seriously ill and dying children have also been reported as an outcome of participation in caregiver to caregiver mentorship (Acri et al., 2017; Cohen Konrad, 2007). Collaboration was a positive element of social and emotional support reported by people newly diagnosed with bipolar disorder after participation in peer to peer mentoring (Proudfoot et al., 2012). Collaboration is comparable to the benefit of sharing with a person in a similar situation as reported by caregivers of elderly relatives after taking part in caregiver to caregiver mentoring (Bruening et al., 2019). Finally, hope and motivation were reported by people newly diagnosed with bipolar disorder as a result of speaking with someone who had been in their situation and had overcome challenges (Proudfoot et al., 2012). While few have accessed empirical literature on caregiver to caregiver mentorship, success stories and perceived social and emotional support benefits may be part of the motivation for caregivers with children with developmental disabilities and/or FASD to engage in caregiver to caregiver mentoring programs.

Informational Support

Another reported form of support derived from peer to peer mentorship is informational support, wherein knowledge and skills are taught by mentor and learned by mentee. Knowledge and skill development were benefits of caregiver to caregiver mentorship as identified by new foster parents receiving informational support from seasoned foster parent mentors (Pope et al., 2020). Informational support can include advice about physical development in children newly diagnosed with Type One Diabetes (Sullivan-Bolyai et al., 2010). Likewise, clinical knowledge was sought through caregiver to caregiver mentorship by caregivers for elderly relatives (Bruening et al., 2019). Similarly, information about illness through education and enhanced confidence in health care decisions were detailed as a benefit of caregiver to caregiver mentorship in interviews with parents of children who were seriously ill and dying as well as parents of children with health problems (Cohen Konrad, 2007; Acri et al., 2017). Strategy sharing is another format by which informational support is obtained through caregiver to caregiver mentorship as suggested by mentees recently diagnosed with bipolar disorder (Proudfoot et al., 2012). Since knowledge and understanding of FASD were often identified by caregivers as an area requiring support, the perception of the potential benefit of informational support through caregiver to caregiver mentoring could be motivational.

Benefits associated with increases in skills and knowledge due to peer support have also been reported by mentees in various studies. Some of these benefits include the mitigation of concerns based on having a better understanding of FASD as reported by new foster parents in a caregiver to caregiver mentoring relationship with veteran foster parents (Pope et al., 2020) Mitigation of concerns is of great importance given the fear and anxiety reported by parents of children with FASD (Whitehurst et al., 2011). To create a more harmonious environment for the child with FASD, mitigation of concerns through enhanced knowledge and informational support could be paramount. Further, studies on caregiver to caregiver mentoring programs for families of children with health problems demonstrated that increased knowledge and understanding of health concerns was associated with decreased symptoms of distress and improvement in child behaviours (Acri et al., 2017). These promising outcomes in populations similar to caregivers of children with developmental disabilities and FASD suggest that it is possible mentees are motivated by the hope of obtaining similar positive outcomes in informational and social/emotional support. It will be important to examine whether mentees caring for children with FASD differ in regard to motivation from caregivers of children with other diagnoses.

Mentee Motives/Characteristics

Peer to peer mentorship programming and research is largely carried out in academic spaces and business/organizational settings. The literature reviewed demonstrates the importance of continuing to apply and examine these peer to peer mentorship models with other populations that may reap similar benefits in terms of social/emotional and informational support. Additionally, there has been a narrow focus of research concentrated on the motivation of mentors, with negligible research attention centered on the motivation of mentees. Most of the research that is carried out with a focus on mentees concentrates on participation outcomes. However, this narrow focus does not consider a major contributor to the peer to peer mentoring dynamic and does not allow for a deep understanding of people who do or do not access peer to peer mentoring programs. Recognition of mentee motives may assist program developers in tailoring programs and outreach to engage wider segments of the population, especially those requiring the level of support needed when caring for a child with high needs, specifically FASD. While the current empirical findings on mentee motives and characteristics are not widely generalizable to caregiver populations, it is useful to review current findings to determine similarity and/or difference when research is conducted with caregiver samples.

One motivation to engage in peer to peer mentoring was a learning disposition as self-reported by mentees reflecting on feelings prior to and during a work-related peer to peer mentoring program (Kroll, 2017). Learning and desire for industry – related knowledge was also reported in a study wherein mentees new to the hospitality industry were interviewed after having engaged in peer to peer mentorship with a veteran professional (Scerri et al., 2020). This suggests that for those in career contexts, there is a motivation to learn about and succeed in the field. It is possible that when research is conducted with mentee caregivers of children with high needs after caregiver to caregiver mentorship, motivations might include the desire to learn about the diagnosis and strategies.

Commitment was a specific characteristic identified in research within professional populations, which is not quite a motivation, but is still of interest in the context of the presently proposed research. New teachers who had participated in a peer to peer mentorship program stated in interviews and written essays about the experience that they were committed to the process (Pennanen et al., 2020). Similarly, commitment to the experience was highlighted by a group of professional women as a requirement for participation in pee to peer mentorship (Kroll, 2017). These studies suggest that participants felt they demonstrated a high degree of commitment. It is possible that commitment to the process is an important characteristic of caregiver mentees who have children with high needs as well, therefore, further research is clearly required.

In terms of benefits mentees hoped to obtain through peer to peer mentorship programs, desire for support was consistently communicated. The construction of a strong support system was identified as a need and want in a case study with an academic mentee with a senior academic mentor (Shriever & Grainger, 2019). Similar anticipation of support, both personal and professional, was self-reported by hospitality students engaging in a program with mentors who were hospitality professionals, based on the intake application asking them to state the benefits they hoped to glean (Scerri et al., 2020). While neither study can be adequately generalized to caregivers of children with high needs, it has been previously stated that caregivers of children with FASD desire support and often prefer support be delivered via other caregivers. Therefore, it is possible that FASD caregiver mentees in caregiver to caregiver mentorship might be motivated by the desire to receive support from someone who understands their situation.

Motivations to join peer to peer mentorship programs also included belief that they would assist on the path to achieving goals. In a case study reporting on mentee and mentor motivations in an academic setting, the mentee reported that one of her motivations was to achieve career related goals (Schreiver & Grainger, 2019). The anticipation of goal achievement and having these goals prepared before entering the mentoring relationship was also reported by hospitality students prior to peer to peer mentorship (Scerri et al., 2020). Similarly, there may be goals caregivers of children with high needs hope to achieve through participation in caregiver to caregiver mentorship. Further, it is possible that the goals themselves may differ between caregivers of children with FASD and caregivers of children with other developmental disabilities, if indeed the achievement of goals is part of the motivation to participate.

Finally, and most interesting given the proposed research, participants in peer to peer mentorship for professional women stated that comfort with vulnerability and discussing challenges was required for engaging in the program (Kroll, 2017). While this is a different population, comfort with admitting struggling and being able to reach out for help in the face of that struggle could be an important motivation for caregivers of children with high needs. While none of the mentee motivation related findings discussed are readily generalizable to the caregiver mentees involved in the present research, it is possible that admitting to struggle is a strength of those participating in caregiver to caregiver mentorship, and it may be easier for some mentees than others. For example, due to the stigma associated with FASD, it is possible that these caregivers are less likely than caregivers of children with other disabilities to admit to struggle because of the potential for blame and shame. Motivations and barriers to participation in caregiver to caregiver mentoring must be empirically addressed in order to adequately service as many people as possible thereby limiting the impacts of secondary conditions and enhancing the quality of the ecological system and outcomes for children with FASD and their families.

Chapter 3: Methodology

By utilizing qualitative methodology, mentee motives for accessing a caregiver to caregiver mentor were examined to facilitate understanding of FASD caregivers. This is a novel area of inquiry given that no prior literature has examined the motives of caregiver mentees of children with FASD engaging with caregiver to caregiver mentorship. This study was designed to determine why caregiver mentees would access caregiver to caregiver mentorship programming. The research on caregiver to caregiver mentorship from the perspective of mentees is lacking, even more so for populations of mentees that are caring for children with FASD. I will begin with a discussion centered around my position within the conducted research as a graduate student with interest around disabilities. Following a statement on positionality, participants, interview questions and data analysis methods are outlined.

Positionality

I grew up in a home with two parents and a younger sibling. The earliest years of my memory involve some financial struggle, however, most of my youth was spent in relative comfort and privilege, especially given that I am a white, cisgender, able-bodied woman in Canada. After graduating high school, I had the privilege of pursuing my Bachelor of Arts in Psychology at Trent University, during which I learned about mental health challenges, social justice, and cognitive processes. While completing my undergraduate degree, I interacted with members of the community through volunteer opportunities. I became a student board member at a non-profit community space wherein I participated in a project designed to enhance building accessibility which allowed for greater inclusion of community members with disabilities.

My interest in working with people with developmental disabilities began early as a result of my mother’s career as an educational assistant in specialized classrooms. Due to my interest and knowledge, I later became involved with Community Living Dufferin as a Direct Support Worker (DSW) for adults with developmental disabilities. While employed as a DSW, I worked closely with a client who had received a diagnosis of FASD as an adolescent and developed an understanding of the variability that is observable in this broad spectrum of diagnoses. While becoming more aware of the symptoms associated with FASD, I began to recognize the numerous coinciding social implications. Specifically, FASD is regarded as preventable which means that receipt of this diagnosis often entails blame assigned to the biological mother. Harsh judgement has become even more evident due to negative comments others make when I explain my research topic, including remarks on the unfairness and tragedy of FASD blamed on mothers. As such, I began to recognize the importance of pursuing research around FASD and continuing to humanize these stories so that judgement can be minimized, and compassion enhanced.

Through watching my mother work with students with disabilities, employment as a DSW, my undergraduate program, and volunteer experiences, I have gained an understanding of the strengths, challenges, and areas of need that people with disabilities and their caregiver's exhibit. While micro level needs, strengths, and challenges are important to address, societal shifts in thinking and support for people with developmental disabilities, specifically those with FASD and their caregivers, are required to create a more understanding and navigable world.

Participants

Sixteen participants were drawn from the caregiver to caregiver mentorship program at the partner agency through convenience sampling. The caregiver to caregiver mentorship program was expanded partway through its implementation to include caregivers of children with various developmental disabilities, not just FASD. This was done to ensure nobody felt they would be judged or stigmatized by virtue of disclosing a FASD diagnosis. Not everyone who participated in the program was invited to engage in the interviews conducted for this study, participation was limited to FASD caregivers. Mentees were included in the study when they were contacted and consented to engage in the interview process with a trained interviewer, importantly, I did not conduct the interviews as data had been mostly collected by the time I became involved. Interviews lasted between thirty minutes and one hour and they occurred both over the telephone and via zoom depending on participant preference. Inclusion criteria included that mentees were over the age of 18 providing primary care to someone with FASD, and resided in southwestern Ontario. Participants consented to have their responses examined for the purposes of the present study.

Questions

Engaging in the role of mentee did not require the same level of training as mentors typically undergo prior to participating in the FASD mentorship program. Mentee participants received the Letter of Information (see Appendix A) detailing the present study. Once the Letter of Information had been read and understood, the written informed consent form (see Appendix B) was disseminated. Those that agreed to the terms of informed consent by signing were contacted after participation in the program for interviews. Interviews consisted of open-ended questions asked by a trained interviewer in private. The primary question asked of mentees was, “Why do you want to have a peer to peer mentor?” which was followed by a number of probing questions to allow for greater detail including: Have you had personal mentorship experience? Do you have life challenges that you want help with? What are the most important things about mentoring? What have you learned as a caregiver that you want advice about? All questions were from the mentee motives questionnaire (see Appendix C). Given the circumstances of

COVID-19, all interviews took place over the telephone using the telephone script (see Appendix D). Letters of information and consent were read to participants and copies were also available via email or physical mail if requested. Interviews were conducted over the course of approximately one hour per participant with time after completion for questions.

Data Analysis

Qualitative content analysis was utilized to examine mentee responses as guided by Creswell's (2003) procedures. Creswell's (2003) procedures include: (1) data is arranged into major units for analysis (i.e., by research question), (2) data is reviewed in its entirety with the goal of identifying general meaning, (3) codes for a small number of categories are developed and (4) themes emerge through the coding process. Using Microsoft Word, data resulting from the interviews was arranged, coded, and organized based on theme.

Raw data was recorded in Microsoft Word with each response written verbatim. Interviews were not audio recorded, they were transcribed in real time by the interviewers. All interviews were read and reread to develop overall sense of the data and emerging issues. A total of 161 meaning units were derived from the interview responses of 16 mentees. From those 161 meaning units, similarities led to a smaller number of detailed categories in the form of 59 codes which all centered around a similar idea that could be organized and compared. Codes went through several review and grouping processes to ensure they were grouped as consistently as possible. Next, codes were grouped together to construct themes. For a break down on the number of codes and meaning units contributing to each of the 7 themes, see the chart below. Throughout the entirety of this data analysis process, reflexivity through memo-ing occurred which included establishing positionality and an orientation around the research question before beginning analysis procedures, as well as noting thoughts that arose during analysis.

For example, one meaning unit was, “Get perspective from someone who has been through it.” The main idea that was derived from this statement was that a primary reason to connect with a caregiver to caregiver mentor would be to understand the experience of someone who has also raised a child with FASD. As such, this meaning unit was coded under the umbrella of, “someone with similar life experiences” wherein other meaning units with the same sentiment were also filed. This code then contributed to the larger theme of, “Comparable Life Experience” which included other codes that all shared similar content.

Themes	**Codes**	**Meaning Units**
1. Comparable Life Experiences	5	26
2. Information and Resources	7	34
3. Mentor with Positive Characteristics	13	22
4. Social and Emotional Support	6	12
5. Understanding of FASD Symptoms	12	40
6. Mentee Characteristics	8	14
7. School and Learning Concerns	6	13

Chapter 4: Results

In response to the question “Why do you want to have a peer to peer mentor?”, mentees involved with the FASD Connect program shared their perspectives. On the basis of a qualitative content analysis conducted in accordance with Creswell’s (2003) procedures, seven themes emerged from the data.

The first theme suggested caregiver to caregiver mentorship was accessed because mentees desired connection with someone who had experienced comparable life circumstances. The second theme highlighted the importance of obtaining information and resources from a caregiver to caregiver mentor. Within the third theme, mentees anticipated positive characteristics in a caregiver to caregiver mentor, thereby motivating them to access the FASD Connect program. The receipt of social and emotional support was the fourth theme as it was observed that mentees hoped for support through difficult emotions as well as a lack of assistance from family and friends. The fifth theme centered around mentees’ need for clarity about FASD symptoms, as such, mentees hoped caregiver to caregiver mentors could increase their knowledge of the disorder as well as comorbid diagnoses and enhance wellbeing in the process. The sixth theme suggested that specific mentee characteristics led them to desire a caregiver to caregiver mentor because of their circumstances, attributes, previous experiences, and referrals. The final theme focused on mentees’ hope that caregiver to caregiver mentors would help with school and learning challenges including cognitive difficulties, issues with teachers, and barriers at the level of the school system.

Theme: To obtain a connection with someone who has encountered comparable life experiences.

This theme demonstrates that mentees who accessed a caregiver to caregiver mentor were motivated to engage in a supportive relationship with someone who had similar life experiences in raising a child with FASD. Mentees hoped their mentor would be similar to them, relatable, someone who they could learn from due to their first-hand experience, would serve as a model, and would be understanding of their situation.

Someone with similar life experiences. Mentees indicated that they were motivated to acquire a mentor who had similar life experiences as them. The importance of similarity was exemplified by Participant O who said they “really liked the sound of it that you were going to get someone who has dealt with FASD in some capacity.” Furthermore, participant D was hoping to “get first-hand experience from someone who has lived it. Gaining from someone’s past experience with issues as they come up.” The importance of similarity was further identified by Participant J who hoped to have a mentor that had experienced “similar behaviours and has a similar lifestyle.” While knowledge based in similar experiences was important, so was simply knowing that the mentor shared a similar lifestyle and encountered similar FASD behaviours.

Relatable person to connect with. Mentees reported that connecting with a relatable person was a primary reason to obtain a caregiver to caregiver mentor. Participant J stated that “the main reason why I wanted to have a peer mentor was to be in connection.” In describing who they might want to engage with, Participant A stated that they wanted to, “have someone that we can relate to.”

Learning from an experienced other. When interacting with someone who had similar life experiences, mentees were motivated to learn from an experienced other. Participant P elaborated in saying that their mentor should be “hopefully someone who knows just a little bit more than you do.” Clearly, the mentor may not have extensive knowledge but, as Participant P clarified, even the tiniest bit more knowledge would be worthwhile. In addition, Participant D stated that they would ideally be learning from, “someone with the experience to guide us.”

Mentor who serves as a model. Modelling carried out by someone with comparable life experiences was another motive for mentees to acquire a caregiver to caregiver mentor. Participant C was adamant that the mentor would help by “modelling what they did and what helped.” Modelling may be defined as the observation of an individual performing a task in the hope of learning the skills necessary to complete the same task (Tanaka & Wantanabe, 2018).

Someone who understands. Finally, mentees were hoping to connect with a caregiver to caregiver mentor who would understand their situation due to comparable life experiences. Participant K stated they would “like to talk to someone that understands what I am going through,” suggesting that they were motivated to connect with someone who could appreciate their reality. The importance of this source of understanding was further elaborated when Participant H stated that, “people who do not know FASD they just do not get it. It will be helpful to have someone get it.” According to Participant H, most people do not fully understand what mentees are going through in providing care for children with FASD, as such, it was essential that mentees find that source of understanding in a caregiver to caregiver mentor. Finally, Participant N wanted, “someone to reach out to who knows what I am talking about and going through. That feeling of camaraderie.” The feeling of understanding also includes an element of camaraderie, which highlights the importance of establishing a close bond allowing for deep understanding.

Theme: To gain practical, first-hand information and relevant resources that experienced mentors have found beneficial.

This theme encompassed reports from mentees that suggested they were motivated to engage with a caregiver to caregiver mentor who could provide information and resources. Information and resources were desired in the form of direction toward services, informational support, strategies, help, advice, resources, referrals, getting inquiries answered, filling in the blanks, and learning what to anticipate.

Services. A motive reported under the theme of gaining information and resources was the desire to be directed towards services. Participant A stated that they wanted assistance in "finding… services to help children." It appears that a source by which important services could be found is through direction from a mentor who has presumably already found valuable services in the community.

Support. One reason for mentees to access a caregiver to caregiver mentor was to obtain practical support. Participant D said they were hoping to find "helping, guidance, support." Additional support required was evident when Participant G said they wanted a caregiver to caregiver mentor in order to see "if there are community supports that I do not know about." Aside from one-on-one support, mentees wanted to find community supports, suggesting that informational support on multiple levels was a motive to access a mentor.

Strategies, help, and advice. Mentees described that they hoped to access strategies, help, and advice through a caregiver to caregiver mentor. In the absence of strategies tailored to FASD, mentees like Participant C elaborated that they desired "strategies that we don't get." Similarly, Participant F stated that they were in search of "strategies that I haven't applied to my own situations." Participant G further suggested that they were motivated to access a caregiver to caregiver mentor who could help "strategize when issues come up." When challenging circumstances arise, stress often does as well. Considering elevated stress, Participant J hoped a mentor could provide “potential strategies when you are feeling flustered or frustrated.” In addition to strategies, Participant K stated that they, “need all the help and advice I can get.” Similarly, Participant N emphasized that they wanted “to have a peer to peer mentor because I wanted someone else’s advice on what they do in certain situations moment to moment.”

Resources and referrals. Mentees motives to engage with a caregiver to caregiver mentor were linked to their need for referrals to resources as well as resources themselves. As Participant H stated, “having a mentor will help provide me resources for my child.” The emphasis on the importance of accessing resources was further explored by Participant C who expressed that they were “just looking for every resource, every learning opportunity.” It appears that mentees who are caregivers for children with FASD endeavor to be well equipped to raise their child with FASD by seeking out any resource available. Meanwhile, it can be difficult to navigate available community services for FASD. Given these difficulties, Participant G required a mentor to help with “connecting the dots between resources.”

Getting inquiries answered. With a diagnosis as complex and multifaceted as FASD, numerous questions arise for caregivers. Given the complexities, Participant C stated that they were looking for “answers to questions we have” from a caregiver to caregiver mentor who had experience with FASD. Echoing this sentiment, Participant O said they wanted to “have questions answered.”

Filling in the blanks. In terms of information mentees were hoping to receive, filling gaps in knowledge and ensuring nothing was missed was a rationale for mentees to connect with a caregiver to caregiver mentor. Participant P stated that they hoped that a mentor “would know something that I wouldn’t know – maybe there is something that I am missing in between the lines that they might be able to fill in more for me.” In contrast to questions mentees wanted answered, filling in the blanks suggested uncertainty on whether mentees were missing anything. As such, the intent of filling in blanks for mentees was to ensure they were on the correct path, rather than asking questions about how to get onto the right path as above.

Learning what to anticipate. In obtaining information and resources from a mentor, mentees wanted to gain an understanding of what they should anticipate as a caregiver to a child with FASD. Participant E noted that they wanted to "know what to expect," and elaborated by stating they wanted to determine whether "actions are typical to age or if the actions are a result of FASD. He is young so it's hard to tell what is typical for a two-year-old and what is FASD." It was important for caregiver mentees to determine whether behaviours were to be expected, cause for concern, or fit the developmental profile of FASD that others have observed. Participant F suggested that knowing what to anticipate was also important for decreasing stress when they said it "helps me feel less anxious as well knowing what to do or expect."

Theme: To connect with a mentor who exhibits positive characteristics that facilitate beneficial interactions.

A primary purpose for caregivers engaging with a caregiver to caregiver mentor was the hope that the experience would be constructive by virtue of positive mentor traits. Specifically, mentees hoped to connect with a mentor who was attentive, non-judgmental, sincere, respectful, trustworthy, empathetic, knowledgeable, compassionate, and patient.

Mentor who is attentive. Mentor's listening skills were important to mentees seeking positive traits in a caregiver to caregiver mentor. Participant G stated they wanted their mentor to be, "a good listener." According to Participant F, part of being a good listener is creating space for the speaker to "be able to talk and let some stuff out," as well as "sharing thoughts."

Additionally, Participant P discussed that a mentor who is attentive would contribute to dyadic sharing by being “someone you can bounce ideas off of.”

Mentor who doesn’t judge. Another grounds for mentees to seek caregiver to caregiver mentors was the thought that a caregiver to caregiver mentor may be someone who would not judge them and their children. This was emphasized by Participant G who stated they wanted a mentor who was “non-judgmental.” This sentiment was echoed by Participant M who stated it was important to have a mentor that was “not judging.”

Mentor who provides assistance. Caring for a child with FASD can be demanding for caregivers; as such, mentees desired a mentor who could provide assistance. This was identified by Participant G who stated they wanted a mentor who would be “helpful.” While mentee responses under the theme of information and resources outlined that they were motivated to access help, this statement demonstrates that the mentor should also embody helpfulness.

Sincere/candid mentor. One motive for mentees to connect with a mentor was the hope that a mentor would be willing to honestly share their experience by exhibiting “openness,” as identified by Participant M. Additionally, mentees hoped mentors would be “honest” and “willing to share,” as elaborated on by Participant I.

Respectful mentor. Mentees reported the need to engage in a relationship that included what Participant K referred to as, “some type of respect between the two people.” Evidently, it was important for mentees to experience a respectful relationship in order to make the most of the caregiver to caregiver mentorship opportunity.

Positive interactions with mentor. To facilitate positive interactions between mentor and mentee, Participant K identified that, “there needs to be good, effective communication.” As such, it appears that the potential for beneficial interactions and communication with a mentor was a motive for mentees to access caregiver to caregiver mentorship. The definition of good communication for Participant M encompassed, “communication skills, consistency of connection.”

Mentor that is trustworthy. Reaching out for help can include feelings of vulnerability which that are further exacerbated for caregivers of children with FASD due to judgement and stigma. Mentees like Participant K were motivated to connect with a caregiver to caregiver mentor that they could “trust.” Trust is foundational in relationships, and the mentoring relationship is no different, especially when mentor and mentee are both caregivers to children with FASD.

Seeking empathy. Most people in the general population are not widely informed on the diagnosis of FASD and cannot truly empathize with the experience of providing care to a child with FASD. Considering the lack of empathy mentees experience, Participant L highlighted the desire for a mentor who is “empathetic.”

Mentor with wisdom. Given that the opportunity for learning was identified above as a primary motive for mentees, it makes sense that mentees would also require that their mentor have wisdom. Participant L highlighted that their mentor should be “knowledgeable” about caring for a child with FASD. The importance of wisdom was further explained by Participant O who said, “the most important thing is knowledge – to be fully, have a full understanding of the issues or ability to find the answers quickly. Not a junior person that says, ‘I think’, I want them to know, and I want them to be confident about the issue.”

Mentor with compassion. The desire for a compassionate mentor was discernable when Participant N said they wanted their mentor to be “gracious… someone who has… grace.” Grace may involve freely given virtuousness mainly displayed through forgiveness regardless of whether the recipient is deserving, thereby leading to a sense of freedom and growth. In this study, participants were clear that grace and compassion also included believing that the caregiver mentee can rise to the challenges of raising a child with FASD.

Mentor with composure. There is a lot to learn when embarking on the experience of caring for a child with FASD, so it is important to have a mentor who is composed. As Participant N put it, they wanted "someone who has patience" during the learning process.

Mentor with good intentions. Mentees described their wish that a mentor would be genuine and have good intentions with no hidden agenda beyond provision of support. The desire for a mentor with good intentions was identified by Participant N when they said they hoped to have a mentor who "wants the best for me and my family."

Seeking positivity. In discussion surrounding FASD, the focus is often on limitations, symptoms, behaviours, and stress common to the caregiving experience. Given the proliferation of negative topics concerning FASD, Participant E demonstrated the motive to seek positivity in saying they wanted "some positive feedback" from their caregiver to caregiver mentor.

Theme: To increase social and emotional support in light of loneliness, difficult emotions, and lack of support system.

Mentees disclosed that their support systems were often limited for several reasons, which led them to enhance social and emotional support by connecting with a caregiver to caregiver mentor. Mentees said social and emotional support included validation and reassurance while tackling the lack of support from family and friends. Additionally, mentees hoped to gain a social bond, decrease loneliness, gain emotional assistance, and decrease distressing emotions like guilt and shame through a caregiver to caregiver mentor.

Validation and reassurance. Mentees, like Participant C, expected to connect with a caregiver to caregiver mentor who would "validate your experience" raising a child with FASD so that their feelings could be affirmed and accepted. In addition to validation, Participant C also highlighted that their mentor would ideally, "reassure me that I'm not alone." Providing care for a child with FASD can involve a sense of isolation and the feeling that nobody else understands, whereas having a caregiver to caregiver mentor can validate feelings and demonstrate that others are on a similar journey.

Lack of support from family/friends. One contributor to loneliness and invalidation reported by mentees was the lack of support from friends and family. Participant A described a lack of support by stating that since they began caregiving for a child with FASD "no one in family came forth." In describing the motive to access a caregiver to caregiver mentor, Participant M wanted "to receive the support that I do not have from extended family."

Seeking social bond. For some mentees, the social relationship with a caregiver to caregiver mentor in and of itself was a reason to obtain a caregiver to caregiver mentor. As stated by Participant F, "the relationship" was the rationale for connecting with a caregiver to caregiver mentor. This need for a social bond was underscored by Participant I who stated they were looking for "any kind of peer connection."

Decreasing loneliness. As has been explored, there is a lack of support and connection for caregivers of children with FASD, thereby increasing loneliness. Feelings of loneliness motivated mentees to access a caregiver to caregiver mentor as clarified by Participant G when they said a mentor may provide "less of a sense of isolation." In addition, Participant J hoped that mentors could provide "assurance that you are not alone when dealing with the children."

Emotional assistance. In contrast with desire to access support in the form of information, caregivers of children with FASD also experienced emotional challenges requiring support from a mentor. Participant H hoped to obtain “emotional support when dealing with challenges as it relates to my child.” Additionally, Participant J said they hoped to receive “just kind of that support in the moment.” Receiving support from someone who understands the emotional needs of FASD caregivers and how to meet them at their peak difficulty was crucial for mentees in the program.

Decreasing guilt and shame. Given that FASD is linked to maternal consumption of substances while pregnant, shame and blame can often be experienced by caregivers. In light of the prevalence of guilt and shame, mentees were motivated to connect with a mentor who could, as stated by Participant C, “reassure me… that it’s not my fault.” Participant C went on to outline, “that’s the issue, all the blame” as a primary struggle in raising a child with FASD that a caregiver to caregiver mentor might help alleviate.

Theme: To navigate the realities of FASD, the associated symptoms, and their impacts on caregiver wellbeing.

Symptom management was a significant intention associated with engaging in caregiver to caregiver mentorship for mentees that were interviewed. Symptoms of note included conduct challenges, emotional issues, and lack of motivation. Additional struggles connected with the realities of raising a child with FASD that prompted mentees to seek peer motorship were stress, changing relationships, hectic schedules, enhancing optimism for the future, managing their own reactions, help noticing and addressing FASD problems, doing right by the child, little prior FASD experience, and assistance with multiple diagnoses.

Stress management. In discussing the feelings associated with caregiving for a child with FASD, Participant A described the experience as “overwhelming.” Given these overwhelming experiences, mentees were motivated to be in connection with someone who both understood the overwhelming nature of the circumstances and may also have ideas on how to alleviate distress. Participant A further elaborated that they “didn’t fully think about all of the difficult aspects that came with it, it’s challenging.” Thereby further underscoring the need for someone who has experienced similar challenges to step in and assist in managing stress.

Increasing motivation in FASD youths. Given that symptoms of FASD are so broad and can include a number of behavioural and cognitive issues, Participant L reported wanting a mentor that could assist with, “learning how to motivate [their child] more.”

Coping with changing relationships. One specific reality of FASD that Participant N wanted to address through the assistance of a caregiver to caregiver mentor was “a real shift in my relationship with my son from being really close and needed to not being wanted and things suddenly flipped.” Children with FASD, like all developing children, come to rely less on their parents as time goes on. This reduced need for a caregiver can be challenging due to the high need for closeness and care that the child with FASD once required. A caregiver to caregiver mentor has likely experienced similar challenges with their child’s progression through stages of development and can help caregiver mentees in terms of coping.

Conduct challenges. A primary symptom of FASD that caregivers led mentees to accessing a caregiver to caregiver mentor was their child’s conduct issues. In exemplifying behavioural challenges requiring interventions, Participant D reported that, “there are worrying situations, he hits and bites himself.” Participant F noted, “acting up in public” as a challenge which was echoed by Participant D who mentioned, “temper tantrums.” Additionally, Participant

H reported that their child was “quite defiant” with “challenges in all areas.” In addressing challenges, Participant H hoped a mentor could “help me make sense of the behaviours that we see.” Meanwhile, Participant D wanted a mentor to help determine “whether [conduct challenges] are potential issues or developmental stages.” Participant F hoped that they would receive “strategies on being able to handle those behavioural situations if acting up in public… to develop plans and be prepared for those outbursts.” Mentees wanted mentors both to help understand the behaviours they were observing as well as provide strategies to address their child’s conduct challenges.

Challenges with affect. Emotional difficulties are another prevalent array of symptoms for FASD. In response to challenges with affect, Participant E required “advice on emotional outbursts” from their caregiver to caregiver mentor who had experienced similar challenges Specifically, Participant E wanted assistance from their caregiver to caregiver mentor to develop a way of, “reacting to [emotional challenges] in a positive wat to help them develop.”

Coping with hectic schedule. Part of the drive for mentees to contact a mentor was to obtain assistance with organization considering busy caregiver schedules. Organization is required considering high needs of children with FASD and busy caregiver schedules. Indeed, Participant F stated, “my life is so busy, some organization would be good.”

Enhancing optimism for future. Hope for the future can be in short supply for caregivers of children with FASD given the numerous challenges described above. As such, Participant N stated they were motivated to bolster “that feeling of… hope” by connecting with a caregiver to caregiver mentor who had experienced some success in caring for a child with FASD.

Managing their own reactions. Given the numerous symptoms and challenging realities of FASD, caregivers have their own reactions and frustrations. In response to these reactions, Participant N wanted help with "parenting stuff and my own triggers and getting to them and have them not be as much triggers."

Help noticing and addressing FASD problems. Mentees in the present study desired assistance in noticing and addressing their child's problems related to FASD. Participant D hoped their caregiver to caregiver mentor would help "spot potential problems… help us identify problems as they come up." Participant D also said that help noticing FASD related issues was not enough; the caregiver to caregiver mentor should also help them "find the appropriate help" to address the issues as well.

Doing right by the child. Mentees suggested that a motive to obtain a caregiver to caregiver mentor was to fulfill their desire to do right by their child. As Participant D put it, "our focus is to help him the best we can." This was reiterated by Participant C who stated that they were motivated "to get more ideas to do what is best for this kid." The desire to do right by the child with FASD cannot be overstated, indeed, Participant D noted that their family had begun to "change our lifestyle because of him, moved to London because of him, wife retired because of him."

Little prior FASD experience and understanding. Knowledge of FASD is not common for people without a direct link to someone who has received this diagnosis. As stated by Participant H, "it is brand new to me." This sentiment was echoed by Participant D when they highlighted that they had "no experience bringing up a child with FASD problems." It makes sense when experiencing brand new circumstances that mentees would require assistance from a caregiver to caregiver mentor who has more experience. Participant O wanted a caregiver to caregiver mentor "so that [they] and [their] child can understand this fairly new diagnosis better." Additionally, Participant N said they were motivated to obtain "help with explaining FASD to my son and to his siblings in a way that does not dishonor him but also helps everyone understand."

Assistance with multiple diagnoses. Mentees' need for a caregiver to caregiver mentor was also related to the challenge of multiple diagnoses. Participant F said their child had, "seven diagnoses, each one of those alone is a case in itself, hearing impairment, anxiety issues, ADHD, targeting one at a time and it is a challenge." Obviously, numerous diagnoses can be challenging, so a connection with someone who can empathize and provide clarity in these areas would be useful. Another challenge a mentor might help with identified by Participant I was "how FASD intersects with addiction… learning from a practical point of view how to help him overcome his drug issues."

Theme: Drawn to caregiver to caregiver mentorship due to mentee characteristics including life circumstances, previous mentorship experiences and referral to program.

Mentees noted some of their own characteristics and circumstances that motivated them to engage with a caregiver to caregiver mentor. Attributes included monetary concerns, eagerness for learning, previous mentorship experiences, valuing of self-care, ability to be vulnerable, and referral.

Monetary concerns. Due to the expenses associated with caregiving for a child with FASD and limited support, mentees expressed financial difficulties. As stated by Participant D, raising a child with FASD "causes financial challenges." In order to confront financial strains, participants were motivated to connect with a mentor who had first-hand experience and may have overcome these difficulties.

Prioritizing support early in life. A characteristic of mentees who were drawn to caregiver to caregiver mentorship, like Participant E, was the desire to “get prepared.” Mentees accessed a caregiver to caregiver mentor because they prioritized “getting early intervention,” according to both Participant D and E who saw caregiver to caregiver mentorship as a key way to intervene early in the child’s life.

Eager to learning anything. Mentees driven to obtain a caregiver to caregiver mentor were “open to whatever to sharing and whatever they have to offer,” as outlined by Participant F. Similarly, Participant I shared that they were “open to possibilities of learning and understanding my child through other people.”

Previous mentorship experiences. Many mentees described that the motive to connect with a caregiver to caregiver mentor was a result of positive experiences with previous peer support programs. Participant G said they had been in a “post-adoption support group” that had been useful. Additionally, Participant D was “adopted, talking to others that were adopted helping them through it” had been a worthwhile experience for them. For Participant D, experience as a mentor motivated them to become a mentee to rise to the challenging experience of caregiving for a child with FASD.

Prioritizing care for self/family. The desire to engage in self-care in light of challenging circumstances was a reason for mentees to connect with a caregiver to caregiver mentor. Participant G said it best in stating, “it is good to discuss self-care and keep it in mind and if the mentor has something specific that works for their family in terms of self-care, step back and take a moment and acknowledge that you are heading towards burnout that would be ideal.” Not everyone is open to discuss and engage with self-care, as such, this is a unique mentee characteristic that led participants to engage in caregiver to caregiver mentorship.

View learning as consistent. Mentees identified their perception of learning as consistent as a motive for engaging with caregiver to caregiver mentorship. As Participant P put it, “parenting is an ongoing learning process; it’s really experiential the kids learn things every day, so I do too.” Many people view learning as something that occurs in school and ends when it is finished; however, mentees that connected with a caregiver to caregiver mentor viewed learning as an ongoing process.

Referred to program. For some, the motivation to access the caregiver to caregiver mentorship program was as simple as the receipt of a referral. As discussed by Participant P, “it was recommended to me so that was one of the reasons why and I thought that it could be helpful.”

Ability to be vulnerable. An important mentee characteristic involved in reaching out for a caregiver to caregiver mentor was an ability to be vulnerable in acknowledging the need for help. As stated by Participant P, “part of being a mentee is not being afraid to ask for that help.” In a society that values independence and self-sufficiency, it takes courage to admit help is required and mentees displayed this unique characteristic in their drive to access a caregiver to caregiver mentor.

Theme: To obtain assistance with school and learning related concerns.

Mentees discussed that an important reason they engaged in caregiver to caregiver mentorship was to address school and learning related challenges. Specifically, mentees hoped caregiver to caregiver mentors could help with learning and cognitive challenges, future concerns for children, difficulties with the school system and teachers, and preparing for anticipated issues in the broad area of schooling.

Learning differences for FASD. Mentees hoped that a caregiver to caregiver mentor would assist in understanding and addressing FASD learning differences. As Participant J said, it was important to gain an “understanding how their learning is different, how their comprehension is slower, and even with problem-solving, everything is just a bit harder or different.”

Cognitive challenges for FASD. Specific cognitive challenges characteristic of FASD were a reason for mentees to access a caregiver to caregiver mentor. Specifically, Participant P said, “her ability to focus is very limited. It is not like ADHD where they are on many highways it is more than that.” Noting that there are complexities beyond that which is seen with ADHD, mentees were motivated to access the wisdom of a mentor who had experience with FASD.

Future success of child. For mentees including Participant H, it was important to have a mentor to help their child “grow to be independent, secure, responsible, safe.” Mentees in the present study had already begun to think about the future outcomes for their child with FASD and were thereby motivated to enhance the potential for success with the help of a caregiver to caregiver mentor.

Challenges with teachers. Mentees identified that they were in search of a mentor to assist with teacher specific challenges. Participant M stated that they, “struggle a lot with the schools and teachers actually listening, they think they know better than I do about his disorders.” Another specific challenge Participant M acknowledged was how “routine is really important for [their child] and some teachers just don’t understand that.”

Challenges with school system. Mentees, including Participant A, identified the anticipated issue of the “school system, that’s going to be an age challenge.” Additionally, Participant A said challenges were exacerbated by “worries… with the cutbacks,” leading them to question whether they “should home school him.” As can be seen, concerns about the school system and uncertainty about the best course of action led mentees to access a caregiver to caregiver mentor who may have experience navigating this system.

Preparing for broad school issues. Mentees accessed a caregiver to caregiver mentor so they could, as Participant E said, “know what to expect, we know that something is going to happen when he goes to school.” In confronting current schooling challenges, Participant H stated that, “school is a big challenge for her, she demands a lot of time.” In addition, Participant G wanted a caregiver to caregiver mentor to gain “school strategies that are working for someone else.”

Summary of Findings

Seven themes emerged from data derived from interviews with mentees who answered the question, “Why do you want to have a peer to peer mentor?” The first theme centered around mentees’ desire to connect with someone who had experienced comparable life circumstances to foster validation, understanding, and assistance. The second theme showed that mentees wanted to access information, resources, and strategies through engagement with a caregiver to caregiver mentor. Within the third theme, mentees were drawn to caregiver to caregiver mentors who displayed a number of positive characteristics. Given that mentees hoped caregiver to caregiver mentorship would address loneliness, difficult emotions, and lack of assistance from family and friends, the fourth theme that emerged was social and emotional support. Comprising the fifth theme was the central need identified by mentees to gain clarity about FASD symptoms, thereby increasing their knowledge of the disorder while also enhancing wellbeing. The sixth theme related to mentee characteristics in that mentees were driven to engage with caregiver to caregiver mentors due to their own circumstances, traits, prior mentorship experiences, and the receipt of a referral. The focus of the seventh theme was the hope to address school and learning challenges through caregiver to caregiver mentorship including challenges with cognition, teachers, and barriers at the systems level.

Chapter Five: Discussion

Summary of Themes

The aim of the present study was to ascertain motives to engage with a caregiver to caregiver mentor for mentees who were caregivers of children with FASD. In pursuit of that aim, interviews were conducted with participants wherein they were asked, “Why do you want to have a peer to peer mentor?” Utilizing qualitative content analysis in alignment with the procedures outlined by Creswell (2003), responses to interview questions were examined.

While analyzing responses to interview questions, seven themes emerged. The first theme was desire for connection with someone who had comparable life experiences to raising a child with FASD including similarity, relatability, understanding, and modelling parenting behaviours to allow for learning. The second theme was the desire for information and resources from the caregiver to caregiver mentor including help, advice, strategies, services, resources and referrals, having questions answered, learning what to anticipate, informational support, and filling in blanks. The third theme was to connect with a mentor who was able to facilitate positive interactions due to a number of important characteristics including attentiveness, non-judgmental attitude, respect, trustworthiness, patience, knowledge, compassion, sincerity, and empathy. Encompassed by the fourth theme was the desire to enhance the social and emotional support mentees received given reports of loneliness, difficult emotions, and lack of support. Mentees elaborated that elements comprising social and emotional support were validation, reassurance, social bond, addressing lack of support, lessening loneliness as well as guilt and shame, and provision of emotional assistance. Navigating realities of living in society with FASD, the associated symptoms, and their impacts on caregiver wellbeing constituted the fifth theme including the need for stress management, dealing with symptoms, increasing optimism, managing emotions, and doing right by the child. Within the sixth theme, it became apparent that mentee attributes including life circumstances, previous mentorship participation, and referral to the FASD Connect program were instrumental in drawing mentees to a caregiver to caregiver mentor. Essential mentee characteristics included willingness to engage in self-care and to be vulnerable, eagerness to learn, monetary struggles, prior mentorship, and referral to the program. Finally, the seventh theme related to school and learning concerns which encompassed cognitive and learning challenges for FASD children, difficulties with teachers and the school system, and preparation for issues in the broad area of schooling.

Within the discussion below, prior evidence from the literature is compared and contrasted with the themes observed in the current study. This process allows for findings to be examined with respect to what has been previously reported in studies with caregivers of children with FASD and various populations of mentees. Evidentiary support for identified themes in the present study emerged, while also reporting new findings and potential differences from prior publications, suggesting the need for additional research going forward.

Summary of Literature

In previous literature, caregivers of children with FASD have not been studied with respect to their motivations to connect with a caregiver to caregiver mentor. One research area that has been explored in great depth prior to this study is examination of FASD prevalence, cost, symptoms, and impacts on caregivers. The cost of FASD on the level of the individual child is $21, 642 based on the annual adjusted cost estimated for Canada (Stade et al., 2009), and diagnosis itself is an astronomical cost, which can be a barrier to receiving services in the absence of a confirmed diagnosis (Popova et al., 2013). Services can also be in short supply even with a diagnosis due to geographical location, stigma, and limited awareness of this disorder (Caley et al., 2009).

It has been reported that primary effects and secondary behaviours are essential to a diagnosis of FASD; with considerable variability based on alcohol exposure, level of consumption, and patterns of use by the biological mother (Chudley et al., 2005). Primary effects are evident in the qualities with which people with FASD are born while secondary behaviours are associated with physical qualities but can be limited with proper support (Rutman & Van Bibber, 2009).

In examining which interventions are preferred and best for families with children who have FASD, family centered approaches are highly recommended and preferred by caregivers of children with FASD (Acri et al., 2017; Caley et al., 2009; Whitehurst, 2011; Brown et al., 2005). Previously, caregivers have cited their preference for programs that occur throughout the lifespan and are in a support group format (Petrenko et al., 2014), Additionally, studies on the caregiving environment have determined a link between quality of environment and outcomes for children with FASD (Koponen et al., 2009), and parents can take protective actions for their child at many levels to reduce impacts of secondary conditions (Petrenko et al., 2019).

An abundance of research around challenges associated with caring for a child with FASD has been conducted prior to the present study. Challenges that have been well established include parenting stress due to behaviours and sensory difficulties, concern for the future, lack of social connections, and mental struggles like anxiety, fear, and guilt (Payley et al., 2006; Jirikowic et al., 2012; Watson et al., 2013; Michaud & Temple, 2013; Caley et al., 2009; Whitehurst et al., 2011).

While challenges have been the primary focus of prior research, strengths of caregivers for children with FASD have also been empirically examined. FASD caregivers can demonstrate adaptability in changing the environment to fit the child as well as altering parenting strategies (Michaud & Temple, 2013; Kapasi & Brown, 2016). Additionally, FASD caregivers often engage in self-education, advocacy, gaining information about the diagnosis, seeking community services, unconditional love, acceptance, understanding, patience, and self-care (Petrenko et al., 2019; Coons et al., 2019; Kapasi & Brown, 2016; Kautz et al., 2020). Locating and obtaining support was also a strength reported in previous studies, especially support from families of children with FASD with similarities in life circumstances (Whitehurst, 2011; Coons et al., 2016; Kapasi & Brown, 2016; Petrenko et al., 2019).

Information sharing between families of children with FASD was described as beneficial for household functioning, and an understanding of FASD is a self-reported need for caregivers to function at the best of their abilities (Kapasi & Brown, 2016; Brown et al., 2005). Caregivers of children with FASD outlining their preferred interventions pointed towards parent education as a good way to learn how to advocate and navigate systems like education and healthcare (Petrenko et al., 2014). Benefits of social support have also included reductions in isolation, stress, secondary behaviours, and increases in hope, ability to overcome challenges and positive relationships (Petrenko et al., 2019; Kapasi & Brown, 2016; Coons et al., 2016; Petrenko et al., 2014; Brown et al., 2005).

Research on peer to peer mentorship has been conducted with populations similar to caregivers of children with FASD. While most studies focus on the mentor experience, some have also examined mentees. Beneficial social and emotional outcomes of peer support include increased sense of normalcy, relatability, social comparison, empowerment, emotional health and well-being, collaboration, hope, motivation, and reduced isolation, (Moody et al., 2018; Cohen Konrad, 2007; Preyde et al., 2003; Proudfoot et al., 2012; Taylor, 2020; Breuning et al., 2019; Acri et al., 2017; Pope et al., 2020). In past research, social comparison allowed mentees recently diagnosed with bipolar disorder to see that is possible to overcome challenges (Proudfoot et al., 2012). Informational support has been another reported utility of peer to peer mentorship according to mentees, which includes knowledge and skill development, advice about physical development, clinical knowledge, confidence in health care decisions, and strategy sharing, all for populations similar to FASD caregivers (Pope et al., 202; Sullivan-Bolyai et al., 2010; Bruening et al., 2019; Cohen Konrad, 2007; Acri et al., 2017; Proudfoot et al., 2012). Additional benefits resulting from increased skill and knowledge through peer support are mitigation of concerns, limited anxiety, decreased distress, and fewer behaviour difficulties in children (Pope et al., 2020; Whitehurst et al., 2011; Acri et al., 2017).

Mentee motives to access a peer to peer mentor have been reported on in a handful of studies. However, none of the populations engaging in peer to peer mentorship and reporting motives have been overly similar to FASD caregivers. Regardless, some of the motives reported by mentees include learning dispositions, desire for industry related knowledge, commitment, desire for and anticipation of support, goal achievement, and comfort with vulnerability (Kroll, 2017; Scerri et al., 2020; Pennanen et al., 2020; Shriever & Grainger, 2019).

Theme: To obtain a connection with someone who has encountered comparable life experiences.

Within this theme, mentees reported that they prioritized accessing support from someone who had similar experiences in terms of caregiving for a child with FASD. Aspects of this theme included similarity between mentee and mentor experiences, connection with a relatable mentor, learning from someone with experience, a mentor who can serve as a model for behaviour, and connection with someone who understands the experience of providing care for someone with FASD.

Given prior research on the utility of similarity between mentor and mentees, it makes sense that a primary mentee motive to connect with a mentor were the beneficial outcomes of engaging with someone who has comparable life experiences. There have been previous reports of mentees hoping to speak with someone relatable who has experienced similar circumstances (Taylor, 2020). Additionally, learning from and engaging in social comparison with a peer to peer mentor was important to mentees in other studies with similar populations (Proudfoot et al., 2012). It was important for mentees in this and other studies to connect with someone who would truly understand where they were coming from, due to their similar life experiences (Petrenko et al., 2019).

Connecting with a peer to peer mentor so that mentees could observe modelling has not been explored or reported in prior literature. The majority of peer to peer mentorship research centers the experiences and motivations of mentors, while mentee motives are underexamined. Additionally, research on caregivers of children with FASD primarily centers challenges, rather than strengths and actions to address difficulties through sources like peer to peer mentorship.

Someone with similar life experiences. Mentees’ desire to connect with someone who had similar life experiences aligns with evidence that the preferred source of support for families raising a child with FASD is others who have done the same (Petrenko et al., 2019). Studies have uncovered that similarity is desired because it will satisfy needs mentees have not yet met, including loneliness, hope of overcoming obstacles, and reducing FASD symptoms, specifically secondary behaviours (Bruening et al., 2019; Petrenko et al., 2014). It is possible that mentees in the present study were motivated to connect with a mentor who had similar life experiences for these same reasons reported in prior research. Similarity also has the potential to normalize mentee experiences and decrease loneliness, which may explain why mentees in the present study were motivated to connect with a caregiver to caregiver mentor (Proudfoot et al., 2012). Having seen that a caregiver to caregiver mentor has successfully overcome similar challenges, mentees may get the sense that they too can overcome, thereby enhancing hope and motivation (Proudfoot et al., 2012).

Relatable person to connect with. Mentees outlined that they wanted a caregiver to caregiver mentor in order to establish connection with a person to whom they could relate. Relatability has been paramount in prior literature on peer to peer mentorship, wherein social support was instrumental in increasing a sense of normalcy and reducing isolation for mentees (Proudfoot et al., 2012; Taylor, 2020; Bruening et al., 2019). Similarly, perceived sameness in a peer to peer mentor has been effective in decreasing loneliness for mentees (Cohen Konrad, 2007). In alignment with these prior studies, it is possible that mentees in the present research wanted a relatable mentor in hopes that feelings of normalcy would increase while loneliness would decrease. Furthermore, relatability may have been necessary for social comparison, thereby instilling hope and motivation to confront challenges similar to those mentors overcame (Proudfoot et al., 2012).

Learning from an experienced other. Results demonstrated that the potential for engaging with an experienced other who could facilitate learning was a motive for mentees to obtain a caregiver to caregiver mentor. While prior research has not reported learning from an experienced other as a mentee motive, household functioning and skill development were enhanced by engaging with caregivers who had more practice and information to share for populations of caregivers (Kapasi & Brown, 2016; Pope et al., 2020; Brown et al., 2005). Given prior research suggesting that learning from an experienced other allows for context specific knowledge and skill acquisition, it is possible that obtaining similar outcomes motivated mentees in the present analysis to obtain a caregiver to caregiver mentor with more experience that they could learn from. Additionally, it is possible that because information and assistance for people with FASD and their caregivers is scarce that caregiver to caregiver mentors become a primary source from which to learn (Burd & Popova, 2019).

Mentor who serves as a model. Within the present study, mentees hoped to obtain a mentor who would serve as a model for optimal caregiving behaviour. Within the published literature there is no specific reference to modelling as a key motivation for mentees accessing peer to peer mentorship. It is possible that there are key differences in learning when it comes to receiving information and advice as compared to seeing how strategies may be implemented in practice via modelling.

Someone who understands. For the theme of accessing a caregiver to caregiver mentor with comparable life experiences, someone who understands was an important element explaining why mentees desired a caregiver to caregiver mentor. It has been reported that caregivers of children with FASD prefer connection with someone who has lived the experience and understands the realities associated with raising a child with FASD, rather than a professional (Flannigan et al., 2020; Whitehurst, 2011). It may be that mentees are searching for the feeling of validation that results from deep mutual understanding and the gratifying sense of camaraderie. It is also possible that the lack of support and understanding from society at large, close social circles, and healthcare professionals motivates mentees to seek a caregiver to caregiver mentor who understands by virtue of first-hand experience.

Theme: To gain practical, first-hand information and relevant resources that experienced mentors have found beneficial.

A theme that became apparent upon reading participant responses to why they were motivated to obtain a caregiver to caregiver mentor was the desire to gain access to information and resources. Mentees reported that they wanted their mentor to point them towards services and provide informational support as well as strategies, help, and advice. Additionally, mentees were interested in obtaining resources and referrals, having questions answered, learning what to anticipate, and having mentors fill blanks in their understanding of FASD.

In prior literature about FASD caregivers' needs, practical first-hand knowledge and information has repeatedly been highlighted as a benefit of peer support (Kapasi & Brown, 2016; Pope et al., 2020; Sullivan-Bolyai et al., 2010). In alignment, informational support from caregiver to caregiver mentors was a reason for participants in the present study to connect with a caregiver to caregiver mentor. Support from others was identified as a necessity for caregiver skill development, which coincides with the current participants' desire for a caregiver to caregiver mentor who could provide strategies, help, and advice (Coons et al., 2019). Changing strategies is essential for enhancing the home environment and potentially improving outcomes for children with FASD; it is possible mentees view caregiver to caregiver mentorship as a method for learning new ways of parenting (Kapasi & Brown, 2016). Evidence based benefits of peer to peer mentorship include knowledge, skill development, and information specific to children's' medical conditions (Pope et al., 2020; Sullivan-Bolyai et al., 2010). As can be seen, similar outcomes in prior literature provides information as to why FASD caregivers in the present study may have been drawn to caregiver to caregiver mentors.

Within the theme of information and resources, several findings from the present study have not been reported in prior research with mentees outlining their motives to engage in caregiver to caregiver mentorship. Previous studies on peer to peer mentorship for caregivers of children with FASD have not revealed the desire to be directed to services, gain resources or referrals, have questions answered, determine what to anticipate, or have gaps in knowledge filled.

Services. Direction toward relevant services was a reason to obtain a caregiver to caregiver mentor for mentees in the present study. Desire for services has not been reported in prior literature on peer to peer mentorship, especially for caregivers of children with FASD. It may be the case that scarcity of services and limited conversation around FASD within society contribute to difficulties locating services to assist children with FASD. As such, it seems likely that mentees would seek those that have first-hand experience in caregiving for a child with FASD and have navigated and accessed available services which they can then point mentees towards.

Support. Participants in the present study reported wanting a caregiver to caregiver mentor in order to gain informational support, and support from others was identified as a necessity in developing skills for caregivers of children with FASD in a prior study (Coons et al., 2019). Peer to peer mentorship was also perceived as a potential method by which to construct a strong support system facilitating achievement of goals for a mentee in an academic setting, which corresponds with the desire for support in the form of information (Shriever & Grainger, 2019). Given the prior research, it is possible that mentees were motivated to access informational support from a mentor in hopes of developing a strong support system to assist with caregiving skill development.

Strategies, help, and advice. The desire to gain strategies, help, and advice through caregiver to caregiver mentorship could reflect mentees' characteristic learning disposition, which was a motive for peer to peer mentorship in a professional setting (Kroll, 2017). While it is not clear whether motives to obtain strategies, help, and advice are indicative of a learning disposition, this could be explored in future studies on mentee motives and characteristics, especially with caregivers of children with FASD. Family wisdom and traditional parenting practices are often not suitable for raising a child with FASD and for this reason, it is possible mentees are motivated to gain strategies from caregiver to caregiver mentors who have accumulated useful strategies, help, and advice.

Resources and referrals. Mentees hoped that their caregiver to caregiver mentor would deliver resources and referrals for their child with FASD. Concern for the future has been reported by mothers raising children with FASD who hoped to address these concerns through community support (Michaud & Temple, 2013). It is possible that mentees in the present study hoped to accomplish similar goals by receiving resources and referrals from experienced caregiver mentors.

Getting inquiries answered. Caregivers who accessed caregiver to caregiver mentors hoped for answers to questions from someone with experience and knowledge in raising a child with FASD. The desire to have questions answered by a caregiver to caregiver mentor has not yet been explored in published literature. FASD is not a widely acknowledged or understood diagnosis, as such, it is likely that caregivers have a multitude of questions and few reliable sources for answers, demonstrating why a caregiver to caregiver mentor may be a suitable source for answers.

Filling in the blanks. Mentees expected to address gaps in knowledge by connecting with an experienced FASD caregiver mentor who could provide any missing information. Prior literature has not explored mentees' motives to utilize caregiver to caregiver mentors as a source for filling in gaps in knowledge for caregivers of children with FASD. It may be the case that, given the limited understanding of the experience of caregiving for a child with FASD exhibited by professionals, mentees sought a mentor with experience to address gaps in knowledge that a professional may not foresee (Flannigan et al., 2020; Caley et al., 2009).

Learning what to anticipate. In the process of raising a child with FASD, learning what to anticipate down the line was an important motivation for mentees. Elements of learning what to anticipate included knowing what to expect, determining whether the children's' behaviours were typical, and the potential for knowledge to decrease stress. Literature about peer to peer mentorship has not previously identified learning what to anticipate as a reason to connect with a mentor. It is possible that the best source for learning what to anticipate is someone who has been in mentees' situation and is equipped with relevant information about future expectations.

Theme: To connect with a mentor who exhibits positive characteristics that facilitate beneficial interactions.

An overarching reason mentees gave for wanting a caregiver to caregiver mentor was to engage with someone who exhibits positive characteristics. Positive traits outlined by mentees included a mentor who was attentive, non-judgmental, respectful, trustworthy, patient, knowledgeable, compassionate, sincere, and empathetic. However, very little research has been conducted on desirable traits for mentors from the perspective of mentees.

Within established research, it has been determined that anticipation of professional and personal support was a motivation for student mentees to connect with a peer to peer mentor

(Scerri et al., 2020). The importance of wisdom in mentors has not been widely reported for FASD caregiver mentees, however, information sharing between families and parent education have been highlighted as essential elements of intervention programs (Kapasi & Brown, 2016; Petrenko et al., 2014).

Aside from the current findings, research has not explored FASD caregiver mentee motives to obtain a caregiver to caregiver mentor who demonstrates the positive characteristics outlined above. Positive characteristics that mentees hope to find in a peer to peer mentor that have not been previously reported include a mentor who is attentive, non-judgmental, helpful, sincere, candid, respectful, facilitating positive interactions, trustworthy and empathetic, compassionate, composed, positive, and has good intentions and wisdom.

Mentor who is attentive. Mentees hoped that their mentor would exhibit good listening skills that fostered space to share thoughts. It is possible that given the lack of support reported by FASD caregivers in their personal lives, there are few people who listen to their experiences and provide an outside perspective (Caley et al., 2009). Considering this lack of support and listening from close others, caregiver to caregiver mentors may appear to be the best option to meet the need for mentees to be heard.

Mentor who doesn’t judge. Given the judgement and stigma around the diagnosis of FASD, it makes sense that mentees hoped to engage with a non-judgmental caregiver to caregiver mentor (Caley et al., 2009). The motivation to obtain a non-judgmental caregiver to caregiver mentor suggests that it is important for programs to ensure mentors are trained to withhold judgement, thereby facilitating a positive relationship centered on growth and understanding.

Mentor who provides assistance. Help, as discussed above, is sought by mentees engaging with caregiver to caregiver mentorship. Aside from obtaining broad help, mentees hoped that the mentor themselves would be a helpful person. It appears that access to help, both as a broad need and as a need from a specific person, are important motivators to gain a caregiver to caregiver mentor so exploration of elements that make up a helpful mentor may help improve mentorship experiences.

Sincere/candid mentor. Mentees in the present study valued the opportunity to connect with a caregiver to caregiver mentor who would be honest and open about the realities of providing care for a child with FASD. Mentees hoped to gain access to a sincere and candid discussion about the experience of caring for a child with FASD. These discussions may not be readily available from other sources, like professionals, who have not lived the experience of caregiving in all its complexity (Whitehurst, 2011).

Respectful mentor. Mentees wanted to connect with a caregiver to caregiver mentor who would foster mutual respect between mentor and mentee as two people on a similar life path. Desire for mutual respect from another person has not yet been widely reported in the literature on peer to peer mentorship, especially with caregivers of children with FASD. It could be the case that mentees do not often feel respected in interactions with professionals as well as friends and family who do not have direct FASD caregiving experience. This lack of experience may lead professionals and close others to undervalue the difficulty of raising a child with FASD, whereas a caregiver to caregiver mentor would have that first-hand understanding and respect.

Positive interactions with mentor. Positive interactions facilitated by consistency and good communication skills motivated mentees in the present study to reach out to a caregiver to caregiver mentor. Consistency and communication skills may be seen as facilitative conditions for learning and connection by mentees, as such, it may be important for caregiver to caregiver mentorship programs to emphasize these characteristics as essential for mentors going forward.

Mentor that is trustworthy. Considering the vulnerability required to acknowledge the need for assistance, further amplified by the experience of caregiving for a child with FASD, a caregiver to caregiver mentor worthy of trust was a motive for mentees. It is possible that mentees who are caregivers of children with FASD are protective of their children, meaning those they share information with and receive advice from must be trustworthy.

Seeking empathy. Understanding and empathy from a caregiver to caregiver mentor was a driving factor for mentees deciding to engage with a caregiver to caregiver mentor. Given that FASD is not widely understood or discussed and is subject to judgements, it makes sense that a caregiver to caregiver mentor may be viewed as a possible source of much needed empathy.

Mentor with wisdom. Mentees needed a caregiver to caregiver mentor with knowledge, experience, and confidence in their wisdom so that mentees could learn from a reputable source. It is possible that prior advice did not lead to positive outcomes with FASD children, especially if sources did not have direct caregiving experience, so mentors' wisdom was prioritized.

Mentor with compassion. A mentor who displayed compassion, grace, and belief in mentee abilities was highly sought after by participants in the present study. Knowing a caregiver to caregiver mentor believes in them and will exhibit grace when mistakes are inevitably made may be a comforting thought for mentees, especially when others in their lives may be less compassionate.

Composed mentor. Mentees hoped to connect with a mentor who would demonstrate patience throughout the learning process. This need for composure from a mentor has not been reported in previous literature, specifically for caregivers of children with FASD. Composure may not be abundant in mentees’ personal lives leading them to seek a mentor who will provide that which they lack and thereby facilitate a safe space for learning to occur.

Mentor with good intentions. Caregiver mentees have reported they want to do right by their child, and this extended to connecting with a caregiver to caregiver mentor who wanted the best for them and their families. It is possible that mentees have experienced ingenuine and ill-intentioned people on their FASD caregiving journey that has led them to require a well-intentioned mentor.

Seeking positivity. The receipt of positive feedback was a reason for mentees involved in the current research to connect with a caregiver to caregiver mentor. It is conceivable that positive feedback is not common in other areas of mentees lives or support teams, leading mentors to be viewed as a possible source for positive learning experiences inlaid with understanding.

Theme: To increase social and emotional support in light of loneliness, difficult emotions, and lack of support system.

One of the primary themes that emerged in participant interview responses for the present study was the motive to receive social and emotional support from a caregiver to caregiver mentor. According to mentees, elements of social and emotional support include validation, reassurance, addressing the lack of support from family and friends, presence of a social bond, decreasing loneliness, emotional assistance, and limiting guilt and shame.

Previous reports have found that social support was instrumental in decreasing loneliness and increasing the hope of overcoming challenges for caregivers of children with FASD, with similar findings reported for other mentee populations (Petrenko et al., 2014; Proudfoot et al., 2012). Prior research has also established that difficulty maintaining social connections is a struggle for FASD caregivers, who then address this and other difficulties by increasing social connections, especially with others who understand their experience (Caley et al., 2009; Kautz et al., 2020; Brown et al., 2005). One motive similar to those under the umbrella of desire for social and emotional support from a peer to peer mentor reported in prior research was construction of a stable system of support (Shriever & Grainger, 2019). Furthermore, it has been reported that in order to decrease isolation, families of children with FASD prefer support from families with similar experiences (Petrenko et al., 2019; Petrenko et al., 2014). The feeling of being less alone was reportedly useful for enhancing caregivers' belief in their ability to handle challenges with FASD and similar studies have determined that social support from peer to peer mentorship have increased a sense of normalcy and decreased loneliness (Petrenko et al., 2014; Proudfoot et al., 2012). In addition, perceived sameness reduced loneliness for mentees in a study on mothers of seriously ill or dying children who connected with a mentor (Cohen Konrad, 2007). While studies on reducing loneliness have not examined this as a motive to access peer support, there are established benefits associated with social and emotional peer support for caregivers of children with FASD. Additionally, parent populations similar to FASD caregivers have reported that peer support groups may enhance coping skills and provide emotional support (Kapasi & Brown, 2016; Moody et al., 2018; Pope et al., 2020; Cohen Konrad, 2007; Preyde et al., 2003).

While prior literature does correspond with some of the current findings under the theme of social and emotional support, there are also novel findings reported herein. Research on caregivers of children with FASD and their motivation to obtain a caregiver to caregiver mentor with regard to lack of support from family and friends has not been previously published. Other elements of social and emotional support driving mentees to obtain a caregiver to caregiver mentor that have not been previously examined are desire to decrease guilt and shame.

Validation and reassurance. Mentees sought caregiver to caregiver mentorship due to a desire for validation of their experience as well as reassurance that they were not alone in caregiving for a child with FASD. Similar findings have been reported in prior literature wherein social support decreased loneliness and increased hope in abilities to overcome challenges in raising a child with FASD (Petrenko et al., 2014). With a similar population, less isolation and increased sense of normalcy was reported by mentees due to peer to peer mentorship (Proudfoot et al., 2012). It is possible that like mentees in previous studies, the present sample hoped a caregiver to caregiver mentor could decrease loneliness by validating and normalizing the situation in providing reassurance that others have encountered similar experiences.

Lack of support from family/friends. Unfortunately, isolation and lack of support from family and friends is often reported by caregivers in the wake of a diagnosis of FASD, and mentees in the present study were no different (Caley et al., 2009). It may be the case that for caregivers who have greater support from family and friends, caregiver to caregiver mentorship does not seem as necessary or valuable as it does for those who lack social and emotional support.

Seeking social bond. The possibility of creating a social bond was a reason for mentees to engage with a caregiver to caregiver mentor. Previously published research has underscored the many benefits and great importance of social connections for caregivers of children with FASD and similar populations (Acri et al., 2017; Coons et al., 2019; Kautz et al., 2020). It may be the case that having a child with FASD limits caregivers’ ability to maintain relationships, especially with those who do not understand their circumstances. Due to diminished social connections, it could be of importance to create a social bond with a caregiver to caregiver mentor.

Decreasing Loneliness. As has been widely reported, including by mentees in the present study, the experience of raising a child with FASD often involves loneliness and isolation (Petrenko et al., 2019). Given literature on reducing loneliness as a reason to connect with families who have similar experiences, it makes sense that mentees in the present study reported a similar motive for accessing a caregiver to caregiver mentor who may understand their experiences and be the social connection they wanted in their own journey (Petrenko et al., 2019).

Emotional Assistance. In contrast to informational support, caregiver mentees also hoped a caregiver to caregiver mentor could provide emotional assistance due to the challenges of raising a child with FASD. Emotional difficulties resulting from constantly evolving circumstances and limited social support have been reported by FASD caregivers in prior studies (Caley et al., 2009). Given the emotional challenges, it is possible that caregivers of children with FASD want to enhance functioning in their role as a result of receiving emotional support from a mentor.

Decreasing guilt and shame. Stigma is consistently reported as part of the experience of caregiving for a child with FASD due to the link between the diagnosis and maternal substance use during pregnancy (Caley et al., 2009. Given the presence of stigma, mentees were motivated to obtain a mentor for the purposes of limiting guilt and shame. Literature has supported the idea that anxiety, fear, and guilt are prominent for caregivers of children with FASD (Whitehurst et al., 2011). However, no other studies have reported the finding that a motive to connect with a caregiver to caregiver mentor for FASD caregivers is to decrease guilt and shame associated with the experience. It could be that mentors are seen as sources of understanding and non-judgemental regard due to similar experiences with stigma, thereby alleviating mentee guilt.

Theme: To navigate the realities of living in society with FASD, the associated symptoms, and their impacts on caregiver wellbeing.

Considering symptoms and implications of FASD, it makes sense that a major theme emerging from interviews with caregiver mentees was the desire to receive assistance from a caregiver to caregiver mentor with FASD symptoms and realities. Mentees wanted assistance with stress management, increasing motivation in their children, coping with changing relationships, children's' behavioural and emotional challenges, enhancing optimism, managing their own reactions, and doing right by the child. Additionally, mentees needed help from a mentor in light of little prior experience with FASD in order to notice and address FASD problems, handle multiple diagnoses, and increase understanding of FASD.

Published research pertaining to FASD symptoms and the challenges associated with providing care for a child with FASD is in no short supply. However, research on FASD caregiver motives to access a caregiver to caregiver mentor in order to learn about and meet the needs of their child with FASD is less common. FASD involves behavioural and sensory problems that have been linked to caregiver stress, which prior studies have shown to be decreased through support groups of peers with similar experiences (Paley et al., 2006; Jirikowic et al., 2012; Petrenko et al., 2014; Kapasi & Brown, 2016; Acri et al., 2017). A positive outcome of peer to peer mentorship reported by caregivers was a better understanding of how to deal with challenges associated with FASD (Brown et al., 2005). Understanding FASD can encompass knowledge of modifications for the environment, enhanced patience, information on the experience from families with practice, and mitigation of concerns about FASD outcomes (Michaud & Temple, 2013; Kapasi & Brown, 2016; Pope et al., 2020).

While many challenges mentees hoped to address have been explored in previous publications, there have been no reports on understanding FASD realities as a motive for caregiver to caregiver mentorship. No prior studies have examined caregiver to caregiver mentorship as a way to increase motivation in FASD youths, cope with changing relationships, address conduct and emotional challenges, enhance optimism for future, manage reactions, help notice and address FASD problems, do right by the child, overcome little prior FASD experience, or assist with multiple diagnoses.

Stress management. Mentees in the present study were overwhelmed by numerous challenges as caregivers for children with FASD, which sparked interest in engaging with a caregiver to caregiver mentor. Similar challenges have been reported in previous studies wherein stress was associated with two classic symptoms of FASD - behavioural and sensory problems (Paley et al., 2006; Jirikowic et al., 2012). Literature has also suggested that stress and FASD symptoms can be addressed via support groups, interaction with experienced caregivers, and gaining knowledge (Petrenko et al., 2014; Kapasi & Brown, 2016; Acri et al., 2017). Given evidence in favour of peer to peer mentorship as a mechanism for reducing stress, it makes sense that mentees would list stress management as a motive for accessing a caregiver to caregiver mentor.

Increasing motivation in FASD youths. FASD caregiver mentees reported the desire to address children's' low motivation through contact with a caregiver to caregiver mentor. There is no prior research on increasing youths' motivation as a reason to access a caregiver to caregiver mentor for FASD caregivers; however, literature has reported that secondary behaviours of

FASD that can be limited and possibly prevented given a supportive environment (Rutman & Van Bibber, 2009). Considering these findings, mentees may have had the goal of limiting and possibly preventing secondary conditions in mind when they sought a caregiver to caregiver mentor with experience.

Coping with changing relationships. Mentees in the present study noticed their children with FASD began to desire greater independence with age. To cope with increasing autonomy required by developing children, caregivers were motivated to receive assistance from a caregiver to caregiver mentor. The shift from childhood dependence to adolescent desire for autonomy has not been widely explored in the literature on FASD and even less so in literature on motives to obtain a peer to peer mentor. It may be that the challenges caregivers encounter related to their child's developmental trajectory seem to be best addressed by someone who has experienced that transition already.

Conduct challenges. Given the prevalence of these symptoms, it is no surprise that mentees in the present study cited assistance with conduct challenges as a primary motive for engaging with a caregiver to caregiver mentor. Published research could not be clearer that parenting stress is associated with primary symptoms of FASD including difficulties with reasoning, social situations, judgement, and other essential mental functions (Paley et al., 2006; Rutman & Van Bibber, 2009). Furthermore, it has been suggested that increased ability to remain patient and understanding as well as increased knowledge on FASD are associated with enhanced coping, decreased distress, and improved behaviour in FASD children (Kapasi & Brown, 2016; Acri et al., 2017). While no prior studies have cited struggles with FASD children's conduct as a motive to access peer support for caregiver mentees, it may be the case that mentees see caregiver to caregiver mentors as a way to overcome challenges associated with

FASD behaviours. It is possible that mentors are viewed as experts in decreasing behaviours due to their first-hand understanding of behaviours and associated stress.

Challenges with affect. Similar to conduct challenges, difficulties with emotions are a primary effect associated with FASD due to brain damage with which people with FASD are born (Rutman & Van Bibber, 2009). This is the first study to determine that a key factor in the decision to obtain a caregiver to caregiver mentor is the desire to address emotional challenges in children with FASD. The present mentees discussed the importance of having a caregiver to caregiver mentor who could advise on overcoming emotional challenges, possibly in the interest of facilitating optimal development for FASD children by addressing primary effects (Rutman & Van Bibber, 2009).

Coping with hectic schedule. Mentees involved in caregiver to caregiver mentorship outlined that one of their primary challenges was coping with a hectic schedule. There are no prior studies examining the chaotic nature of FASD caregiver schedules and coinciding challenges or how these circumstances may lead mentees toward caregiver to caregiver mentorship. It may be the case that mentees viewed caregiver to caregiver mentors as experts on managing and coping with the hectic schedule associated with providing care to a child with FASD.

Enhancing optimism for future. Previous studies have emphasized that caregivers of children with FASD rarely have high expectations for future outcomes due to statistics on jail time, abuse, and bullying for people with FASD (Watson et al., 2013). Caregivers of children with FASD have reported fear around current functioning and possible future experiences, especially if they and their children lack support (Whitehurst et al., 2011). Given that a lack of support contributes to worry about children's' future, it makes sense that a motive to connect with a caregiver to caregiver mentor is to quell worries and enhance optimism through support and reassurance.

Managing their own reactions. Anxiety, guilt, fear, and distress have been listed as common experiences for caregivers of children with FASD (Whitehurst et al., 2011; Kautz et al., 2020). In the present study, mentees noted that they had specific caregiving triggers they wanted to address with a caregiver to caregiver mentor. Strategies that have reportedly been useful for managing distress in light of FASD are increasing abilities in the areas of patience, understanding, and self-care (Kapasi & Brown, 2016; Kautz et al., 2020). FASD caregiver desires to manage triggers by accessing peer support has not yet been reported prior to the current study. Given the importance of an environment of patience, understanding, and support for FASD children, exploration into how caregivers manage their triggers through caregiver to caregiver mentorship is paramount.

Help noticing and addressing FASD problems. Mentees suggested that part of the appeal of gaining a caregiver to caregiver mentor was assistance with noticing and addressing problems related to FASD. Given the primary effects and secondary behaviours of FASD, it makes sense that mentees would want an experienced mentor to provide information on what to watch out for and manage (Jirikowic et al., 2012). While FASD caregiver motives for accessing caregiver to caregiver mentorship have not been widely explored, a positive outcome of caregiver to caregiver mentorship for FASD caregivers was a better understanding of how to deal with challenges (Brown et al., 2005). It is possible that the desire to have a caregiver to caregiver mentor assist in noticing and addressing FASD problems is related to the hope that an understanding of how to manage problems will lead to enhanced outcomes.

Doing right by the child. The desire to do right by the child was a reason to obtain a caregiver to caregiver mentor reported by mentees in the current study. Mentees believed that a caregiver to caregiver mentor would know where attention should be allocated, have ideas about what is best for the child, and help mentees make necessary lifestyle changes and accommodations. It has been determined that systems level protective actions, like enhancing the quality of the environment and fitting it to the child, facilitate positive outcomes for FASD children (Michaud & Temple, 2013; Petrenko et al., 2019). Protective parenting attitudes have been outlined in prior studies which include accepting and understanding FASD, unconditional love, and enhancing happiness for the child (Petrenko et al., 2019). While various methods by which parents try to do right by the child are evident in the literature, the perception of caregiver to caregiver mentorship as a mechanism by which to achieve this goal has not been examined previously. It is possible that caregivers intend to do right by their child through gaining information from experienced others to help focus attention and proactively alter their lifestyle.

Little prior FASD experience and understanding. Many caregiver mentees began raising a child with FASD having limited prior knowledge of and experience with FASD. In light of scant prior FASD experience, mentees hoped to learn from a caregiver to caregiver mentor who could provide insight and information. Interestingly, lack of FASD knowledge on its own has not been widely explored in the literature, especially as a motive for caregivers to obtain a caregiver to caregiver mentor. Mentees wanted help explaining FASD to others in addition to gaining an experiential understanding of the diagnosis. The clinical manner by which healthcare providers may explain the diagnosis is not what the family necessarily wants to share, however, a caregiver to caregiver mentor who has experience with FASD may be more suited to providing an understanding that honours everyone’s experience.

Assistance with multiple diagnoses. Multiple diagnoses and the resulting impacts on caregivers have not been widely explored in previous research. The present study is the first to report that caregivers of children with FASD access caregiver to caregiver mentorship to obtain assistance with multiple diagnoses. Continued exploration on this subject is of importance due to the common experience of raising a child with more than one diagnosis.

Theme: Drawn to the program due to mentee characteristics including life circumstances, previous mentorship experiences and referral to program.

Many of the mentees involved with the present study accessed a caregiver to caregiver mentor as a result of specific characteristics, which comprise another theme uncovered through the process of this research. Some of the attributes of mentees that contributed to their desire to obtain a caregiver to caregiver mentor were financial struggles, eagerness to learn, previous experience with mentorship, appreciation for self-care, willingness to be vulnerable, and referral to the program. Literature on both peer to peer mentorship and FASD caregivers has suggested that specific characteristics are associated with these two populations which contributes to the desire to obtain a caregiver to caregiver mentor, as will be explored below.

There is no doubt that FASD involves costs due to the diagnostic process, provision of support, and potential future maladaptive behaviours (Burd & Popova, 2019). While high costs are evident, addressing financial struggles has not been previously reported as a motive for FASD caregivers to seek caregiver to caregiver mentorship. In terms of mentee priorities that were observed, self-care was one that has been previously determined to encompass a wide range of activities including accessing supportive interventions (Kautz et al., 2020). Additionally, it has been found that self-education by various means is a protective action FASD caregivers can take for their child and a preferred method for self-educating is parent-to-parent (Petrenko et al., 2019; Coons et al., 2019; Petrenko et al., 2014). Professional women who became mentees flagged the ability to be vulnerable as a requirement for engaging with a mentor; while this is a different population from caregiver mentees, corresponding motives are of interest (Kroll, 2017).

Several driving characteristics that have not been observed in prior research led mentees to seek a caregiver to caregiver mentor. To date, no literature on the motives of FASD caregiver mentees, has identified monetary concerns, prioritizing support early in life, previous mentorship experiences, view of learning as consistent, and referral to program as motives to obtain a caregiver to caregiver mentor.

Monetary concerns. Mentees were motivated to connect with a caregiver to caregiver mentor to address monetary struggles associated with FASD. Financial concerns are prevalent for caregivers of children with FASD given the lack of support from society and monumental expenses associated with FASD diagnosis and behaviours (Burd & Popova, 2019). However, addressing financial struggles has not been reported as a reason to seek peer to peer mentorship in previous studies on caregivers of children with FASD. Given that mentees may assume caregiver to caregiver mentors experience similar financial circumstances associated with FASD, it is possible that mentees view mentors as a superior source for advice on overcoming monetary concerns as compared to standard financial advisors or professionals.

Prioritizing support early in life. Mentees indicated one motive for accessing caregiver to caregiver mentorship was prioritizing support for their child in early life, thereby improving their chances of positive life outcomes. While many caregivers view early developmental years as an invaluable time for support and learning, this disposition has not been identified as a motive or positive outcome of caregiver to caregiver mentorship with FASD caregivers until now. It may be of interest to explore whether FASD caregivers that access peer support demonstrate a greater understanding of milestones of child development and whether the intended outcomes in the realm of child behaviour and potential are obtained through caregiver to caregiver mentorship.

Eager to learning anything. A keen desire to learn anything a mentor may have to offer was reported by mentees in the current study as a motive to access a caregiver to caregiver mentor. Previously, self-education for caregivers has been described as a protective parenting action that often occurs due to a willingness to learn by various means, such as a caregiver to caregiver mentor (Petrenko et al., 2019; Coons et al., 2019). Caregivers suggesting quality interventions have pointed towards parent-to-parent relationships as a useful source of education (Petrenko et al., 2014). Career professionals have cited desire to learn as a key factor in their decision to obtain a peer to peer mentor, so the finding that mentees are eager to learn is not new for research on mentee motives (Scerri et al., 2020). It may be the case that, like career professionals, mentees were eager to learn and chose caregiver to caregiver mentors to learn from because of their experience with FASD (Scerri et al., 2020).

Previous mentorship experiences. Knowing that caregiver to caregiver mentorship has been useful in the past appears to facilitate openness to the potential utility of caregiver to caregiver mentorship for providing care to a child with FASD. Prior literature has not reported previous mentorship experiences as a reason for accessing a caregiver to caregiver mentor. It is possible that through creating positive mentorship experiences in programming, mentees may one day see the value in becoming a mentor themselves or access additional peer support in other areas of life.

Prioritizing care for self/family. Mentees in the current study cited prioritizing self-care as a reason to access a caregiver to caregiver mentor. In prior literature, self-care has been described as a strength that if valued could enhance caregivers' ability to meet the needs of the family and feel satisfied (Kautz et al., 2020). Self-care can be carried out through a variety of activities such as accessing supportive interventions, thereby reducing the burden of caregiving (Kautz et al., 2020). It could be that mentees who are motivated to engage in caregiver to caregiver mentorship recognize the need to engage in self-care in light of difficulties associated with caregiving for a child with FASD.

View learning as consistent. The perspective that learning occurs consistently in life was a characteristic of mentees that influenced their decision to obtain a caregiver to caregiver mentor. In published research, parents have suggested they would prefer interventions for their children with FASD that are individualized, comprehensive, and coordinated throughout the lifespan (Petrenko et al., 2014). Additionally, it has been recommended that interventions for FASD capitalize on lifelong learning abilities offered by plasticity (Scerri et al., 2020; Warren et al., 2011). While neither of these findings indicate that caregivers view their learning as consistent, they suggest that there is value in lifelong learning, which may be a view that is present in people who access a caregiver to caregiver mentor.

Referred to program. In the current study, mentee referral to the program was a motive for participating in caregiver to caregiver mentorship. No published literature on caregiver to caregiver mentorship has referenced referral as a reason for mentees to engage in programming, however, the process of referral as well as the source could be important areas for further investigation with FASD caregivers who cite this as a reason to obtain a caregiver to caregiver mentor.

Ability to be vulnerable. Mentees reported that a characteristic leading them to become involved with a caregiver to caregiver mentor was their ability to be vulnerable and open to help.

Research on the ability to be vulnerable has been scarce for mentees who are caregivers of children with FASD, however, mentees in a professional context acknowledged preparedness to be vulnerable as a requirement (Kroll, 2017). Given that the appropriateness of being vulnerable is culturally bound and may be unique in the population of caregivers for children with FASD who become mentees, future research in this area is of great importance.

Theme: To obtain assistance with school and learning related concerns.

The final theme that emerged from interviews conducted with caregivers of children with FASD who accessed caregiver to caregiver mentorship was the desire to address school and learning related concerns. This theme encompassed learning and cognitive differences for FASD, future success of their child, challenges with teachers and the school system, and preparing for broad school issues.

Learning and school related concerns for FASD are well documented given that they correspond to FASD symptoms categorized as both primary effects and secondary behaviours (Rutman & Van Bibber, 2009). FASD caregivers have reported little hope for children’s futures, concern regarding consistently changing needs, and anxiety about future experiences if their children are unsupported throughout life (Watson et al., 2013; Michaud & Temple; Whitehurst et al., 2011). In response to these challenges, mentees reported accessing a caregiver to caregiver mentor who might have experience and advice around challenges with teachers. Previous research has also demonstrated that parent to parent support helped parents’ interface with the education system and advocate on behalf of their child (Petrenko et al., 2014).

While research has addressed caregiver concerns about prospects, teachers, and learning for children with FASD, there is little research on mentee motives to address these concerns through caregiver to caregiver mentorship. No prior research has examined learning and cognitive differences for FASD, future success of the child, challenges with teachers and the school system, or preparing for broad school issues as motives for caregivers of children with FASD to access a caregiver to caregiver mentor.

Learning differences for FASD. Mentees in the present study had observed learning challenges for their children with FASD like slower comprehension time, problem solving difficulties, and school in general being harder or different for them compared to same age peers. As such, mentees hoped a caregiver to caregiver mentor could help them understand and determine a course of action to assist their child. It makes sense that learning difficulties are encountered by caregivers because brain damage is a primary feature of FASD (Rutman & Van Bibber, 2009). Brain damage can lead to difficulties in speech and language, short term memory, reasoning, analysis, judgement, and other higher order mental functions that occur during learning (Rutman & Van Bibber, 2009). Researchers have observed that changing parenting strategies and the environment to suit the needs of children with FASD can improve outcomes for children and caregivers (Michaud & Temple, 2013; Kapasi & Brown, 2016). It is possible that knowledge of primary effects and the desire to alter strategies and the environment to best support the child led caregivers to consider caregiver to caregiver mentorship as an option by which to achieve these goals due to mentors' experience in similar situations.

Cognitive challenges for FASD. Mentees reported that they noticed specific cognitive challenges for their children with FASD that led them to view caregiver to caregiver mentorship as a resource to address and understand the observed challenges. Like with learning difficulties, cognitive challenges are expected for those diagnosed with FASD given the brain damage associated with difficulties in higher order mental functions required for success in school (Rutman & Van Bibber, 2009). However, cognitive challenges have not been widely explored as a reason that mentees seek caregiver to caregiver mentors. Future research should explore the possibility that mentees turn to caregiver to caregiver mentors to address their children's' cognitive challenges because they have encountered and hopefully managed similar difficulties. Some cognitive challenges are within the realm of secondary behaviours, which can include difficulties in engaging in academics (Rutman & Van Bibber, 2009). As such, it is important to examine peer support in this area because secondary behaviours have been found to be limited and possibly prevented if the child receives proper support and understanding (Rutman & Van Bibber, 2009).

Future success of child. Addressing concerns about their child's future was a motive for FASD caregiver mentees to access a caregiver to caregiver mentor in the present study. Mentees hoped that a caregiver to caregiver mentor would assist their child in becoming more independent, secure, safe, and responsible on their own. In prior research, FASD caregivers have reported concern about their children's ever-changing needs as well as anxiety and little hope for the future if their children are unsupported (Michaud & Temple; Whitehurst et al., 2011; Watson et al., 2013). While caregiver concern for the future of their children with FASD is well established in the literature, no prior research has been conducted on how these concerns motivate caregivers to access a caregiver to caregiver mentor. It is possible that anxiety about the future can be alleviated by taking action in the direction of supporting their child with FASD, therefore caregivers seek assistance from a mentor who has confronted similar challenges and concerns.

Challenges with teachers. Mentees reported challenges with teachers who were unable to maintain necessary routines, did not respect caregivers' knowledge about FASD, and did not listen to caregivers. In response to these challenges, mentees reported the desire to obtain a caregiver to caregiver mentor who might have experience and advice in the area of challenges with teachers. It has been reported previously that parent-to-parent support equipped caregivers with the ability to interface with the education system (Petrenko et al., 2014). While research supports the utility of parent-to-parent support, there is limited research on mentees' motivation to obtain peer support in challenges with teachers. It may be the case that a caregiver to caregiver mentor is viewed as a useful source for advice, support, and understanding when it comes to challenges with teachers as mentors with experience raising a child with FASD have likely encountered similar difficulties and have found ways to cope with and address concerns.

Challenges with school system. In the current study, mentees hoped to access a caregiver to caregiver mentor in order to address potential challenges with the school system, including cutbacks to services and support. Like challenges with teachers, the ability to interface with the school system was a useful outcome of parent-to-parent support groups for FASD caregivers (Petrenko et al., 2014). Despite the potential utility of peer support programming, limited research has examined addressing challenges with the school system as a caregiver motive to connect with a caregiver to caregiver mentor. Mentees may be concerned about the level of support that will be available and/or feasible for the school to provide, leading them to connect with a mentor who has encountered and overcome this challenge.

Preparing for broad school issues. It was reported by mentees in the present study that concerns about schooling were quite broad, given that they did not know exactly what challenges to anticipate. Prior literature has not examined the desire to prepare for broad school issues as a motive for FASD caregivers to engage with a caregiver to caregiver mentor. In determining what they should prepare for and how best to strategize for schooling, it is possible that mentees view a caregiver to caregiver mentor as someone who has experience and wisdom proven effective by their own challenges associated with their child's schooling.

Discussion Summary

Comparing results and prior literature. A number of findings were consistent between this and prior research including challenges and strengths of FASD caregivers. Additionally, some of the motives that have been observed in the limited available research on mentee motives to engage in caregiver to caregiver mentorship with populations unrelated to FASD caregivers overlap in some ways with the present data. However, many of the reported motives to obtain a caregiver to caregiver mentor in the present study are novel because, while related to strengths and challenges that have been previously reported, this is the first study to record them as reasons to obtain a caregiver to caregiver mentor.

Similarities. For the first theme, connecting with someone with comparable life experiences, mentee responses somewhat overlapped with prior research. In previous studies, caregivers of children with FASD have stated that professional support staff do not understand first-hand experiences with FASD, similar to the current mentees who hoped for a mentor with similar life experiences (Flannigan et al., 2020; Whitehurst, 2011). Families of children with FASD have also previously reported a preference of receiving support from similar others which can decrease isolation (Petrenko et al., 2019), and potentially limit secondary FASD behaviours (Petrenko et al., 2014), which may partially explain the mentee motive to obtain support from a similar other. Positive outcomes of interacting with similar others have included enhancing household and caregiver functioning (Kapasi & Brown, 2016; Brown et al., 2005). Additionally, social support from a peer to peer mentor has led to outcomes of increased feelings of normalcy and less isolation (Proudfoot et al., 2012). For populations similar to FASD caregivers, having a similar other to connect with increased relatability (Taylor, 2020; Bruening et al., 2019), hope (Proudfoot et al., 2012), and decreased isolation (Bruening et al., 2019). Information sharing between FASD caregivers has also reduced isolation and stress (Petrenko et al., 2019; Kapasi & Brown, 2016). It is important to note that no previous studies with FASD caregivers have examined the motives to obtain a mentor, rather, they report on positive outcomes of engaging with a mentor and useful interventions as reported by caregivers.

For the second theme of gaining practical, first-hand information and resources that experienced mentors have found beneficial, there was overlap with prior research. Specifically, informational support has been identified as important for caregivers of children with FASD (Coons et al., 2019), as well as an element of facilitating goal achievement for mentees in an academic setting reporting on their motive for a peer to peer mentor (Shriever & Grainger, 2019). Additionally, mentees in a professional setting were motivated to obtain peer support due to their learning disposition, which could relate to mentees' desire to obtain strategies, help, and advice from a mentor (Kroll, 2017). Community support has been cited as a way to address concerns for FASD caregivers, however, this was not identified as a specific reason to access caregiver to caregiver mentorship in any prior literature (Michaud & Temple, 2013).

The third theme of connecting with a mentor exhibiting positive characteristics that facilitate beneficial interactions had some connections with prior findings in the area of mentee motives and preferred interventions for FASD caregivers. In particular, it has been found that mentees in a professional setting hoped to receive both professional and personal support from a mentor (Scerri et al., 2020). It seems that mentees who are caregivers of children with FASD do share some similarities with mentees in other settings insofar as their motives to receive specific support overlap. Meanwhile, in relation to the desire for a mentor with wisdom observed in the present study, it has been stated by caregivers of children with FASD that information sharing between families with children with FASD would be of value, which is similar to the positive trait of wisdom (Kapasi & Brown, 2016; Petrenko et al., 2014).

For the fourth theme of increasing social and emotional support in light of loneliness, difficult emotions, and lack of support, similar findings have been reported. Specifically, an outcome of peer support recorded previously for FASD caregivers was decreased loneliness (Petrenko et al., 2014; Proudfoot et al., 2012) as well as increased sense of hope in their parenting abilities (Petrenko et al., 2014), and elevated sense of normalcy (Proudfoot et al., 2012). These prior findings overlap with the present observation that mentees hoped to gain validation and reassurance of not being alone through a social connection with a peer to peer mentor and their desire to decrease loneliness through social and emotional support. Regarding emotional assistance, emotional difficulties have been previously reported for FASD caregivers, so it makes sense that caregiver to caregiver mentors would be obtained to address these concerns in the present study (Caley et al., 2009). Finally, guilt has been reported for caregivers of children with FASD especially given the link between maternal substance use during pregnancy and FASD (Whitehurst et al., 2011). While none of these prior findings relate to FASD caregiver motives to access a caregiver to caregiver mentor, they do allow for a better understanding of the challenges mentees might be hoping to address and overcome through caregiver to caregiver mentorship.

The fifth theme of accessing a caregiver to caregiver mentor to navigate the realities of living in a society with FASD, the associated symptoms, and their impacts on caregiver wellbeing involve some overlap with research previously published. In regard to some of the challenges of providing care to a child with FASD, behavioural and emotional issues have been observed and associated with caregiver stress which are challenges mentees in the present study hoped to address through caregiver to caregiver mentorship (Paley et al., 2006; Rutman & Van Bibber, 2009). It is possible that caregivers in the present study hoped the advice of a caregiver to caregiver mentor would help them develop skills and knowledge to decrease their children's behavioural and emotional challenges (Paley et al., 2006; Rutman & Van Bibber, 2009), which may thereby limit parenting stress and enhance coping (Kapasi & Brown, 2016; Acri et al., 2017; Jirikowic et al., 2012). Parenting stress has been addressed through support groups previously, which may be a positive outcome mentees in the present study hoped to obtain (Petrenko et al., 2014; Kapasi & Brown, 2016; Acri et al., 2017). Other challenges that have been observed in prior studies that overlap with mentee concerns they hoped to address through caregiver to caregiver mentorship included low hope for the future of their children with FASD (Watson et al., 2013; Whitehurst et al., 2011), and managing their own emotions in caring for a child with FASD (Whitehurst et al., 2011; Kautz et al., 2020).

Mentees were drawn to a caregiver to caregiver mentor due to mentee characteristics including life circumstances, previous mentorship experience, and referral to the program, which comprised the sixth theme. The financial strain associated with the life circumstances of providing care to a child with FASD has been reported on extensively (Burd & Popova, 2019). Prior studies have also reported on the utility of self-care (Kautz et al., 2020), eagerness to learn by various means (Petrenko et al., 2019; Coons et al., 2019; Petrenko et al., 2014), and lifelong interventions that demonstrate learning as consistent (Petrenko et al., 2014). The desire to engage in learning has also been reported as a motive for career professionals to engage with a peer to peer mentor, which overlaps with the present findings of FASD caregiver mentee motives as related to the characteristic eagerness to learn (Scerri et al., 2020). A mentee characteristic essential to professional women mentees was the ability to be vulnerable so that the intended benefits could be attained, which was an important trait of the present mentees as well (Kroll, 2017).

The final theme observed in the present study was the motive to obtain assistance with school and learning related concerns through a caregiver to caregiver mentor. Concerns and challenges in the realm of learning and school for FASD children have been well established due to research on primary effects and secondary behaviours (Rutman & Van Bibber, 2009). Also well documented is the lack of hope reported by caregivers of children with FASD for their children's' futures (Michaud & Temple; Whitehurst et al., 2011; Watson et al., 2013). In previous literature, it has also been reported that a quality method for addressing some of these challenges and concerns is through parent-to-parent support allowing for increased ability for caregivers to interface with the education system (Petrenko et al., 2014).

Differences. There are novel findings observed within the first theme of connecting with someone who has encountered similar life experiences. Observational learning through modelling as a motive to engage in caregiver to caregiver mentorship has not been reported previously. This may be due to limited research on mentee motives as well as minimal focus on strengths of FASD caregivers and mentees in that they recognize the potential value of learning via modelling.

There were a number of key differences between prior literature and current findings when it comes to the second theme of gaining practical, first-hand information and relevant resources that experienced mentors have found beneficial. Prior literature has not reported the hope that a caregiver to caregiver mentor would be capable of directing mentees to services, assist with recourse and referrals, answer questions, describe what to anticipate in caregiving, or fill in gaps in knowledge. The lack of prior literature on these subjects could be related to the limited focus on mentee motives as well as the over emphasis on FASD caregiver challenges, rather than their abilities to adapt and strengths in learning and engaging with services.

Many of the findings reported under the umbrella of the third theme, to connect with a mentor who exhibits positive characteristics that facilitate beneficial interactions, have not been previously observed. Attentiveness, non-judgmental stance, helpfulness, sincerity and candor, respectfulness, the ability to facilitate positive interactions and give feedback, trustworthiness, empathy, compassion, composure, good intentions, and wisdom have not been previously observed as motives to obtain a caregiver to caregiver mentor for any mentee population. It is possible that the lack of prior data overlapping with the present findings is related to the lack of research pertaining to mentees and their needs, rather, the majority of research centers traits mentors already exhibit, not those that mentees desire.

Prior literature overlapping with the theme of increasing social and emotional support in light of loneliness, difficult emotions, and lack of support system is lacking in some areas. Specifically, there have not been prior reports of caregivers for children with FASD wanting a caregiver to caregiver mentor to address the lack of support from family and friends, even though this lack of support has been observed in prior studies (Petrenko et al., 2014). Additionally, while guilt has been reported for caregivers of children with FASD, it has not been observed as a reason to obtain a caregiver to caregiver mentor in any prior literature (Whitehurst et al., 2011). Research has often focused on challenges involved with providing care for a child with FASD like isolation, lack of support, and guilt; however, no studies have examined how caregivers engage in actions to address those challenges and exhibit strength, such as accessing a caregiver to caregiver mentor as in the present study.

Within the fifth theme of hoping a mentor can help navigate the realities of living in society with FASD, the associated symptoms, and their impacts on caregiver wellbeing, there are several motives under this umbrella that have not been acknowledged previously. Motives unexplored in prior research include elevating FASD youths' motivation, coping with changing relationships, addressing conduct and emotional challenges, enhancing optimism for the future, managing emotional reactions, noticing and addressing FASD problems, doing right by the child, overcoming little prior FASD experience, and gaining assistance with multiple diagnoses. While previous literature has established that these challenges are prevalent for FASD caregivers, as outlined above, few studies focus on caregivers' ability to overcome these challenges and the methods by which they do this, like caregiver to caregiver mentorship.

Few contributing elements to the theme of mentee characteristics drawing them to caregiver to caregiver mentorship including life circumstances, previous mentorship experiences, and referral have been identified as FASD caregiver mentee motives to obtain a caregiver to caregiver mentor. Monetary concerns, prioritizing support early in life, previous mentorship experiences, view of learning as consistent, and referral to the program have not been previously found as motives to obtain a caregiver to caregiver mentor. Numerous studies have explored monetary concerns for FASD caregivers and have suggested the importance of early life interventions and lifelong learning, however, caregiver to caregiver mentors have never been identified by mentees as a way to do this, possibly because of the lack of research on mentee motives.

Within the final theme of the motive to obtain assistance with school and learning related concerns through caregiver to caregiver mentorship, challenges and concerns have been well documented as outlined above. However, research has not examined mentees' desire to address learning and cognitive differences, future success of the child, challenges with teachers and the school system, or preparing for broad school issues through caregiver to caregiver mentorship. It is possible that the deficit focus of FASD research has allowed for deeper exploration of the challenges themselves than the methods by which caregivers of children with FASD address and overcome these challenges. Additionally, it is likely that the lack of focus on mentee needs, characteristics, and motives as compared to mentor traits and motives contributes to the lack of prior research related to the present findings under this theme.

Implications

The existing base of literature is infused with new insights evident in the results of the present study including characteristics, strengths, and motives for obtaining a caregiver to caregiver mentor for caregivers of children with FASD. Caregiver interview responses from this study will be of use for the continued refining of counselling practices, policy, and ongoing research.

Counselling. This research demonstrated repeatedly the importance of empathy, understanding, and non-judgemental attitudes towards mentees who are caregivers of children with FASD. Counselling professionals are encouraged to engage in active empathy in trying to understand the world from the client’s perspective while operating from a stance of non-judgement. Based on the overlap between core counselling principles and the needs that drew mentees to participate in caregiver to caregiver mentorship, it seems that counselling for these populations could be of great benefit. It is important for counsellors to consider that many of the mentees in the present study referenced finances as an issue, given the high costs associated with FASD (Stade et al., 2009). As such, counsellors must consider whether there are effective, low-cost solutions for these populations while also considering whether they are able to engage with an adequate degree of empathetic understanding and non-judgemental care. It may be the case that caregiver to caregiver mentorship in tandem with receipt of counselling services may be of the greatest benefit to caregivers of children with FASD. However, caregivers also have busy schedules and high demands associated with raising a child or youth with FASD. It is also evident based on the present study that counselling professionals should engage in education about FASD, especially considering the prevalence of this diagnosis (Burd & Popova, 2019). This will assist counsellors in avoiding the assumptions and lack of understanding that is cited by mentees as a reason they prefer caregiver to caregiver mentorship over professional support.

Policy. Given the lack of services and support available for FASD and caregivers of children with FASD, it is important for policy makers and activists to determine how they might address these issues. Mentees in the present study were interested in obtaining a caregiver to caregiver mentor due to their desire for direction to services, resources, referrals, having questions answered, understanding what to anticipate in caregiving, and having gaps in knowledge filled. It is possible that tools for finding services could be useful so that caregivers of children and youth can easily and quickly determine what services are available in their community to answer questions, elaborate on what to anticipate, and fill in gaps in knowledge. Caregiver to caregiver mentors were viewed as a way to determine the useful sources of support and services in the community; however, it is uncertain whether mentees received the direction they hoped to obtain. It is the responsibility of social services to ensure there are adequate programs in place and that they are easy to find and navigate given the intense demands on caregivers of children with FASD.

School and learning related concerns were prominent enough to be their own theme drawn from the interview data obtained in this study. Given the concern and challenges reported around school and learning for caregivers of children with FASD, it is important to continue to examine how best to support FASD children and youth within the school system. It will be necessary to examine how best to prepare teachers and the school system to meet the needs of children with FASD and interact respectfully with caregivers. It is also important to consider the essential qualities of FASD, namely primary effects and secondary behaviours, and how they impact abilities to learn and engage in cognitive functions, so that caregivers, teachers, and other relevant parties can best provide the necessary level of understanding and assistance.

Additionally, stigma around the diagnosis of FASD was cited as a source of guilt and shame for caregivers of children with FASD in the present study. It appears that there is a severe and judgemental view of FASD within Canadian society, so it is essential to ensure that there is education concerning the nature of addiction and FASD for all citizens. It is unhelpful to lay blame and engage in shaming for the FASD diagnosis when effort should be devoted to best supporting the child and the environment within which they exist so that the best possible outcomes can be attained. People predominantly regard FASD caregivers through a lens of challenges and difficulties, however, this study demonstrates that a perspective of empowerment, and strength is appropriate given the actions taken to become the best possible caregiver.

Research. This study allowed for insight on the specific needs caregivers were trying to address through the program. Future studies should examine whether caregiver to caregiver mentorship for FASD caregivers adequately meets these needs and determine the additional services or mentor training that must occur in order to ensure mentees experience positive outcomes. Additionally, future research should continue to view caregivers of children and youth with FASD through the lens of empowerment, strength, and positive action because as demonstrated by the current mentees, there is much to understand about these populations beyond the deficit-based understanding that presently dominates research in this area.

Past research has focused heavily on mentor motives and characteristics, which is of great use. The present study demonstrates that mentees are driven by their own characteristics and circumstances as well. Some of these characteristics and circumstances driving the decision to access a caregiver to caregiver mentor that have not been previously observed include financial concerns, prioritizing support in early life, previous mentorship experiences, view of learning as consistent, and referral to the program. Clearly, caregiver to caregiver mentorship is a dynamic made up of two individuals, who both bring their own motives, traits, strengths, circumstances, and experiences to the table so it is important for future studies to continue to explore the mentee perspective and experience so that the entire dynamic can be empirically understood and possibly improved to satisfy the needs of all parties.

Mentees outlined a number of specific characteristics they hoped a caregiver to caregiver mentor might display which led them to access a caregiver to caregiver mentor. These traits, which have not been reported previously, included a mentor who is attentive, non-judgmental, helpful, sincere, candid, respectful, facilitating positive interactions, trustworthy and empathetic, compassionate, composed, positive, and has good intentions and wisdom. Further research should examine FASD caregiver mentorship to determine whether these characteristics are present in caregiver to caregiver mentors and if mentees felt like their mentor lived up to their expectations, allowing for improvements in mentor training, program delivery, and outcomes.

Limitations

It must be noted that there are a number of limitations associated with the present research. Due to the ongoing COVID-19 pandemic, all interviews were conducted over the telephone with difficulty reaching all participants due to their lack of time and ability to complete interviews. As such, it is possible that participants who were able to complete interviews differ in important ways from mentees that could not, possibly in terms of finances, job flexibility, and demands of caregiving. It is also possible that interviews conducted via telephone miss important information that could be gleaned from observing in-person behaviour, reactions, and emotional responses that could allow for deeper discussion on any number of motives, needs, and abilities.

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Appendix A

Mentorship for Caregivers

Letter of Information

Dr. Kim Harris, Assistant Executive Director

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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 information concerning child maltreatment. The files will be held by the Partner agency 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 PARTNER AGENCY. 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 PARTNER AGENCY.

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, Partner agency, at redacted.

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 at redacted.

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 redacted, email: redacted. 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

Partner agency,

254 Pall Mall St., Suite 200, London, ON N6A 5P6

Dr. Jason Brown, Principal Investigator

1110 Althouse, Faculty of Education,

1137 Western Road, London, Ontario

N6G 1G7

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-

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

___________________ __________________ _________________

Print Name of Person Signature Date (DD-MMM-

Obtaining Consent YYYY

Appendix C

Motives Questionnaire

MENTEE Motives Questionnaire (MenteeQ)

1. Why do you want to have a peer to peer mentor?

Probes:

- Have you had personal mentorship experience?
- Do you have life challenges that you want help with?
- What are the most important things about mentoring?
- What have you learned as a caregiver that you want advice about?

Appendix D

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 at redacted. If you would like more information on the research study please contact Dr. Jason Brown via email at redacted or telephone at redacted.

Appendix E

Mentorship for Caregivers

Consent Form

Dr. Jason Brown, Principal Investigator

1110 Althouse, Faculty of Education,

1137 Western Road, London, Ontario

N6G 1G7

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

Name: Jocelyn Blake

Education:

Master of the Arts – Counselling Psychology
Western University
London, Ontario, Canada
2020-2022 M.A.

Bachelor of the Arts – Honours in Psychology
Trent University
Peterborough, Ontario, Canada.
2015-2019 BA.

Honours and Awards:

Western University Entrance Scholarship
2020

District Council 46 Scholarship
2017

Trent University Deans Honour List
2015-2019

Trent University Yearly Renewable Scholarship
2015-2019

Academic Experience:

Masters Thesis
Motives for Caregivers of Children with FASD Who Connect with a Caregiver to Caregiver Mentor

Undergraduate Practicum

Review on the Efficacy of Quests: Instructional Design

Related Work Experience:

Direct Support Worker

Community Living Dufferin

2018 – 2020

Volunteer Experience:

Psychotherapy Intern

Thames Valley District Schoolboard

2021-Current

Student Board Member

Sadlier House

2018 - 2019