A Qualitative Investigation into Barriers and Enablers for the Development of a Clinical Pathway for Individuals Living with FASD and Mental Disorder/Addictions

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ABSTRACT

It is common for individuals with fetal alcohol spectrum disorders (FASD) to require support for mental health and addictions but there are challenges associated with receiving appropriate care in Canada. This qualitative investigation of the barriers and enablers to the development of a clinical pathway in mental health and addictions included focus groups of individuals with FASD, caregivers, family members, and clinicians. Data was thematically coded and the following themes are described: the absence of support outside of crisis, the struggle of navigating separated services, the common experience of service providers who lack understanding of FASD, and the benefits of FASD-informed care.

Keywords: clinical pathway, mental health, addictions, fetal alcohol spectrum disorder, qualitative research

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RÉSUMÉ

Il est fréquent que les personnes atteintes d'un trouble du spectre de l'alcoolisation fœtale aient besoin de soutien en matière de santé mentale et de toxicomanie, mais il existe des défis associés à la prestation de soins appropriés au Canada. Cette enquête qualitative sur les obstacles et les catalyseurs à l'élaboration d'un cheminement clinique en santé mentale et en toxicomanie comprenait des groupes de discussion composés de personnes ayant un trouble du spectre de l'alcoolisation fœtale, des soignants, des membres de la famille et des cliniciens. Les données qui ont été codées thématiquement et les thèmes suivants sont décrits : l'absence de soutien en dehors de la crise, la difficulté de naviguer dans des services séparés, l'expérience commune des fournisseurs de services qui ne comprennent pas l'ensemble des troubles causés par l'alcoolisation fœtale et les avantages des soins éclairés.

Mots clés ：cheminement clinique, santé mentale, addictions, trouble du spectre de l'alcoolisation fœtale, recherche qualitative

BACKGROUND

It is common for individuals exposed to alcohol in the prenatal period to experience mental health challenges (Popova et al., 2016; Chasnoff, Telford, Wells, & King, 2015; Himmelreich, Lutke, & Travis, 2017). An additional mental disorder is diagnosed in over 90% of individuals with FASD (Pei, Denys, Hughes, & Rasmussen, 2011; Streissguth, Barr, Kogan, & Bookstein, 1996; Streissguth et al., 2004). Substance use challenges are also prominent among those prenatally exposed to alcohol (Alati et al., 2006; Popova et al., 2016) with rates of substance use challenges five times greater than that of the general population (Streissguth et al., 1996). The mechanisms by which mental health issues relate to FASD are still being explored, as summarized in a published review (Pei et al., 2011). In a recent large scale systematic review and meta-analysis of the comorbidities of FASD, both conduct disorder and alcohol/drug dependence were reported amongst the comorbid disorders of FASD with an estimated pooled prevalence over 50% (Popova et al., 2016).

In 2013, the Diagnostic and Statistical Manual for Diagnosing Mental Disorder (DSM-5; American Psychiatric Association, 2013) incorporated criteria for FASD under Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure 315.8 (F88) and Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (Section III). This has broadened the scope of mental health professionals in recognizing FASD. Despite the increased psychiatric risk and expanded DSM diagnostic recognition of FASD, individuals with FASD are commonly not well-supported through the Canadian mental health and addictions (MH/A) services (Anderson, Mela, & Stewart, 2018; O'Connor & Paley, 2009). Due to lack of specific training, most MH/A professionals do not recognize the relevance of FASD despite commonly encountering it in clinical practice and individuals with FASD continue to experience adverse outcomes (Tough, Clarke, & Hicks, 2003). MH/A professionals lack resources, evidence, or recommendations regarding helpful healthcare paths for this population (Brown, Herrick, & Long-McGie, 2014; Lockhart, 2001; Paley & O'Connor, 2009).

Clinical Pathways

The implementation of clinical pathways (CPW) has shown great potential to reduce inconsistencies within patient care and to improve patient outcomes (Nielsen & Nielsen, 2015; Panella, Marchisio, & Di Stanislao, 2003; Rotter et al., 2010; Smith & Hillner, 2001). The goal of developing a CPW (also known as critical pathways, care maps, integrated care pathways, etc.) is to provide up-to-date recommendations for care in keeping with the best existing evidence for a specific condition (Panella et al., 2003; Rotter et al., 2013). CPWs were defined as "structured multidisciplinary care plans which detail essential steps in the care of patients with a specific clinical problem" (Rotter et al., 2011). CPWs can support partnerships amongst healthcare professionals while also empowering patients and caregivers as they navigate their care path (Rotter et al., 2013). The development, implementation, and evaluation of CPWs is becoming a commonly utilized healthcare intervention, inclusive of MH/A (Centre for Addiction and Mental Health, 2016; D'Entremont, 2009; Government of Saskatchewan; Vanhaecht et al., 2006). CPWs continue to be implemented and evaluated with more frequency across Canada and internationally (Rotter et al., 2011).

CPWs in FASD and MH/A

A literature review was conducted to establish the evidence base regarding CPWs for FASD, or FASD and MH/A. In a search of MEDLINE, Cochrane Library, EMBASE, CINAHL, and Google Scholar with no language restrictions, using terms including fetal alcohol, foetal alcohol, fetal alcohol spectrum disorders, fetal alcohol syndrome, *and* clinical path, clinical pathways, pathways, and care maps, we were not able to locate a single peer-reviewed study discussing the development of a CPW for FASD in Canada or internationally. However, despite the current lack of evidence for CPWs in FASD, recommendations have been made urging future action with this type of approach. Following a systematic review of the FASD assessment and diagnosis within adults, the Public Health Agency of Canada suggested that "Major trend(s) in the new millennium in FASD research must include the evolution of research agendas that focus on post-diagnosis supportive practice and casework for adults. Diagnosis needs to be followed with a response that includes developing a support system and case planning tailored to the specific needs of the individual" (Badry & Bradshaw, 2011). It is timely to utilize an evidence-based approach towards understanding the feasibility of development of a more systematic approach, like a CPW, to support individuals with FASD and MH/A.

Considerations Prior to the Development of a CPW

Given the lack of currently published guidelines to provide guidance and the complexity of FASD, there are many considerations to take into account to effectively lay a foundation for the development of a CPW in FASD and MH/A in Canada. In a systematic review of CPWs, Panella et al. (2003) noted that successful pathways were often developed with strong involvement from the healthcare providers who would be utilizing them. They emphasized that this contribution seemed to be a key factor in whether the pathway has positive outcomes or resulted in no impact (Panella et al., 2003). Furthermore, CPWs are more effective if they provide flexibility for tailoring in various settings (Shaw et al., 2016). This may be especially crucial in our context due to the extreme variability of services accessible to individuals with FASD in different parts of Canada (Goodman, Pivarnyik, & Lwin, 2014).

Understanding Enablers and Barriers of a CPW

When considering an intervention like a CPW, it is important to evaluate the gap between the current level of care and the proposed recommendations (Campbell, Bradshaw, & Porteous, 1998, Rotter et al., 2010, 2017). Starting by understanding the existing environment for which the pathway is being developed is imperative to effective development. These mapping activities should include the identification of potential obstacles to implementation as well as the means to facilitate successful adherence. Understanding barriers and enablers has been demonstrated as a vital component in the successful development of healthcare interventions (Baker et al., 2010; French et al., 2012; Gibson et al., 2015; McCluskey, Vratsistas-Curto, & Schurr, 2013; Travers, Martin-Khan, & Lie, 2009). In a 2010 review of effectiveness of interventions it was concluded that "interventions tailored to prospectively identified barriers are more likely to improve professional practice than no intervention or dissemination of guidelines" (Baker et al., 2010). For example, this approach was utilized in the development of a multi-diagnostic CPW for anxiety and depression in cancer care (Butow et al., 2015; Rankin et al., 2015; Shaw et al., 2016). Their method included an initial investigation into the barriers and enablers that currently exist regarding the implementation of a future CPW. These barriers and enablers would lay the groundwork for their recommendations to follow up the initial investigation (Rankin et al., 2015).

OBJECTIVES

The objective for this study was to identify barriers and enablers to the potential development of a CPW for individuals with FASD and MH/A challenges. Barriers and enablers typically focus on beliefs and attitudes of relevant clinicians with regard to healthcare interventions. However, given the complexity of the patient population and the high value of lived experiences in our context, we also prioritized the voices of patients and caregivers in the study design. Of importance to note is that we do not contend that MH/A challenges are to be considered as one and the same. We recognize these can exist as distinctive experiences for individuals and are often separated in the care paths they catalyze. Yet, we felt the exploratory nature of this project and the frequency of overlap in the experiences warranted an investigation of both conditions broadly to accurately represent the subject matter.

METHODS AND DATA COLLECTION

CanFASD is a Canadian research network focusing on collaborative and multidisciplinary investigations about FASD. Their approach integrates perspectives of individuals living with FASD, family members and caregivers, policy makers, clinicians, and researchers (http://www.canfasd.ca/) to generate research questions. The perspectives from this group concerning the existing state of MH/A for individuals in Canada was a catalyst for the current study. Individuals living with FASD and their caregivers relayed their unpleasant experiences when seeking care for MH/A. CanFASD's Family Advisory Committee members were integral in the direction of this project, as well as playing an active role in facilitation of the research.

This research was approved on ethical grounds by the University of Saskatchewan Research Ethics board. A qualitative methodology working from the theoretical approach of Grounded Theory was chosen because the research questions represented an area of inquiry which needed to be initiated by a better understanding

of the viewpoints and experiences in an area without clear directives (Al-Busaidi, 2008; Birks & Mills, 2015; Paradis, O'Brien, Nimmon, Bandiera, & Martimianakis, 2016). Homogenous focus groups were purposely selected to capture the interactions between participants. This method fostered richer conversations compared to having a researcher-to-participant dynamic when discussing a stigmatized topic within an arguably marginalized population (Kitzinger, 1994; Liamputtong, 2011; Morgan, 1996). Furthermore, homogenous focus groups allow for participants to generate dialogue with others who have common central experiences, facilitating a comfortable circumstance which encourages mutual sharing (Stewart, Shamdasani, & Rook, 1990).

A total of five focus groups were completed between fall of 2016 to spring of 2017, and details are summarized in Table 1. Questions for these groups centred on people's journey with seeking support for MH/A, specifically inquiring about barriers and enablers for pathways to care (Table 2). All focus groups

Table 1

Data Collection Procedures

Focus Group	Format	N	Recruitment	Provinces	Locations
Lived experiences	In-person focus group	4 (males and females over 18 years of age)	Community-based organization	SK	Urban
Lived experiences	In-person focus group	3 (females over 18 years of age)	Community-based organization	AB	Rural
Family members/caregivers	In-person focus group	6 (birth mothers, adopted parents, caregivers)	Community-based organization	SK	Urban
Family members/caregivers	Web meeting	5 (adopted parents, foster parents, caregivers)	CanFASD	MB, AB, BC, YK	Urban/Rural
FASD clinic coordinators	Web meeting	6 (professional FASD clinic coordinators or similar roles)	Email to listed FASD clinic contacts	BC, ON, AB	Urban/Rural
Healthcare professionals	Online survey	10 (managers, addiction counsellors, psychologists, social workers)	Email to listed FASD clinic contacts	SK, AB, MB, NS, ON, NWT, NB, NVT	Urban/Rural

*British Colombia (BC), Alberta (AB), Saskatchewan (SK), Manitoba (MB), Ontario (ON), Nova Scotia (NS), Yukon (YK), Northwest Territories (NWT), Nunavut (NVT)

Table 2

Questions for Data Collection

Questions for Professionals

1. What is the entry point for most of your clients with FASD to mental health or addictions? And, do you think there would have been a better place for them to start?

2. What course of treatment do you feel is common for these individuals? Is it beneficial or needing improvement?

3. What would you consider "essential services" for individuals with FASD and mental health/addictions challenges? Are these accessible to your clients?

4. Do your clients have access to a multidisciplinary team? Why or why not? Where is the team housed?

5. How do you take FASD into consideration when creating a treatment plan for mental health/addictions? What has been the most helpful consideration?

6. What do you feel is the biggest barrier for these individuals having positive outcomes in their treatment of mental health/addictions?

Questions for Individuals with FASD
(modified wording for parents/caregivers to say "the individual in your life with FASD")

1. Who first referred you to mental health or addictions support? Do you think there would have been a better place for you to start?

2. What came first, your diagnosis of mental health/addictions or your diagnosis of FASD?

3. Can you describe the steps you had to take to help find support for mental health/addictions?

4. What professional person or people provided you with the most support related to your mental health/addiction?

5. Who do you think could have helped you with your mental health/addiction issues along the way that wasn't available? How do you wish you could have been helped?

6. Did people take FASD into consideration when making a treatment plan for you? If so, how?

were moderated by the same researcher who had research experience with vulnerable populations. The focus groups of individuals with lived experience were limited to a small number of participants and kept to a shorter length of time (approximately one hour). In seeking the perspective of healthcare professionals, we discovered the inherent challenges of gathering the group across multiple time zones, thus, an online survey was conducted for this group. The online survey was done with Fluid Surveys (Fluid Surveys, 2017) and the web meeting utilized WebEx (Cisco, 2017). Questions for the professionals specifically queried about the current environment of providing services for individuals with FASD and MH/A, focusing on the barriers and enablers to providing care (Table 2).

DATA ANALYSIS

All focus group data was transcribed and open-ended comments from the survey were imported into NVivo qualitative data analysis software (QSR International Pty Ltd. Version 11). A Grounded Theory approach to data analysis was implemented (Birks & Mills, 2015; Martin & Turner, 1986). The Social Sciences

Research Laboratories at the University of Saskatchewan has a Qualitative Research Laboratory (QRL) that provides resources for researchers conducting qualitative and exploratory research at the University of Saskatchewan. The QRL specializes in qualitative data analytics and support. Their services were used and the service providers were QRL employees who had no prior connection to the study. An external audit, in which iterative peer review and debriefing throughout analysis (ongoing meetings between the QRL and the researcher) occurred as a validation strategy to provide a third-party review of the analytical process and product. Specifically, an initial coding framework was created by the first author (TA) and was reviewed by the QRL, in order to examine whether or not the findings, interpretations and conclusions were supported by the data. Coding for themes continued in a constant comparative, iterative process until saturation was achieved. Of significant importance, analysis of the data revealed interconnected themes. Similar overlapping concepts were reflected in much of the content from the various perspectives represented in the data. The resultant thematic analysis is reported in this article.

RESULTS

Thematic coding generated four interconnected themes regarding the barriers and enablers of a CPW for MH/A for those living with FASD.

Theme A: Support being Primarily in Response to Crisis

A strong barrier to provision of effective MH/A support was the very common experience of the MH/A support received by individuals with FASD being almost completely isolated to major crisis situations. The data contained various descriptions of contact with justice being the first entry point into MH/A services. Other examples of crises that brought people with FASD into contact with supports for mental health included suicide attempts, overdose, alcohol poisoning, child protection services, and emergency room visits. In the cases of the crisis-based interactions with MH/A support, the incident was often the first-ever contact despite having experienced MH/A struggles extensively in the past. These crisis situations seemed to be the fulcrum on which the contact with MH/A services rested, in that individuals were often not supported prior to, or outside of, the crises.

> I didn't actually get any help until after a suicide attempt and I was put into a psychiatric unit that was when I actually got help, before that it was just like "you're on your own." – person with FASD and MH/A challenges

> So the only time he started to get some help was when he was charged with assault, and they identified that he had anger management issues, so he got into a group anger management program and I guess he went through that as a part of his sentence, so I don't know how much help that was for him. – parent

The obvious need for preventative and proactive mental health support as enablers to support in this population was described on multiple levels, including examples like housing, income, wellness, and family system support. In response to a question related to essential services for providing effective MH/A support, one clinician's immediate comment was "Housing. Anyone else think of housing?"

Other comments from participants included:

> If this individual has a visible syndrome, they would have housing, they would have support, they would not be allowed, they would be protected from engaging in some of these issues and we wouldn't get there but for whatever reason, our FASD folks are very underservice and under-protected, so I'd like to see some prevention conversation about mental wellness and protection. – FASD clinic coordinator

> The basic needs for housing, food, clothing and personal safety are a priority. – clinician

Theme B: Access and Navigation Difficulties

Based on our data, the road to support through MH/A services appeared to be unclear and difficult. Access to services was presented as a typically encountered barrier. Lack of available professionals (i.e., psychiatrists), limited or restricted services (especially in rural areas), long waitlists and a general scarcity of supports were a theme both from a diagnostic and MH/A care perspective.

> He has just started seeing a psychiatrist, the waitlist was a year and a half, it took me a year and a half to get the appointment. – parent

> Being in an isolated area, what I got from my professionals when I got him admitted through ER was "we are not equipped to deal with your son, we don't have the equipment or services to deal with your son, there is nothing in this entire city that can support you" and that's not very supportive… – parent

For many of the existing supports, the experiences of many were that individuals with FASD don't meet the criteria for services. The data described a circumstance where individuals with FASD seem to occupy an unfortunate "no-man's land" regarding support for mental health. Many participants faced experiences where their problems were deemed FASD-related by mental health professionals who decided to categorize them outside of their scope and therefore they could not access services. Moreover, the notion that individuals with FASD can't be helped seemed to be a myth frequently encountered by those seeking services for someone with FASD to access MH/A services. Participants were denied services because the interventions were deemed useless anyway, or based on beliefs that "nothing works" and there are no effective methods to help someone with FASD. Scenarios were even described where having FASD was exclusionary criteria for accessing specific services.

> In fact, our mental health services here now for adults are hesitant to work [with] individuals with FASD, they just say what they know about mental health doesn't work for individuals with FASD, so they won't consider them as clients. – parent

> And then what was sad is then they're going "well, now I don't think she even qualifies for our services." And then you wish you could shut your mouth instead. The idea was for them to understand how to adapt their services not to drop her. – FASD clinic coordinator.

> I believe that individuals diagnosed with FASD are often set aside as the damage is done and there is no way to effectively help them. – clinician

> Many of the addictions programs are now, right on the criteria, saying we're going to exclude people with FASD. So, it keeps getting harder. – clinician

The concept of difficult system navigation as a barrier was also reinforced through multiple explanations. Intake processes were described as a significant obstacle because they were unaccommodating due to

being language-heavy, difficult to understand, fear-evoking, and requiring multiple layers of administration. For example:

> And to access detox or treatment, usually it's up to the person themselves to get up and call to see if there's a bed for that day, and have to do that every day and they have to get up early in the morning, and if they can't do that then "they're obviously not willing or motivated to participate…" – FASD clinic coordinator

Participants reported experiences of being bounced around, from one care service to another, with obvious obstacles when navigating the intersections of those services.

> It's been a messy road, like a messy year of being shoved around from place to place, from, you know, service to service, saying "we can help you" but then they don't. They say either you have too much need or you don't have enough need or whatever. – person with FASD and MH/A challenges

> Trying to find a smooth transition, where all the different organizations kind of to work together and it flows so it's a smooth transition, instead it's like we can't help you so we're gonna refer you here and you're not gonna have any support between here and here, and it could take over a month to get in over here so there's no transition into this program, or we're not going to explain to you what's going to happen in this program, and then it's "No we can't help you at this program" so were gonna send you over here but it's a 6 month wait list so you're on your own again for another 6 months so any progress you make you get here "oh we can't help you over here" you crash down here there's no transition and follow up and after care in any of these other programs so it's a big up and down roller-coaster of broken transitioning all over the place." – person with FASD and MH/A challenges.

Siloed and separated services created barriers for support as well. This concept included the separation between FASD and MH/A diagnostic services, mental health services and addiction services, not to mention the gap between primary care and other specialists. The importance of being sensitive to individual vulnerability and in turn providing mental health support through the FASD diagnostic process and the current absence that exists there also arose.

> I got handed a 37 page report on everything that was wrong with me, Here you go, I spiraled down, I had a suicide attempt, because in my world all along I knew something was wrong with me and here is that solidified, there needs to be follow up supports put in place before that diagnosis is handed to somebody. – person with FASD and MH/A challenges.

Difficulties were encountered related to communication and information sharing between services.

> I really liked the comment about taking things out of the silos, because even as we're talking about this, mental health is more than just an "-ist"– like a recreational therapist or a whatever "-ist" you are, it's having, I really think, that point person who can help you navigate to help maintain your mental health, before we need intervention, we have a healthy state. – FASD clinic coordinator

Similarly, siloed and separated services were described in relation to the transition from youth to adulthood which was a point in the lifespan identified as noteworthy from a MH/A perspective, based on the data.

> But after 18 all this support disappeared, and she was back left, and when she was 18 we had to decide to drop her, let her do whatever, and she will survive or not, or we take care of her. – parent

Theme C: Care Needs to be FASD-Informed

A central theme throughout the data, and a common thread woven amongst the descriptions, was the importance of care being FASD-informed. Accommodating for FASD in service provision was strongly

emphasized. Specific components included a focus on strengths-based approaches. The importance of in-dividualized care, both related to an individual's strengths and needs, but also in relation to an individual's specific impairments were brought up.

> We have had very little help from any professionals in the lives of our kids, mostly because they haven't been informed about the disability, they're afraid of people with FASD, they don't know what to do with them and they don't fall into their understanding of therapy, they don't know how to work with individuals with a cognitive disability and early trauma, it's a complex set of disorders that most professionals don't know what to do with. – parent

> In any treatment plan, I think it should support the individual's strengths and weaknesses. Consider the client in its uniqueness is the most important thing for me. – clinician

The viewpoint that FASD-informed care must be trauma-informed was evident. Experiences of trauma were prominent from within the data and the importance of care which included considerations of the individual's traumatic experiences were also emphasized from a clinical perspective. The current lack of trauma-informed care was seen as a problem.

> In terms of where would be better for them to start, I think a lot of the entry into mental health and addic-tions stems from their trauma background…they're not looking at those connections, and the mental health and addictions, they don't take into account their trauma. – FASD clinic coordinator

The value of a supportive advocacy relationship was a strong enabler presented throughout the data. Of great importance and commonly expressed was the need for a person to help an individual navigate the system and advocate for appropriate care. Based on the descriptions, supportive relationships seemed to be a vital factor for positive mental health journeys.

> So the best help for us has to be somebody who would go to him and be with him, like for him to even go to a counsellor is a huge thing, he almost needs someone to go to him or at least somebody to take him to a counsellor. – parent

> It's like I take my worker to everything because if I go to an addictions appointment she has to be there because I won't remember anything when I leave. – person with FASD and MH/A challenges

Professionals with an understanding of FASD was seen as crucial for providing helpful support. Those who interacted with professionals without such knowledge reported negative experiences. Many circum-stances were described where professionals lacked understanding of the disorder and the data described the disadvantageous effects that resulted.

> So some of the mental issues that develop in our children as they age are in reaction to a system that doesn't understand them. So being preventative or proactive in early years where they're understood and supported I think could go a long [way] in reducing mental health and addiction issues later in life. – parent

> When I'm feeling overwhelmed by people who don't understand FASD and are treating me poorly, I just shut down. – person with FASD and MH/A challenges

Alternatively, professionals and services based on an understanding of FASD and have expertise in working with individuals with the disorder, were deemed to be enablers. This was particularly impactful for improving trajectories.

[A psychiatrist who understands FASD] has been a real godsend for us, for our son, mostly for medication, prescriptions. – parent

She tried to figure out how to best work with him, she used lots of different types of therapy with him and now he sees her as a friend to him in his life and he always sees if someone has an anger issue, he says "oh that person needs my Debbie.* – Debbie was this counsellor who helped him with his anger. – parent (*named changed)

Examples of potential enablers from the data similarly highlighted the way things would change if systems were understanding of FASD. The shifts included focusing on trust-building with clinicians, wrap-around services, and no demerit-based consequences or penalties for what gets confused as "non-compliance." Long-term consistent care was desired, rather than the usual 6- or 8-week block sessions. Other characteristics of FASD-informed therapies included a neurosequential approach with an emphasis on developing recognition of emotional responses and building up coping strategies to respond. Understanding of FASD in service provision would also move away from interventions which rely heavily on introspection, language-based material, or dependence on recall (which can be challenging for individuals with FASD).

They hand you a pamphlet, and it's like, okay, that taught me nothing, especially having FASD, I'd probably have to read the pamphlet 6 times for it to click. – person with FASD and MH/A challenges.

Finally, the value of peer mentorship as an enabler was underscored. Individuals living with the realities of FASD have a capacity to understand the disorder at a level that far surpasses any professional or service. Continuing to generate opportunities for peer mentorship and relationship-building amongst other individuals living with FASD was seen as useful for both those mentoring and those who are being mentored.

I'd like to advocate a bit more for is some peer mentorship around some of these pieces when we're talking about things specific to people with FASD, we're just finally getting to a place in the field where there's a whole group of adults that have grown up understanding their diagnosis and speaking about their diagnosis, and really have more maturity about understanding their needs and are able to understand each other in a way that no service provider ever will be able to, if you don't live with it you don't understand it to it's really core depth, and I think there's a lot of potential that's not being tapped into right now in terms of people supporting each other, in terms of helping them through some of those strategies, coping mechanisms et cetera. – FASD clinic coordinator

Theme D: Stigma

An unfortunate, recurrent barrier was experiencing stigma towards FASD while seeking MH/A support. Stigma was a common thread that seemed to underlie the other three themes and have many connections with the aforementioned findings. Embedded with many of the narratives within the data was the stigma associated with seeking MH/A help specifically as someone who lives with FASD.

It does feel like as soon as you tell someone in those kind of professions you have FASD, they shush you away. It's like "you're too much for us." – person living with FASD and MH/A challenges.

An individual [with FASD] can't walk into most mental health clinics or clinicians and be really in crisis need, because that's going to get the receptionist to call the police, because they're stigmatized, well "that's not compliance and you need to make an appointment." – FASD clinic coordinator

They don't want to deal with it [FASD], they'd rather just shove us out the door and write a prescription, see you later. – person living with FASD and MH/A challenges.
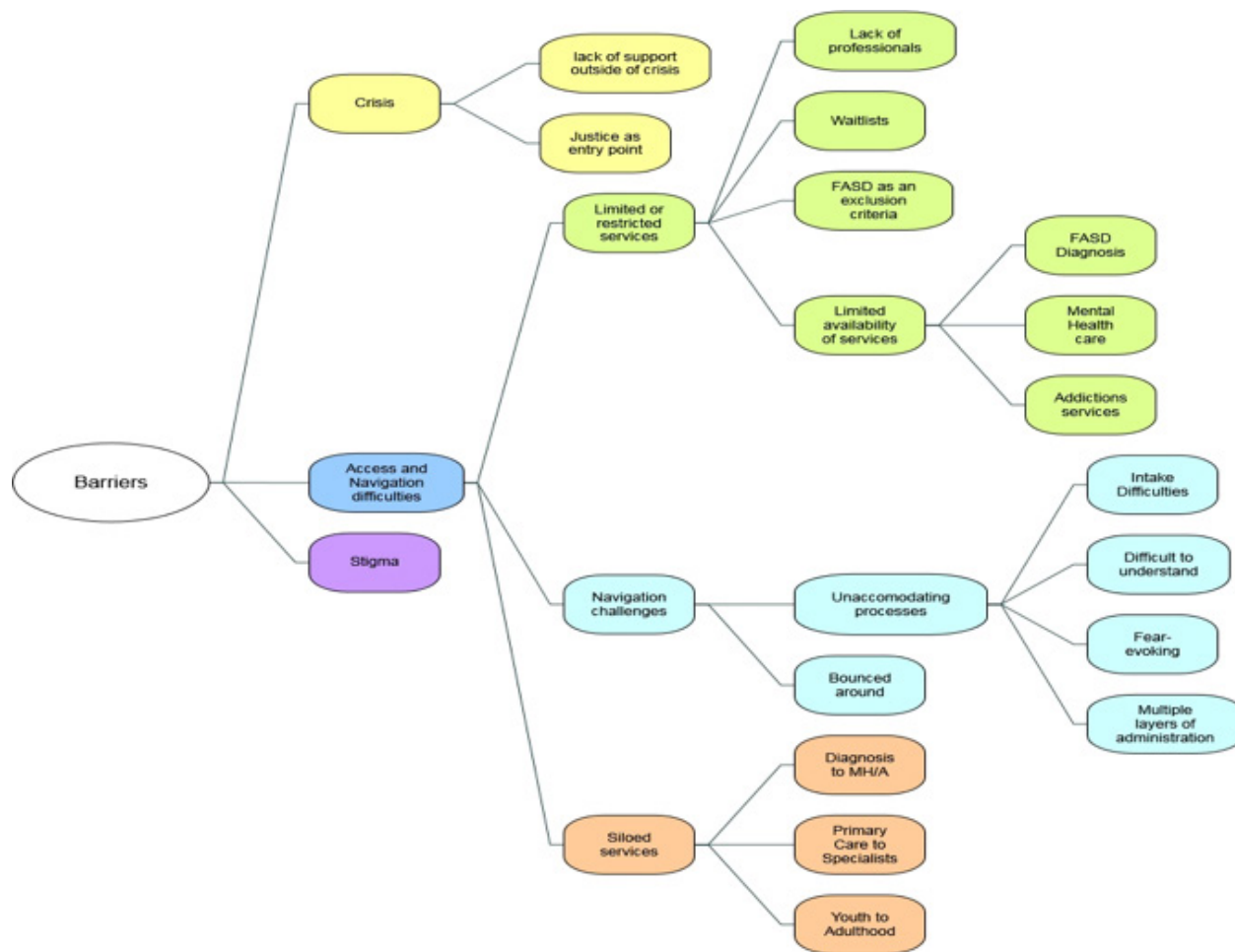
Figure 1

Map of Barriers

Figure 2

Map of Enablers

DISCUSSION

The barriers to the development of a CPW described in Theme A: Support being Primarily in Response to Crisis point to a current situation where too often the entry point for individuals with FASD engaging in MH/A services is only in unavoidable and forced predicaments. Rather than a typical or proactive entry point that would exist in an ideal CPW, individuals are encountering care in extremely inopportune ways. Lack of diagnosis or misdiagnosis of FASD, with rates as high as 85%, contributes to, and aligns with, this unfortunate reality with cost implications (Chasnoff, Wells, & King, 2015). If FASD is poorly recognized, negative outcomes including involvement with the criminal justice system are common (Streissguth et al., 2004; Fast & Conry, 2009). A recent cost-analysis of FASD in Canada revealed that the costs being contributed to corrections for individuals with FASD ($378.3 million) far exceeded the costs for healthcare (between $128.5 and $226.3 million; Popova, Lange, Burd, & Rehm, 2015). The data in this research would support the idea that the imbalance of finances being invested in justice versus health in Canada for those with FASD is indicative of our current state of knowledge, structure, and capacity to effectively support individuals within the healthcare system and in turn avert adverse life consequences.

Many of the barriers encountered in Theme B: Access and Navigation Difficulties are not unexpected as people with MH/A challenges across Canada struggle through a currently strained and trying system (Sunderland & Findlay, 2013). However, individuals being excluded from services on the basis of their FASD diagnosis is disconcerting and points to a direct need for progress. System reform which would guide clinicians to broaden their margins and incorporate the aforementioned relatively new DSM-5 description of FASD will hopefully bring about inevitable inclusion over time (American Psychiatric Association, 2013). However, many of the exclusionary experiences also shed light on a system where clinicians currently do not possess operative therapeutic strategies to have confidence in effectively helping individuals with FASD. Rather than blaming often well-intentioned, albeit undereducated clinicians, our research would support a focus on cultivating understanding of FASD broadly amongst MH/A professionals as a means to bring about great improvements in the usefulness of a more structured approach, such as a CPW. Similar recommendations were made in a study wherein more than 60 experts in a multi-stakeholder symposium identified the need to increase capacity in training, education, and awareness of frontline professionals (Canadian Fetal Alcohol Spectrum Disorder Research Network, 2016).

The data described numerous potential checkpoints through the MH/A journey including encounters with education, social services, justice, health, and community-based organizations (CBOs). It was notable that people's experiences with FASD-specific CBOs often seemed to be described as most beneficial, specifically above the health-based services, despite the CBOs lacking precise MH/A expertise. This finding relates to Theme C: Care needs to be FASD-Informed in that the understanding of FASD was portrayed as a very appealing reason to find support in an FASD-specific CBO. Our study described experiences where discovering a place of understanding and acceptance of FASD was viewed as the most supportive point along the journey. To be FASD-informed is to increase the clinicians' capacity in communication, reflection and action (Tremblay et al., 2017). Perhaps this notion of success reflects the thinking of Moltu et al. (2017) who suggest that often our perspective of assessing improvements of mental health outcomes is "overemphasizing symptomatic distress, and underemphasizing situational, functional and contextual domains of outcomes." Their articulation that "this possible bias points toward a need for developing more knowledge regarding

meaningful outcome concepts for patients with more complex and long-standing suffering" may have relevance for individuals with FASD in that symptomology of mental disorder is likely not the only mental health outcome of prominence for this population (Moltu, Stefansen, Nøtnes, Skjølberg, & Veseth, 2017). When driving towards these more broadly defined outcomes of wellness, progress needs to be made so the outcomes of a CPW would reflect the necessity of a MH/A system with understanding and acceptance of FASD (Paley & O'Connor, 2009).

Again, the presence of Theme D: Stigma is regrettably not surprising. Stigma in relation to mental health care has been discussed at length elsewhere (Corrigan, 2004) and the implications of stigma towards MH/A reducing care-seeking and full participation in care is likely pertinent in this context as well. However, of greater note based on our data, was the stigma that seemed to be associated with having FASD while seeking support from the MH/A systems. The barriers created by stigma towards FASD that were encountered from amidst the clinical settings seemed to be the most prominent. The stigma described in our data has consistent threads with the Descriptive Model of Stigma for FASD that Bell et al. (2015) put forth in their exploration of ethical implications of stigma around FASD and public health (Bell et al., 2015). More specifically, in their theme they title "Anticipated life trajectories for individuals with FASD" where they unpack these stigmatized perceptions and state: "Beliefs that anticipated negative life trajectories are unavoidable lets the community, social and health systems off the hook" (Bell et al., 2015). The falsehood that people with FASD can't be helped anyway, which was incorrectly, but commonly, expressed in the experiences within our data, agrees with these ideas expressed by Bell et al. (2015). The professionals who hold these improper beliefs may feel that they have a limited responsibility to effectively care for individuals with FASD, and may therefore ignore the need to better understand how to provide FASD-informed care.

LIMITATIONS

We acknowledge a number of limitations in this study. The first is that although qualitative methodology is effective for generating themes and capturing lived experiences, generalizations of the findings cannot be made. Furthermore, qualitative focus groups, especially homogeneous ones, can have the potential to generate a dominant narrative where participants offer their contributions that support that narrative rather than capturing the holistic picture. Therefore, although the data collected demonstrated a number of insufficiencies within the participants' experiences of MH/A, these certainly cannot be assumed broadly for generalized areas, services, or subpopulations. The data only reflects the experiences of small, non-sample groups and the participants were from a variety of settings. More intensive and quantifiable investigations would be required to specifically describe geographical, service-based, or demographic indications. Secondly, by recruiting through CBOs and FASD clinics, the participants already represent a group that are likely better supported than many others with FASD. The commonality of individuals with FASD experiencing isolation and not interfacing with service providers means that there are perspectives that have been missed by this research because of recruitment being based solely in support services. Lastly, because of the exploratory beginning and larger-picture nature of the thematic analysis done in this study, it is difficult to draw specific targeted recommendations. To address this limitation and provide a more comprehensive reflection of the various recommendations that arose in this data (such as specific recommended FASD-informed care practices), a second phase of this research has been undertaken. This follow-up component developed specific

one-sentence statements and assessed clinician's levels of agreement on the ability of each recommendation to improve MH/A outcomes for individuals with FASD.

CONCLUSIONS

This study sought to better understand the feasibility of development of a CPW for individuals with FASD who experience MH/A challenges by assessing the barriers and enablers to the development of a CPW. Reviews of the literature caution against CPWs being seen as an effective solution in every situation (Allen, Gillen, & Rixson, 2009; Panella et al., 2003; Vanhaecht et al., 2012). In a systematic review investigating the effectiveness of CPWs, it was concluded that CPWs are more useful in situations where patients are on predictable trajectories and where insufficiencies in services are recognized (Allen et al., 2009). Based on the results of this research, progression within existing MH/A structures towards more FASD-informed care is a primary need. Our data points to the idea that many of the essential checkpoints in a CPW could be improved by targeting the obstacles associated with individuals with FASD receiving effective care. This study seems to suggest that currently, resources would be usefully allocated towards addressing the barriers and enhancing the enablers before a CPW would have wide-ranging utility in this population. The themes of this research emphasize the prevention of crises associated with MH/A, improving the understanding of FASD amongst professionals to aid in the implementation of FASD-informed care, addressing issues related to access and navigation, and continuing to fight against stigmatized approaches to individuals with FASD.

REFERENCES

Alati, R., Al Mamun, A., Williams, G. M., O'Callaghan, M., Najman, J. M., & Bor, W. (2006). In utero alcohol exposure and prediction of alcohol disorders in early adulthood: A birth cohort study. *Archives of General Psychiatry, 63*(9), 1009–1016.

Al-Busaidi, Z. Q. (2008). Qualitative research and its uses in health care. *Sultan Qaboos University Medical Journal, 8*(1), 11–19.

Allen, D., Gillen, E., & Rixson, L. (2009). Systematic review of the effectiveness of integrated care pathways: What works, for whom, in which circumstances? *International Journal of Evidence-Based Healthcare, 7*(2), 61–74.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-V* (5th ed.). Washington, DC: American Psychiatric Association.

Anderson, T., Mela, M., & Stewart, M. (2018). The implementation of the 2012 mental health strategy for Canada through the lens of FASD. *Canadian Journal of Community Mental Health*.

Badry, D. E., & Bradshaw, C. M. (2011). *Assessment and diagnosis of FASD among adults: A national and international systematic review*. Public Health Agency of Canada.

Baker, R., Camosso-Stefinovic, J., Gillies, C., Shaw, E. J., Cheater, F., Flottorp, S., & Robertson, N. (2010). Tailored interventions to overcome identified barriers to change: Effects on professional practice and health care outcomes. *The Cochrane Library*.

Bell, E., Andrew, G., Di Pietro, N., Chudley, A. E., N. Reynolds, J., & Racine, E. (2015). It's a shame! Stigma against fetal alcohol spectrum disorder: Examining the ethical implications for public health practices and policies. *Public Health Ethics, 9*(1), 65–77.

Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide*: Sage.

Brown, J., Herrick, S., & Long-McGie, J. (2014). Fetal alcohol spectrum disorders and offender reentry: A review for criminal justice and mental health professionals. *Behavioral Health, 1*(1), 1–19.

Butow, P., Price, M. A., Shaw, J. M., Turner, J., Clayton, J. M., Grimison, P., … Kirsten, L. (2015). Clinical pathway for the screening, assessment and management of anxiety and depression in adult cancer patients: Australian guidelines. *Psycho-Oncology, 24*(9), 987–1001.

Campbell, H., Bradshaw, N., & Porteous, M. (1998). Integrated care pathways. *BMJ*. 316: 133–144.

Canadian Fetal Alcohol Spectrum Disorder Research Network. (2016). Learning together. Retrieved from https://canfasd.ca/learning-together/

Centre for Addiction and Mental Health. (2016). Integrated care pathways. Retrieved from http://www.camh.ca/en/hospital/care_program_and_services/ICPs/Pages/default.aspx

Chasnoff, I. J., Telford, E., Wells, A. M., & King, L. (2015). Mental health disorders among children within child welfare who have prenatal substance exposure: Rural vs. urban populations. *Child Welfare, 94*(4), 53.

Chasnoff, I. J., Wells, A. M., & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics, 135*(2), 264–270.

Cisco, 2017. WebEx. Retrieved from https://www.webex.ca/en/

Corrigan, P. (2004). How stigma interferes with mental health care. *American Psychologist, 59*(7), 614.

D'Entremont, B. (2009). Clinical pathways: The Ottawa Hospital experience. *The Canadian Nurse, 105*(5), 8–9.

Fast, D. K., & Conry, J. (2009). Fetal alcohol spectrum disorders and the criminal justice system. *Developmental Disabilities Research Reviews*, *15*(3), 250–257.

French, S. D., Green, S. E., O'Connor, D. A., McKenzie, J. E., Francis, J. J., Michie, S., … Grimshaw, J. M. (2012). Developing theory-informed behaviour change interventions to implement evidence into practice: A systematic approach using the Theoretical Domains Framework. *Implementation Science, 7*(1), 38.

Fluid Surveys. (2017). Online websurveys. Retrieved from http://fluidsurveys.com/

Gibson, O., Lisy, K., Davy, C., Aromataris, E., Kite, E., Lockwood, C., … Brown, A. (2015). Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: A systematic review. *Implementation Science, 10*(1), 71.

Goodman, D., Pivarnyik, S., & Lwin, K. (2014). Appendix 2: Inventory of Canadian FASD services & resources: Regional analysis. Toronto: Child Welfare Institute, Children's Aid Society of Toronto.

Government of Saskatchewan. (2017). Using Patient Pathways. Retrieved from http://www.sasksurgery.ca/provider/patientpathways.html

Himmelreich, M., Lutke, C., & Travis, E. (2017). The lay of the land: Final results of a health survey of 500+ adults with diagnosed FASD. Paper presented at the 7th International Conference on Fetal alcohol spectrum disorders.

Kitzinger, J. (1994). The methodology of focus groups: The importance of interaction between research participants. *Sociology of Health & Illness, 16*(1), 103–121. doi:10.1111/1467-9566.ep11347023

Liamputtong, P. (2011). *Focus group methodology: Principle and practice:* Sage Publications.

Lockhart, P. J. (2001). Fetal alcohol spectrum disorders for mental health professionals – a brief review. *September 2001, 14*(5), 463–469.

Martin, P. Y., & Turner, B. A. (1986). Grounded theory and organizational research. *The Journal of Applied Behavioral Science, 22*(2), 141–157.

McCluskey, A., Vratsistas-Curto, A., & Schurr, K. (2013). Barriers and enablers to implementing multiple stroke guideline recommendations: A qualitative study. *BMC Health Services Research, 13*(1), 323.

Moltu, C., Stefansen, J., Nøtnes, J. C., Skjølberg, Å., & Veseth, M. (2017). What are "good outcomes" in public mental health settings? A qualitative exploration of clients' and therapists' experiences. *International Journal of Mental Health Systems, 11*(1), 12.

Morgan, D. L. (1996). Focus groups. *Annual Review of Sociology, 22*(1), 129–152. doi:10.1146/annurev.soc.22.1.129

Nielsen, A. S., & Nielsen, B. (2015). Implementation of a clinical pathway may improve alcohol treatment outcome. *Addiction Science & Clinical Practice, 10*(1), 1.

O'Connor, M. J., & Paley, B. (2009). Psychiatric conditions associated with prenatal alcohol exposure. *Developmental Disabilities Research Reviews, 15*(3), 225–234.

Paley, B., & O'Connor, M. J. (2009). Intervention for individuals with fetal alcohol spectrum disorders: Treatment approaches and case management. *Developmental Disabilities Research Reviews, 15*(3), 258–267.

Panella, M., Marchisio, S., & Di Stanislao, F. (2003). Reducing clinical variations with clinical pathways: Do pathways work? *International Journal for Quality in Health Care, 15*(6), 509–521.

Paradis, E., O'Brien, B., Nimmon, L., Bandiera, G., & Martimianakis, M. A. (2016). Design: Selection of data collection methods. *Journal of Graduate Medical Education, 8*(2), 263–264. doi:10.4300/jgme-d-16-00098.1

Pei, J., Denys, K., Hughes, J., & Rasmussen, C. (2011). Mental health issues in fetal alcohol spectrum disorder. *Journal of Mental Health, 20*(5), 473–483.

Popova, S., Lange, S., Burd, L., & Rehm, J. (2015). *The burden and economic impact of fetal alcohol spectrum disorder in Canada*: Toronto, ON, Canada: Centre for Addiction and Mental Health.

Popova, S., Lange, S., Shield, K., Mihic, A., Chudley, A. E., Mukherjee, R. A., … Rehm, J. (2016). Comorbidity of fetal alcohol spectrum disorder: A systematic review and meta-analysis. *The Lancet, 387*(10022), 978–987.

Rankin, N. M., Butow, P. N., Thein, T., Robinson, T., Shaw, J. M., Price, M. A., … Grimison, P. (2015). Everybody wants it done but nobody wants to do it: An exploration of the barrier and enablers of critical components towards creating a clinical pathway for anxiety and depression in cancer. *BMC Health Services Research, 15*(1), 1.

Rotter, T., Kinsman, L., James, E., Machotta, A., Gothe, H., Willis, J., … Kugler, J. (2010). Clinical pathways: Effects on professional practice, patient outcomes, length of stay and hospital costs. *Cochrane Database Syst Rev, 3*(3).

Rotter, T., Kinsman, L., James, E., Machotta, A., Willis, J., Snow, P., & Kugler, J. (2011). The effects of clinical pathways on professional practice, patient outcomes, length of stay, and hospital costs: Cochrane systematic review and meta-analysis. *Evaluation & the Health Professions*, 0163278711407313.

Rotter, T., Kinsman, L., Machotta, A., Zhao, F. L., van der Weijden, T., Ronellenfitsch, U., & Scott, S. D. (2013). Clinical pathways for primary care: Effects on professional practice, patient outcomes, and costs. *The Cochrane Library*.

Shaw, J. M., Price, M. A., Clayton, J. M., Grimison, P., Shaw, T., Rankin, N., & Butow, P. N. (2016). Developing a clinical pathway for the identification and management of anxiety and depression in adult cancer patients: aAn online Delphi consensus process. *Supportive Care in Cancer, 24*(1), 33–41.

Smith, T. J., & Hillner, B. E. (2001). Ensuring quality cancer care by the use of clinical practice guidelines and critical pathways. *Journal of Clinical Oncology, 19*(11), 2886–2897.

Stewart, D. W., Shamdasani, P. N., & Rook, D. W. (1990). Focus groups: Theory and practice. Applied social research methods series. *Focus groups: theory and practice applied social research methods series*.

Streissguth, A., Barr, H., Kogan, J., & Bookstein, F. (1996). Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). *Final report to the Centers for Disease Control and Prevention (CDC)*, 96–06.

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

Sunderland, A., & Findlay, L. C. (2013). Perceived need for mental health care in Canada: Results from the 2012 Canadian Community Health Survey–Mental Health. *Health Reports, 24*(9), 3.

Tough, S. C., Clarke, M., & Hicks, M. (2003). Knowledge and attitudes of Canadian psychiatrists regarding fetal alcohol spectrum disorders. *The Canadian Child and Adolescent Psychiatry Review, 12*(3), 64.

Travers, C., Martin-Khan, M., & Lie, D. (2009). Barriers and enablers of health promotion, prevention and early intervention in primary care: Evidence to inform the Australian national dementia strategy. *Australasian Journal on Ageing, 28*(2), 51–57.

Tremblay, M., Pei, J., Plesuk, D., Muchortow, A., Mihai, P., & Jordao, R. (2017). Development of a Clinical Practice Model for Serving Clients with Fetal Alcohol Spectrum Disorder. *International Journal for the Advancement of Counselling, 39*(1), 82–97.

Vanhaecht, K., Bollmann, M., Bower, K., Gallagher, C., Gardini, A., Guezo, J., … Sermeus, W. (2006). Prevalence and use of clinical pathways in 23 countries—an international survey by the European Pathway Association. *Journal of Integrated Pathways, 10*(1), 28–34.

Vanhaecht, K., Ovretveit, J., Elliott, M. J., Sermeus, W., Ellershaw, J., & Panella, M. (2012). Have we drawn the wrong conclusions about the value of care pathways? Is a Cochrane review appropriate? *Evaluation & the Health Professions, 35*(1), 28–42.