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Caring for Children and Youth with Ongoing Mental Health Problems: Perspectives of Family Physicians, Nurse Practitioners, Social Workers and Psychologists in Primary Health Care

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ABSTRACT

Few studies have examined a diversity of professionals' perspectives in providing children's mental health (CMH) care, particularly for ongoing-complex problems. Based on interviews with 16 primary healthcare (PHC) providers, care for ongoing-complex CMH problems depended on provider interest and scope of practice. Most providers felt PHC is where ongoing-complex CMH problems should be cared for, where providers can emphasize advocacy, coordination, and ongoing monitoring; few felt able to provide this type of care. A comprehensive approach for incorporating PHC with specialized MH services is needed. Defining a care coordinator would be a clear step toward improving collaboration and care.

Keywords: children's mental health, children, adolescents, youth, qualitative, psychology, primary care, ongoing mental health problems, complex mental health problems

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RÉSUMÉ

Peu d'études se sont penchées sur les différents points de vue des professionnels impliqués dans la prestation de soins de santé mentale chez les enfants (SME), notamment pour ce qui est des problèmes jugés complexes et permanents. À la lumière d'entretiens réalisés auprès de 16 prestataires de soins de santé primaires (SSP), il apparaît que la prise en charge des problèmes complexes et permanents de SME dépend de l'intérêt du prestataire de soins et de son champ de pratique. La plupart des prestataires de soins estiment que les SSP sont la sphère de services où les problèmes complexes et permanents de SME doivent être traités, et où les prestataires de soins peuvent mettre l'emphase sur la promotion, la coordination et le suivi permanent. Mais peu de prestataires se sentent en mesure de fournir ce type de soins. Une approche globale s'avère donc nécessaire pour intégrer les SSP aux services spécialisés en santé mentale. L'institution d'un coordinateur de soins constituerait une étape déterminante vers un renforcement de la collaboration entre les prestataires de soins et une amélioration des soins à proprement parler.

Mots clés : santé mentale des enfants; enfants; adolescents; jeunes; qualitatif; psychologie; soins primaires; problèmes de santé mentale permanents; problèmes de santé mentale complexes

The literature on children's mental health (CMH) problems suggests that a sizable percentage of children (0–18 years) may have ongoing mental health (MH) problems (Epstein, Kutash, & Duchnowski, 2005). For example, ongoing problems with depression occur for 10–18% of children, and for anxiety, 41–66% (Schraeder & Reid, 2017). Recurrence rates for depression are 50–70% in natural history studies, and 15–47% of children have a relapse following treatment (Schraeder & Reid, 2017). ADHD may also persist (Faraone, Biederman, & Mick, 2006), with 28–60% of children having problems for years (Bussing, Mason, Bell, Porter, & Garvan, 2010; Hurtig et al., 2007; Lecendreux, Silverstein, Konofal, Cortese, & Faraone, 2019). About 20% of children have ongoing problems related to oppositional-defiant behaviour (Boylan, Vaillancourt, Boyle, & Szatmari, 2007); further, about 50% of children with these types of problems go on to develop other types of MH problems years later (Christenson, Crane, Malloy, & Parker, 2016).

In recent studies of children receiving specialized MH care from community-based agencies in Ontario, Canada, we found (1) 20% of children will experience two or more episodes of care within a 5-year period, and (2) 19% of children are involved with a CMH agency for more than three and a half years from the date of their initial visit (Reid, Stewart, Barwick, Carter, et al., 2019; Reid, Stewart, Barwick, Cunningham, et al., 2020). From studies on the natural history of psychopathology and MH service use, we estimate that about one out of every five children receiving specialized MH care could be viewed as requiring complex (i.e., receiving services from multiple sectors) and/or ongoing care (i.e., receiving care for extended periods of time). We know very little, however, about how best to care for these individuals and perhaps even less about the role primary healthcare (PHC) providers can play.

CMH has been labelled the "orphan's orphan" of Canada's healthcare system (The Standing Senate Committee on Social Affairs, 2006). There is an urgent need to improve the evidence base for CMH care in Canada (Mental Health Commission of Canada, 2012). In Canada, "access to the right combination of services, treatments, and supports, when and where people need them" is a strategic direction for MH care (Mental Health Commission of Canada, 2012). Children with MH problems can receive care from multiple sectors, adding to the complexity of understanding what constitutes "the right combination" of treatment(s).

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For example, in Ontario, CMH care is provided within five sectors with different funding sources: health, specialized MH (either publicly or privately funded), education, juvenile justice, and child welfare (Duncan, Boyle, Abelson, & Waddell, 2018; Martin et al., 2018).

Studies of help-seeking and CMH services repeatedly demonstrate cross-sectoral involvement (Reid, Cunningham, et al., 2011; Schraeder, Reid, & Brown, 2018; Shanley, Reid, & Evans, 2008). In a study of 300 children recruited from Ontario CMH agencies, the most common pattern was involvement with MH, health, and education (45%); 21% of families were involved with four or all five of the sectors providing CMH care (Reid, Cunningham, et al., 2011). Similarly, data from the Great Smoky Mountains Study in the United States indicated that nearly 50% of children and youth receiving CMH care used services from more than one sector; nearly a third of CMH service users received services from the health sector (Farmer, Burns, Phillips, Angold, & Costello, 2003).

When trying to obtain help for children with MH problems, family physicians (FP) are commonly the first health professional that parents turn to, and physician referral is a common pathway to obtaining specialized MH care (Angermeyer, Matschinger, & Riedel-Heller, 1999; MacDonald, Fainman-Adelman, Anderson, & Iyer, 2018; Ronis, Slaunwhite, & Malcom, 2017; Zwaanswijk, Van der, Verhaak, Bensing, & Verhulst, 2005). New strategies for improving access to services have often focused on integrating CMH into primary care (Wissow, van Ginneken, Chandna, & Rahman, 2016). However, difficulties in collaborating between professionals in caring for children with MH problems have been reported by primary care providers (PCPs; Pryjmachuk, Graham, Haddad, & Tylee, 2011; Stiffman et al., 2009). Fredheim and colleagues (2013) surveyed FPs, nurses, and psychiatric residents and found that effective communication between FPs and specialist MH professionals was recognized as a core element in effective collaboration. Some studies have examined collaborations between PHC and other sectors providing CMH services, and the need for collaborative care between sectors has been raised previously (Grimes, Kapunan, & Mullin, 2006). Recent data from an epidemiological study of MH problems and service use in Ontario (Georgiades et al., 2019) highlight the magnitude of this issue; 10.6% of parents of 4–17-year-olds reported contacting a family physician with concerns about their child's MH and 5.9% reported contact with a child and youth mental health service (CYMHS) agency (Reid et al., 2020). Despite initiatives aimed at enhancing collaborations, studies have rarely been conducted in Canada (Canadian Collaborative Mental Health Initiative, 2006). Thus, understanding the role of PHC as part of the systems that care for children and youth with MH problems is critical.

New models of PHC in Ontario should enhance access to MH services, as social workers and psychologists have been included in Family Health Teams (Ashcroft, 2015; Ashcroft, Silveira, & Mckenzie, 2016; Grenier, Chomienne, Gaboury, Ritchie, & Hogg, 2008). Studies have shown that integrating mental health care into PHC can improve access to (Rapp, Chavira, Sugar, & Asarnow, 2017) and delivery of (Walter et al., 2019) MH services. A systematic review indicated that FPs with access to an in-house MH professional reduced the likelihood of the FP prescribing psychotropic medications or referring patients to specialist psychiatric care (Bower & Sibbald, 2000). This may help to reduce the burden on families to coordinate care across sectors and improve continuity of care. Recently, de Voursney and Huang (2016) suggested that a "health home" (i.e., a patient-centred medical home in Canada; College of Family Physicians of Canada, 2019) is needed for coordination of care for children and youth with MH problems. However, their article

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suggests that care coordination is needed for *all* children and youth with MH problems. Our CMH systems face significant challenges, and multiple perspectives need to be considered (Reid & Brown, 2008). It is unlikely that *all* children with MH problems require care coordination. Rather, those in highest need should be identified and a coordinated response should be enacted, which has not been the case even in areas where care consistent with a health home model has been implemented (Yonek, Jordan, Dunlop, Ballard, & Holl, 2018). Many children with mild disorders are effectively cared for solely in PHC (Rushton, Bruckman, & Kelleher, 2002). Children with ongoing-complex care needs may be more likely to require specialized MH services, but there is limited literature regarding how PCPs view ongoing-complex MH problems as applied to children, or their roles in caring for children with these MH problems (Storm, Hausken, & Knudsen, 2011). Thus, the aim of this study was to examine the perspectives of FPs and other team-based PCPs (nurse practitioners, social workers, psychologists) in Ontario with respect to caring for children with ongoing-complex MH problems.

We framed our discussion with these providers by focusing on all types of MH problems other than care for children with developmental disabilities and autism. It is well known that children with intellectual or developmental disorders have ongoing care needs, that models of care exist for these conditions, and that there are a number of studies related to service use over multiple years for children with these disorders (Lai & Weiss, 2017; Lubetsky, Handen, Lubetsky, & McGonigle, 2014; Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher, 2016). However, we know far less about ongoing care needs for children with other types of mental health problems. In this study, we sought to determine how and if providers in team-based PHC for children and youth with ongoing/complex MH problems, how these providers conceptualized ongoing/complex MH problems among children and youth, and the role these providers felt they should play in the management of these cases in the overall system of care.

METHODS

This study used a descriptive, qualitative method to explore the perceptions and practice experiences of PHC providers in their care of children and youth with ongoing/complex MH problems. This qualitative approach allows for a detailed description and understanding of the issue under inquiry, often on a phenomenon that has received limited attention in the literature (Sandelowski, 2000; 2010). Furthermore, this methodological approach facilitates identification and classification of the study participants' behaviours and experiences (Liamputtong, 2013).

Recruitment

Participants (FPs, nurse practitioners, social workers, and psychologists) were recruited from interdisciplinary PHC teams within southwestern Ontario using the authors' network of contacts and snowball sampling (i.e., participants forwarded study details to their colleagues). A letter of information was sent to potential participants and interested parties contacted the researchers via email. All interested providers were interviewed. After obtaining informed consent, participants completed a 45–60 minute semi-structured telephone interview conducted by GR or a research assistant. All the interviews were audiotaped and transcribed

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verbatim. Participants received a $40 gift certificate in appreciation for their participation. The study was approved by the ethics board of The University of Western Ontario (#103086).

Data Collection

The interview guide was developed specifically for this study, drawing on the research team's experience in children's mental health and primary care. This includes previous research, along with work being done at the same time the current study was conducted, including patient care in family medicine (Stewart et al., 2014); help-seeking experiences for children with mental health problems (Reid, Cunningham, et al., 2011; Shanley, Reid, & Evans, 2008); continuity of care in children's mental health (Tobon, 2013); parent perspectives on causes of their child's mental health problems (Shanley, 2008; Shanley et al., 2013); issues within the children's mental health sector (Reid & Brown, 2008); and children's mental health service use over extended periods of time (Reid et al., 2015). It was also informed by earlier work related to the experiences of adolescents and young adults with chronic physical health conditions such as congenital heart disease (Reid et al., 2004, 2008). Based on our knowledge and experience, we generated questions to draw out key themes related to perceptions of ongoing-complex MH conditions among children and youth, and issues related to care within primary care and with cross-sectoral collaboration.

Interviews inquired about (a) the participant's role within the PHC practice, and how child and youth MH problems were managed in the practice; (b) reflections on the types of problems or conditions that would constitute a child or youth with ongoing-complex MH problems; (c) collaborations with other sectors (i.e., specialized CMH including private providers, education, juvenile justice, child welfare); and (d) ways that children with ongoing-complex MH problems should be cared for. Probes were used to ensure providers considered all aspects of MH care (e.g., detection, referral, assessment, diagnosis, medication prescription and management, counselling parents and/or children). Coordination of care and monitoring are two activities that are commonly provided within PHC for chronic physical health conditions (Bodenheimer, Wagner, & Grumbach, 2002). If these notions were not mentioned spontaneously by participants, their thoughts on providing this in caring for children with ongoing-complex MH problems were probed. Interviewers also probed for provider successes and challenges in collaborating with other sectors. We asked participants to think about care for children with ongoing-complex MH problems based on our operational definition: (a) individuals whose problems would commonly last more than 2 years and/or be likely to reoccur as ongoing and (b) who are receiving services from 3 or more of the 5 sectors (health, specialized MH, education, juvenile justice and child welfare) involved in CMH care as being complex. We focused on the care of children or youth (up to age 18 years) with academic, behavioural, emotional, psychological, or social functioning problems. Developmental problems (e.g., autism) were not considered, as these problems are already recognized as chronic and treatment recognizes the need for ongoing care.

Data Analysis

The researchers conducted a thematic analysis of the transcripts which was both iterative and interpretative (Liamputtong, 2013). A PhD in psychology (GR) and a master in psychology (research assistant) conducted the interviews, plus a PhD in social work participated in the iterative analysis of the verbatim

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transcripts. All three have expertise in children's mental health and primary care. First, the researchers independently reviewed the transcripts to begin identifying and classifying the participants' behaviours and experiences (Liamputtong, 2013). They then met as a team to collectively compare and discuss their independent analysis. This led to the generation of categories and themes. The final iteration of the analysis focused on themes identified from the data as a whole with summaries for each main theme and exemplar quotations. As the study had a fairly narrow focus, with a specific group of participants, run by researchers with a strong background and understanding of mental health services in primary care, our modest sample of 16 gave us sufficient information power (Malterud, Siersma, & Guassora, 2016). After identifying themes and exemplar quotes across all providers, we went back and re-examined the data, focusing on differences among providers. Social workers and psychologists have much more extensive training related to MH problems and their treatment compared to physicians and nurse practitioners. As such, we specifically looked for differences between social workers and psychologists compared to FPs and nurse practitioners.

Trustworthiness and credibility. Trustworthiness and credibility were ensured by using audio-recorded and verbatim transcripts, independent and team analysis, and detailed field notes following each interview. Having the verbatim transcripts assisted the researchers in staying true to the data. The individual and team analysis protected against research bias and over-interpretation of the data during the iterative analysis. A commitment to reflexivity considered how the researchers' professional backgrounds (i.e., psychology, social work, and anthropology), particularly in the coding and interpretation of the data, could influence the analysis (Malterud, 2001). By collectively reflecting on their own experiences and training, the researchers gave the data prominence.

Final Sample

A total of 16 participants (13 females; age 30–65 years old) were interviewed. Participants included FPs (n = 5), nurse practitioners (NP, n = 4), psychologists (Psych, n = 2), and social workers (SW, n = 5). Participants are reported by their discipline designation and code number. Providers had been in practice for an average of 13 years, ranging from 2 to 34 years.

Participants all worked as part of interdisciplinary PHC teams caring for, on average, about 12,000 patients (SD = 11,555); however, some providers were unable to estimate the total number of patients in the practice. On average, the practices included seven FPs (SD = 4.9), three full-time nurses (SD = 2.9) and one part-time nurse (SD = 1.2), and one full-time NP (SD = 1.0), although not all practices had an NP. On average, practices had one full- and one part-time social worker. Only two of the non-psychologist providers reported that they had a psychologist as part of the team. Six participants reported that a psychiatrist was also part of their practice, either on a part-time or shared-care basis.

FINDINGS

As participants described how they managed the care of children with MH problems in their practices, an overarching theme that emerged was that the management of these patients was seen as complex and multi-faceted. When discussion focused on children with ongoing-complex MH problems specifically, these ideas were expressed even more strongly. These patients often required multiple resources, ongoing monitoring,

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and coordination between providers and across sectors. However, participants strongly expressed how the systems of care were not amenable to appropriately providing these resources and coordination. Areas of concern articulated by participants included a lack of timely access to treatment, suboptimal navigation of patients through services, and limited cross-sectoral collaboration.

Defining the PHC Context for Children and Youth with Ongoing or Complex MH Problems

In order to frame the participants' experiences in managing the care of children with ongoing-complex MH problems, it was important to understand their practice context and views, including (1) their definition of ongoing-complex MH problems; and (2) their experience in caring for children with ongoing-complex MH problems in the PHC context.

Defining ongoing or complex MH problems. Four aspects emerged as features defining ongoing-complex MH problems. Two aspects—duration of the problem and multiple contributing factors—were raised by many participants, and two other aspects—comorbidities (physical and MH) and cross-sectoral care—were raised by a number of participants.

For most participants and across all four types of providers, ongoing MH issues referred primarily to chronicity. "I think like the chronic pain definition… a kind of behavioural issue or a psychiatric issue that goes on beyond three months, I would kind of start seeing that as a chronic issue" (FP #4). When other providers mentioned duration of care, FPs and nurses mentioned 3 or 6 months, while social workers and psychologists mentioned "years."

Participants from all professions described complex MH cases as those that involved multiple factors contributing to the MH problem, which cut across multiple areas of the child's life.

> There's all sorts of factors that are putting the child at risk. So there's issues within the family…, social issues in the school, learning disabilities… (SW #3).

> You've got the whole range, from biological to social and everything in between, plus these elements of what predisposed, precipitated and perpetuated the issues. (FP #3)

> …coupled with psychosocial, environmental factors… trauma, developmental trauma, problems within the family of origin, …family psychiatric history, …I expect that there's things happening within their family environment as well as potentially genetic predisposition to mental health problems. (Psych #2)

> …so often, the child [symptoms are] a symptom of family difficulties, and there's no question that children with difficulties are an issue for the whole family. …abuse…marital breakups …so, my approach, or my thinking, or the model or the framework that I think about these things is within the family context, basically. (FP #3)

Descriptions of complex MH also included the degree to which other MH or physical comorbidities were involved. Across all providers, the presence of multiple MH problems signalled a complex problem. "I'd also maybe define complex as other issues, like they have ADHD but do they also have bipolar… or bipolar with addictions on top of that, or schizophrenia with addictions on top of that" (NP #3). Having both MH and physical health problems was seen as complex by at least one of each type of provider, with the exception of FPs.

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Social workers noted the involvement of multiple sectors as a defining feature of complex MH problems. "Eventually, children's aid as well as wraparound became involved.… And this child literally had every agency involved" (SW #1). "School…. physician appointments or psychiatry appointments… criminal justice system or some other services" (SW #5).

Finally, some of the FPs, nurses, and psychologists struggled with what would uniquely define an MH problem as ongoing-complex. "It depends, because any MH disorder can be chronic and ongoing if not properly treated… I really just see anything having the potential to develop into a chronic presentation" (Psych #2). "So I think I'm different than my colleagues because I would say all mental health is complex and ongoing" (FP #2). Of note, one social worker commented on possible issues with labelling.

> Longstanding, sort of prolonged mental health complex piece, I don't even know, I guess it scares me so much, I don't know how much I spend time thinking about it because I worry about the attachment of that label to a child at that age, … it's… establishing what symptoms exist, versus normal child behaviour… I think that we maybe don't always do a good job of teasing those things out, and kids end up with that label very early on in life and what that's going to mean for them. (SW #2)

Caring for children and youth with ongoing or complex MH problems in PHC. PHC was seen as the place where children with ongoing-complex MH problems would present, most often to the FP or NP. All participants stated they played roles in providing MH care for this population, including assessment and treatment. Social workers and psychologists would typically receive referrals from the FP or NP; they provided supportive care and case coordination when cases were referred outside of the practice, and also consulted on cases within the practice. Counselling provided by FPs and NPs was often limited to supportive counselling, with ongoing management of prescriptions by FPs and NPs, when within their scope of practice; however, there were varying levels of comfort in managing these patients before referring them for assessment/diagnosis or management, beyond initially providing support.

Though there was variability in the problems seen in participant practices, problems with mood and anxiety were routinely cared for within PHC, whereas issues such as psychosis or other "severe" types of psychopathology were typically referred to other MH providers outside of PHC.

> …anxiety, depression, even looking at self-harm, suicidality, grief and loss, peer issues… being bullied, family issues, those are all things I do. …if it's around divorce or peer issues, that's within my scope. But if a child has severe emotional or behavioural issues I would usually refer that to a specialist. (SW #4)

What constituted a "severe" MH problem varied across participants, but not specifically by profession. For example, an FP said, "If I had an OCD [obsessive compulsive disorder] child, I would have to look for help…I wouldn't know what to do" (FP #4). Both FPs and social workers said they would refer cases with psychosis or bi-polar disorder, while some social workers said they would refer cases with anxiety, ADHD or suicidal ideation—"I mean, of course I'd stabilize them, but I would connect them with mental health services at the hospital" (SW #3).

Participants perceived their scope of practice and experience as influencing the degree to which they provided CMH care, or the problems they would manage within their practice. Some NPs, psychologists and social workers all commented that it was rare for them to provide care for young children (i.e., preschool-age children or infants) with MH problems. "We do provide [care for] all ages, but we restrict based on our own personal experience and qualifications. Neither one of us [social workers] feels comfortable working

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with children under the age of [about] four" (SW #3). Other providers reported feeling competent to work with youth, but not children.

NPs and psychologists reported their scope of practice as being limited by their regulatory body or areas of competence. For NPs, this most often affected medication prescription and management. "At this point, nurse practitioners cannot prescribe controlled substances, so I cannot initiate or renew the ADHD medication" (NP #4).

Of note, one social worker and one psychologist each shared that they had experienced pressure to see cases that they felt were outside of their expertise. It was "a girl, about 16, and [I'm not going to] treat them, I'm not doing a formal assessment.… But the physician wanted, you know a more informal, 'am I on the right track… is it worth putting a referral through?' So I did see them and I made it clear that I wouldn't provide ongoing services… one of the struggles with primary care is your limits are sometimes pushed" (Psych #1).

In contrast to social workers and psychologists, physicians' scope of practice was defined more by individual preferences related to treating CMH problems, perceived competence, and/or willingness to seek additional training; some considered CMH an area of interest, while others were more likely to refer cases to others. "I've been interested in MH for a long time and so I don't make a referral right away for almost anybody" (FP #1). Only FPs mentioned seeking additional training: "So I was referring out often and getting, trying to get, consultations often. When you realize that the system that you're working in isn't as responsive or nimble, that forces you to seek out extra training…" (FP #2).

Management of Children and Youth with Ongoing or Complex MH Problems in PHC

Participants articulated two priority areas in the management of children with ongoing-complex MH problems: advocacy/coordination, and monitoring and follow-up.

Advocacy and coordination. Physicians, social workers and nurses suggested that patients with ongoing-complex MH issues required providers to change their approach, and both FPs and social workers noted advocacy and case coordination was common.

> I think definitely case management, trying to link them to appropriate services, even helping parents to understand, educating not only about the system but about the mental health issues, being supportive in that way, helping them to access the services that they need. (SW #4)

> I think "advocate" would be my biggest role. Often times these young people are being passed around, even within an organization, so it can be kind of mind bogglingly, dizzying for the families, and so to have someone who knew them before the trouble started and who's going to be there. That would be me. (FP #2)

There was agreement across participants, regardless of their profession, that PCPs, with their knowledge of the patient and family, were theoretically the most logical care coordinators. However, some providers acknowledged the difficulty in assuming this role:

> I like to be a coordinator but my problem is for complex mental health, I've never had all [other sectors] come to me. If I can be the umbrella to collect all of that then I would actually like to take on that responsibility. But if I'm not getting that then somebody has to be the umbrella. (FP #1)

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All types of PCPs suggested that a navigator or case coordinator would be appropriate. Nurses or social workers were identified as the providers best suited, and no one saw FPs or psychologists in this role. Interestingly, some NPs felt social workers could fill this need; a psychologist suggested a public health nurse, who worked both within the practice and in the community, would be good in such a role; and both FPs and NPs referred to nurse navigators, in part reflecting on their experiences with patients with chronic conditions such as cancer.

> If you had a dedicated nurse navigator who looks after complex mental health cases from all ages to make sure everything's put together, that would be an opportunity… I think they would meet with the family and the child, and then perhaps set up meetings with multiple providers, if that's needed, or at least communicate amongst them to make sure things were coordinated, including the primary care physician or nurse practitioner. (NP #4)

Monitoring and follow up. All participants endorsed the importance of monitoring and regular follow up for children with ongoing-complex MH problems. "I think that that's a great idea—if people could continue to monitor and have people recalled for some of the mental health problems in the same way as they would for the physical problems" (Psych #2).

Some participants (mainly FPs and NPs, along with one SW) were already providing ongoing monitoring. One NP (#4) had regular follow-up visits at least every 6 months, even when patients were asymptomatic. For the most part though, any monitoring done by participants was predominantly opportunistic, rather than regularly scheduled follow-up.

> Maybe I've looked after them since they were children and now they're young adolescents, they've come in because they want birth control pills. That's an opportunity for me to get a sense of where things are at with the rest of their life. I see that as part of understanding the whole person. (FP #3)

Transition points in the patient's life were seen as particularly important times for monitoring of ongoing-complex cases. "I try to encourage them to come in at least yearly if not more just to touch base… especially around times of transition, starting high school, starting university or finishing post-secondary education" (FP #5). The longitudinal patient-provider relationship in PHC promoted ongoing monitoring and education:

> I have one gal, I've been seeing her since grade 7 and she's now in grade 12… she's a perfect example. That connection is what keeps us in the loop and gives me an opportunity to keep educating her about her mental illness as she developmentally changes. (SW #1)

Participants from all four professions identified barriers to the widespread adoption of ongoing monitoring, including the need for appropriate training for PCPs, accommodating the volume of visits within a provider's practice, and encouraging patients to come in for regular visits, particularly youth. "I have a list of my patients who have complex mental health and if I haven't seen them in a while, I'll ask my secretary to call them, bring them in. But a lot of it is patient driven" (FP #5).

Problems in the System for Children and Youth with Ongoing or Complex MH Problems

All participants suggested areas for improvement in the "system" to better care for children with ongoing-complex MH problems, particularly making access to services easier for patients and families by

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improving immediate access, streamlining services to improve navigation, and developing better cross-sectoral collaboration and coordination.

Immediate access and crisis services. Providing more immediate access to services was noted by multiple providers. One social worker felt crisis services outside of emergency departments were needed.

> I think there has to be improved and immediate access because they're constantly going into crisis and so the challenge with that kind of scenario is when they need their crisis support, they're not ever using their primary therapist. They're having to access the ER or a crisis line. (SW #1)

However, both a social worker and a psychologist felt that, for children with complex MH problems, the goal should be to provide sufficient services to *prevent* crises.

Streamlining and navigation of services. Similarly, FPs, nurses, and social workers suggested streamlining services to make it easier for patients to navigate the system. This included simplified referral processes. "I wish there [were] more options for families to be aware [of], getting help directly, without going through their doctor, then going through the social worker, before they get to the place that they need to be at" (SW #5).

Both FPs and nurses felt streamlining services meant having an integrated system and central contact for better navigation of patients through the relevant sectors and providers.

> When they first present, whether unfortunately the youth criminal justice system, school, in a club… or to their primary care provider, [the] system can start. And depending on the comfort of the person, who first encounters this person, there's this one number you can call. And if it requires a formal diagnostic process, then access to a primary care provider… or a pediatric psychiatrist, psychologist, social worker, that system then gets enabled… it's one stop shopping. (FP #2)

Again, both FPs and nurses commented on difficulties in knowing and navigating the pathway for families to get specialized MH care.

> It'd be nice if you had a system that was clear. Right? Take for instance, if somebody has angina, I know clearly who I send them to, I know likely what's gonna happen to them. I know where they end up. I know the pathways. I don't know the pathways for kids. And I don't know if it's because there's too great a need, or the way it's organized. It seems that they change the provision of care about every 5 years. All the acronyms change, all the people change, the system changes, and I think that makes it difficult 'cause you're never really sure where. I have an idea where to start, but I don't know where it's gonna end up. (FP #4)

Participants were not always aware of the pathways to collaborating with other sectors. For instance, none of the participants had experience collaborating with juvenile justice, despite having patients involved with the justice system.

> I had a couple of kids recently charged for marijuana possession, one kid's got conduct disorder and the other kid has oppositional defiant disorder. Their mom came in and said, "What can we do?" And I said, "I don't know." (FP #2)

Cross-sectoral integration and care coordination. Participants identified a need for better cross-sectoral integration and care coordination. All types of providers felt communication was crucial to successful collaboration. "I think the successes [happen with] certain providers who send me notes about our patient. The successes happen when there's good communication" (FP #5). For FPs and NPs, as well as a few social workers, the most common desire was to receive written reports and updates from other professionals

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providing care for the patient. "I'd like closer communication, some more frequent communication… Even having a chat with somebody about it would be quite helpful… but certainly written communication could be more frequent and more complete" (FP #3).

Both FPs and social workers expressed frustration with issues around consent and sharing information amongst professionals in other sectors. "We still have this issue about circle of care,[1] and they're talking about trying to get consent, and you go, 'Well wait a second, the law has changed… and we should be able to share this information'" (FP #1). In particular, collaborations with the education sector seemed to be difficult, due to issues around information sharing. "There can be resistance to talk about anything or share information because they'll be talking about the privacy act, but you're saying, 'Well I have consent from the person'" (SW #4).

All types of providers described challenges in collaborating with providers outside the practice and with other sectors, but their experiences varied depending on which sector they were connecting with. FPs voiced the strongest opinions related to challenges in working with community psychiatrists, pediatricians, and hospital clinics; NPs and one social worker also expressed frustrations, but less often and with less intensity.

> It stinks, they're not accessible. No one returns phone calls, faxes, emails. The government has changed the billing codes so that I can, in theory, email a clinician and they can bill for the email consult, [but] it's gotten no better. People are just busy and when you're the uber subspecialist for sort of a niche part of complex mental health for youth in this province, you're busy. …the relationship is absent. (FP #2).

Coordinating care with schools was a challenge for social workers, FPs and NPs, and rarely occurred. Difficulties in navigating the correct person to contact were raised. The quality of interactions varied, regardless of provider type.

Communication and care coordination was typically, but not always, a challenge with specialized CMH agencies, child welfare, and, although it occurred infrequently, with private providers. Most providers felt that communication was limited after children were referred from PHC. One FP acknowledged that responsibility to communicate was bi-directional: "If they were even to send me a letter and say, 'This is what we talked about or this is what, this is the types of things we're working on.' And you know, it would be helpful if I sent them a letter too" (FP #5).

"[Child welfare] does not communicate at all to us. Once a child is referred there we just typically hear nothing further about it... It is a bit of a black hole for us" (FP #3). However, one FP said, "I've had a fair amount of experience with them [child welfare]; I think that out of anybody the communication with them is one of the best. They, you know they often initiate phone calls and discussions and ask very specific questions, which is helpful" (FP #5).

DISCUSSION

PCPs are often the first point of contact for children and youth with MH problems and PHC is increasingly involved in providing MH care (Craven, Cohen, Campbell, Williams, & Kates, 1997; Olfson, Kroenke, Wang, & Blanco, 2014). Amongst the providers interviewed in this study, the degree to which ongoing and

1. In Ontario, the circle of care only applies to "healthcare custodians" (e.g., healthcare practitioners, hospitals), and does not include other sectors such as specialized MH, education, juvenile justice, or child welfare.

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complex CMH problems are managed in PHC appears to depend mostly on individual scope of practice. This is not a new problem. In 1999, a report by the Surgeon General of United States (U.S. Dept. of Health and Human Services, 1999) noted, "Primary health care providers vary in their capacity to recognize and manage mental health problems" (p. 457). The inclusion of specialized MH providers, such as social workers and psychologists, into PHC teams has been an important step in improving access to MH care (Brown, Ryan, & Thorpe, 2016). However, the variability in training and/or confidence to provide CMH appears to contribute to issues with access to care (Cloutier, Cappelli, Glennie, Charron, & Thatte, 2010; Schraeder, Brown, & Reid, 2018). This is an issue that has previously been identified, with organizations such as the REACH institute (http://www.thereachinstitute.org) developing CMH continuing education programs that have been demonstrated to successfully improve PCP self-reported knowledge and comfort, reduce referrals to emergency services, and increase more appropriate referrals (Burka, Van Cleve, Shafer, & Barkin, 2014; McCaffrey, Chang, Farrelly, Rahman, & Cawthorpe, 2017). Provision of MH services within a specific PHC practice varied depending on the background, training, and confidence of the providers within that team. A child's age also appeared to influence care. In our interviews, it appeared that adolescents were more likely to be treated within the practice, while children tended to be referred to other agencies. Addressing MH problems in preschool-age and young children was rare. This is not surprising as FPs report receiving little training (Cawthorpe, 2005) and efforts to promote addressing MH in young children are not widespread (Clinton, Feller, & Williams, 2016), and often target multiple sectors without specifically focusing on PHC (Paolozza, Packard, & Kulkarni, 2017).

The difference between expectations of what "should" be provided, versus what is provided, may account for the frustration with care received in PHC expressed by parents of children with ongoing MH issues in qualitative studies (Tobon, Reid, & Brown, 2015). Parents can know with a high degree of certainty that if their child has a cough or needs an immunization, a FP or NP can provide this care, regardless of who the provider is. In contrast, a child with "common" anxiety, depression, or ADHD may or may not be able to receive care from their regular PCP. This variability may lead to frustration, particularly as FPs are the healthcare professional that parents commonly turn to if they perceive their child may have an MH problem (MacDonald et al., 2018; Reid, Cunningham, et al., 2011).

How Do PCPs Define Ongoing-Complex Child Mental Health Problems?

It was not surprising that PCPs suggested problem duration was a key factor in their views on ongoing CMH problems. It was somewhat surprising that providers gave time periods ranging from 3 months to years when considering a problem as being chronic. Without treatment, CMH problems such as depression would be expected to last about 7 months (Schraeder & Reid, 2017). Thus, 3 months is likely much too short a time period to be considered as "ongoing." FPs tended to refer to shorter times than social workers. One FP even felt that all MH is complex. Greater knowledge and experience with CMH problems likely account for these differences.

All types of providers saw complexity occurring when children had multiple factors contributing to their MH problems. This notion is consistent with developmental psychopathology theory and research; namely, that the greater the number of risk factors (and fewer protective factors), the more likely a child will develop MH problems (Cicchetti & Toth, 2009). Similarly, many providers saw CMH problems as being

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complex when there were comorbid problems (both MH and physical health) and when the child was having difficulty in multiple domains (e.g., family, school). These factors have also been associated with poor treatment outcomes in reviews (Phillips et al., 2000) and qualitative studies of parent's and MH clinicians' perspectives on treatment outcomes (Baker-Ericzen, Jenkins, & Brookman-Frazee, 2010). The comorbidity of MH and physical health problems, both concurrently and over time, has been identified as an important element in defining a complex condition (Bonavita & De Simone, 2008) and has been shown to be associated with substantially higher use of healthcare (Cawthorpe, 2013; 2018). Physical health factors, trauma history, cross-sectoral involvement, and parent and family factors were also included in the assessment of case complexity when examining the CMH system in the UK (Martin et al., 2017; Vostanis et al., 2015). In summary, PCPs' views of complexity capture elements common in the developmental psychopathology literature, and common with the views of specialist CMH clinicians. At the same time, PCPs, along with others in the field (Fried & Robinaugh, 2020; Martin et al., 2017; Vostanis et al., 2015), are struggling to capture what makes a CMH problem "complex."

Challenges with Cross-Sectoral Collaboration

PCPs expressed difficulties collaborating with other sectors in the provision and coordination of CMH care (Schraeder, Brown, & Reid, 2018). Children with ongoing-complex MH issues are involved with multiple sectors (i.e., MH, health, education, child welfare, juvenile justice), but collaboration across sectors is tenuous (Cappelli & Leon, 2017). Part of the problem lies in the artificial separation of health and MH care, as well as education, that too often exists due to the way governments organize ministries. Efforts to transform MH services and facilitate better integration and continuity of services, over time and across the traditional boundaries of care, are not new and continue to be needed (Kirby, 2008; Mental Health Commission of Canada, 2016). Some communities have developed centralized intake systems that facilitate navigation between primary and specialist MH care (Melathopolous & Cawthorpe, 2019). In Ontario, MH care for children and youth is now part of the Ministry of Health and new initiatives aim to enhance care across the lifespan (Ministry of Health, 2020). Hopefully these system changes can address some of the problems with cross-sectoral collaboration identified by PHC providers in this study.

Part of the issue may also stem from a lack of a clear care coordinator in these cases. The health home model of care in the US or patient-centred medical home in Canada, and the feedback provided here, suggests that there should be a central point of care coordination for children with ongoing-complex MH problems (de Voursney & Huang, 2016). PHC is the logical central point; PCPs are the only providers who may have lifelong relationships with patients. A previous study about continuity of care in CMH identified the importance of an ongoing therapeutic relationship; this would imply that the PCP would naturally be the care coordinator (Tobon, Reid, & Brown, 2015). However, neither the providers in this study nor families in other studies found that the current systems of care support this role for the PCP (Schraeder, Brown, & Reid, 2018). Positive outcomes including a decline in unmet needs have been found when care coordinators have been used in PHC for children with complex needs, although not MH specifically (Farmer, Clark, Drewel, Swenson, & Ge, 2011).

Many participants suggested that a navigator could be helpful. Health system navigation is a model that originated in cancer care (Paskett, Harrop, & Wells, 2011). It has been increasingly applied in other systems

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of care, particularly those that require transitions through various services, such as with multi-morbidities and chronically ill patients (Manderson, McMurray, Piraino, & Stolee, 2012). A recent review highlighted applicability to MH in PHC, but noted the lack of trials (Godoy et al., 2019). Patient navigation, commonly provided by nurses or social workers, helps patients navigate the health or MH systems, and aims to identify and reduce patient-specific barriers impacting timely access to care (Godoy et al., 2019; Paskett et al., 2011). Conceptually, navigators provide emotional support and help patients with instrumental (e.g., identifying and linking patients to resources) and relational (e.g., addressing patient fears, explaining procedures) tasks (Browne, Darnell, Savage, & Brown, 2015; McMurray & Cooper, 2017). A recent pilot study using navigators in MH for youth in Ontario received positive feedback from families but has yet to be more widely applied or quantitatively evaluated in its effectiveness (Markoulakis, Weingust, Foot, & Levitt, 2016). A key issue remains defining the specific population for which a navigator is needed. From the perspective of specialized MH providers, a navigator would be recommended for only the most severe cases. However, from the perspective of PCPs, the need for a navigator would apply to a larger range of cases. Without cost-effectiveness analyses, it would likely be difficult to justify the cost of this service to a large number of patients. This is particularly true in the face of ongoing issues with lack of access to MH care in general. Improving access to care and improved system navigation is one of the four pillars in Ontario's new MH plan (Ministry of Health, 2020). However, it is unlikely that providing a toll-free number for the province or an "easy-to-use website" (Ministry of Health, 2020) will be sufficient navigational support for children, youth, and families with ongoing-complex MH needs.

When asked for their views on the role of PCPs in ongoing care and monitoring, providers agreed with the importance of these activities and that PHC was the best place for these to occur. One NP did report using ongoing monitoring routinely. However, most PCPs felt that PHC did not have the time or resources to take on additional roles in caring for ongoing-complex CMH problems. This lack of resources also exists within the MH care sector. A key first step may be to define the specific sub-population who is at risk for having ongoing/recurring MH problems (Schraeder & Reid, 2017). Certain chronic disorders (e.g., ADHD) already have clinical guidelines for ongoing monitoring that could be implemented (DuPaul, Evans, Mautone, Owens, & Power, 2019; Wolraich et al., 2011). Second, we may need to consider which provider is best able to take on the additional tasks of case coordination. Given the uniqueness of CMH problems versus other patients in PHC, it may be that specialized CMH organizations are the more appropriate central point for case coordination.

Some FPs also expressed frustration with sharing information and the need for consent when working across sectors. CMH problems are fundamentally different than virtually all other conditions FPs address. FPs are familiar with the process of referring cases to their specialist medical colleagues, who in Ontario, are part of the circle of care and do not require specific consent. In contrast, children with MH problems are routinely involved with the specialized MH sector and education. The legislation for these sectors does not fall within health; thus, separate consents for disclosure and requests for information are required. Given how few children with ongoing-complex MH problems exist within a given PHC practice, it is not surprising that understanding and navigating the complexity of cross-sectoral collaboration is challenging for FPs.

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Implications for Caring for Ongoing and Complex Child Mental Health Problems

A comprehensive approach to the care of children and youth with ongoing and complex MH problems that incorporates PHC along with specialized MH services is needed. However, case definitions and how this is achieved are an ongoing challenge, both for PHC and specialized CMH care. First, it is likely that continued efforts to enhance PCPs' abilities to manage CMH problems are needed. This is an issue that has been raised repeatedly, and many initiatives have attempted to enhance FPs' skills and confidence in this area and improve access to CMH (e.g., Healthy Minds/Healthy Children in Alberta, Lipton et al., 2008; the CanREACH program; McCaffrey et al., 2017). In Ontario, including social workers and psychologists in family health teams (FHTs) is one of those initiatives. Broadening the scope of practice for other PCPs may also be needed. For example, psychologists' regulatory bodies require documented competency to practice in child and youth practice, but not all PHC psychologists will have this. Second, enhanced access and functioning of interdisciplinary PHC teams with the ability to work collaboratively to address complex CMH cases is needed (Kates et al., 2011). FHTs were introduced in Ontario in 2005 and about 22% of the patient population receives care from a FHT (Hutchison & Glazier, 2013; Ontario Ministry of Health and Long-Term Care [website], 2016; Rosser, Colwill, Kasperski, & Wilson, 2011). However, there are ongoing challenges with how teams function, which may be even more challenging for MH care (Ashcroft, McMillan, Ambrose-Miller, McKee, & Brown, 2018). Third, efforts to strengthen collaboration between PHC and other sectors is needed (Cappelli & Leon, 2017).

The need for a case coordinator was highlighted as one way of enhancing care specifically for children with complex and ongoing MH problems. On the one hand, PCPs all felt PHC was the appropriate place for coordination of care to happen. However, there were varied opinions about who would play this role and providers were uncertain about the capacity of their teams to take on this role, even within the FHT structure. Specialized CMH sector/providers might be more appropriate, but they face similar challenges with capacity (Reid & Brown, 2008). Defining one individual or agency/team to take the lead on coordinating care for each child would be a clear step toward to improving collaboration. There are recent initiatives in Canada (ACCESS-Open Minds), similar to Australia's headspace programs (Rickwood et al., 2019), that aim to help communities enhance the systems that care for older children, youth, and young adults with MH problems, including co-location of PCPs and specialized MH providers (Abba-Aji et al., 2019; Dube et al., 2019; Malla et al., 2019). However, these programs do not capture younger children. It is unclear if these programs can be scaled up to address all children and youth with ongoing and complex MH needs. The population prevalence of MH contacts with CYMHS agencies is 5.9% (Reid et al., 2020) and we estimated that about 20% of these children have ongoing-complex MH problems (Reid, Stewart, Barwick, Carter, et al., 2019; Reid, Stewart, Barwick, Cunningham, et al., 2020); thus, about 1% of the child and youth population in Ontario could have ongoing-complex MH problems. It would be a challenge for new service models such as ACCESS-Open Minds to provide care for all of these children and youth. Coordination and collaboration of care between PHC and CYMHS is likely to be an ongoing reality in the years ahead.

Limitations

There were difficulties in recruiting psychologists; it is possible that if more psychologists were interviewed, additional themes may have emerged. However, in Ontario there are currently only 36 full-time

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equivalent psychologist positions working in PHC practices (pers. comm., April 13, 2017, Association of Family Health Teams of Ontario). Thus, the relatively low number of psychologists interviewed reflects their involvement in PHC in Ontario. The study did not focus on understanding how different models of PHC might influence providers' perspectives. Many of the FPs and NPs interviewed had access to social workers and/or psychologists within their PHC team. Although a minority of FPs (19% in the most recent National Physician Survey) are still in solo practices, we might expect differences in their perspectives (College of Family Physicians of Canada, Canadian Medical Association, & Royal College of Physicians and Surgeons of Canada, 2017). Some FPs in solo practice might have enhanced experience in MH care and thus feel confident in their abilities to manage a wide range of CMH problems, while others might feel unable to do so due to competing demands of their patient population without other professionals to support them. The study interviewed only providers in Ontario. Variations in how PHC is organized and FPs are paid (Hutchison & Glazier, 2013; Rosser et al., 2011), and how specialized CMH is organized in other provinces (Kutcher, Hampton, & Wilson, 2010) may result in differences in how children and youth with ongoing and complex MH problems are cared for. It seems less likely that the structure of health and MH care differences across provinces or PHC organization would influence how PCPs conceptualize what an ongoing or complex CMH problem is. Further, recruitment focused on PHC practices in southwestern Ontario, beginning with the authors' contacts and using snowball sampling. As such, the views of the PCPs captured may not reflect those in other practices and/or other regions of Ontario.

The interview probed for PHC providers' interactions with the sectors traditionally associated with children's MH care. Myriad factors influence children's mental health. For example, access to appropriate and affordable housing for families and affordable, easily accessible public transportation, recreational services, etc. can play an important role in children's MH and well-being (Jensen, 2016). It would be important for future studies examining PHC providers' views on managing complex/on-going CMH problems to inquire about these types of services. Further, we did not explore providers' perceptions on elements of CMH care contained in documents such as those by the Mental Health Commission of Canada, which advocates for early identification and prevention programs, enhancing CMH care within schools and recovery-oriented and trauma-informed care (Mental Health Commission of Canada, 2012; 2016).

Qualitative studies do not provide metrics for the relative importance of ideas or measures of frequency of endorsement. The current study could serve to inform future quantitative studies examining how different child and family characteristics influence providers' views on complex and ongoing MH problems. Methods such as best-worst scaling (Muhlbacher, Kaczynski, Zweifel, & Johnson, 2016) or discrete choice analyses (Lancsar, Louviere, Donaldson, Currie, & Burgess, 2013) are options to consider (Whitty & Oliveira Goncalves, 2018).

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