# "WHEN YOU'RE IN THE OFFICE, IT MEANS YOU MANAGED TO GET SOMEWHERE": PERCEPTIONS OF ADOLESCENTS EXPERIENCING A MENTAL ILLNESS OF ACCESSING PRIMARY CARE FOR MENTAL HEALTH SERVICES

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the Requirements for the Degree Master of Science in Nursing

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TITLE:	"When you're in the office, it means you managed to get somewhere": Perceptions of adolescents experiencing a mental illness of accessing primary care for mental health services
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#### ABSTRACT

In Ontario, the majority of children and youth with mental illnesses access primary care as their initial source of mental health services (Institute for Clinical Evaluative Sciences [ICES], 2017). Primary care can be an ideal setting for accessing mental health services to prevent symptoms from worsening (Cappelli & Leon, 2017). Adolescence is a time when young people experience several developmental changes and transitions, making them susceptible to mental illnesses (Government of Canada, 2011). Examining adolescents' perceptions of access is critical to examining how primary care is accommodating their mental health needs (Cappelli & Leon, 2017).

The primary purpose of this study was to explore the perceptions of adolescents, living in Hamilton, Ontario, with an anxiety or mood disorder, of accessing primary care for mental health services. Perceptions regarding the role of primary care nurses in facilitating access was also explored.

Qualitative interpretive descriptive methods were utilized. Data collection included: demographic survey, semi-structured interviews, photo-elicitation project, field notes, and reflexive journaling. Analysis was guided by an access framework (Penchansky & Thomas, 1981) and ecological model (McLeroy et al., 1988).

Adolescents ages 15 to 18 years (n=10) participated. Adolescents perceived access to primary care for mental health services as a difficult and

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complex process involving multiple stages including: feeling uncertain about their mental health concerns and if they required help, seeking informal support from parents and friends to initiate receiving help, and obtaining mental health services from primary care.

Implications of this study include addressing adolescents' developmental needs in care through implementing an individualized-approach and supporting development throughout emerging adulthood. Primary care practitioners must provide information to adolescents and parents about mental health concerns and services during routine interactions. Greater organizational support would enable primary care nurses to have an active role in delivering mental health services and providing comprehensive care.

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#### **CHAPTER ONE: INTRODUCTION**

## Research Focus: Adolescent Perceptions of Accessing Primary Care for Mental Health Services

Mental illness is one of the most common causes of disability in Canada (Centre for Addictions and Mental Health, 2018). In Ontario, approximately one in five children and youth between ages 0 to 24 years will experience a mental illness in any given year (ICES, 2017). Anxiety and mood disorders are two of the most common mental illnesses experienced by children and youth (Ontario, 2015). Anxiety disorders are a category of mental illnesses that involve excessive anxiety or fear, such as social anxiety, panic, or generalized anxiety disorder (American Psychological Association [APA], 2013). Mood disorders are mental illnesses that affect how a person experiences emotions and thoughts in relation to themselves, others, and their life (Canadian Mental Health Association British Columbia Division, 2013). This specific category includes the subtypes of depressive disorders, and bipolar and related disorders (APA, 2013). Mental health services for anxiety and mood disorders, or other mental illnesses, consist of services, supports, and programs that facilitate recovery, as well as improvement and maintenance of mental health (Canadian Mental Health Association [CMHA], 2018). These services can include assessment, treatment, health promotion, and illness prevention (CMHA, 2018). Access to publicly funded mental health services for children and youth can occur in several different settings such as primary care, hospital emergency departments, schools, the

community, and through telephone or online services (Canadian Institute for Health Information [CIHI], 2015; ICES, 2017). However, the majority of physician care outside of the hospital setting for children and youth with mental illnesses occurs within primary care; in a three year average, there were approximately 17 visits per 100 Ontarians between ages 0 to 24 (ICES, 2017).

Primary care is the first point of contact for accessing comprehensive and coordinated person-centred care across the lifespan (Starfield, 1994). Primary care is where children and youth have ongoing contact with their primary care practitioners and health care professionals, including physicians, nurse practitioners, and primary care nurses (Glazier et al., 2012). This can be an ideal setting for accessing mental health services before symptoms worsen (Cappelli & Leon, 2017). Despite this, nearly 45% of Ontarians between ages 0 to 24 years who present to the emergency department for a mental health crisis have never had prior contact with a physician for their concern (ICES, 2017). This trend is alarming, as it suggests a lack of early identification of mental health concerns, including within primary care, resulting in preventable acute distress (CIHI, 2015; ICES, 2017). There is a growing concern that primary care may not be adequately recognizing or accommodating the mental health needs of children and youth (Cappelli & Leon, 2017). In particular, the Penchansky & Thomas (1981) definition of access places importance on the fit between the services and the person receiving services, as described further below. This suggests that in order to understand the challenges in the delivery of mental health services for young

people experiencing anxiety or mood disorders within primary care, it is essential to explore the lived-experiences and perceptions of adolescents who have accessed services for their mental health concerns.

#### Adolescents and Mental Health in Canada

Adolescence is the life stage after childhood and can be defined as ages 10 to 19 years (World Health Organization [WHO], 2018); however, there are various definitions of which age period constitutes adolescence. For example, Erikson's Stages of Psychosocial Development (McLeod, 2018) state adolescence occurs between ages 12 to 18 years and is when independence, autonomy, and self-identity begin to emerge. This period also marks the beginning of responsibility for one's health (Christie & Viner, 2005). There are several life stressors during this time that affect adolescent mental health, including puberty, transitioning into and out of high school, and peer and social media influence (Boak et al., 2016; WHO, 2018). These multiple developmental changes and life transitions can make adolescents vulnerable to experiencing a mental illness (Government of Canada, 2011). As adolescents begin to develop more selfsufficiency, they move toward what is known as emerging adulthood; this stage spans from late teenage years into the twenties (Arnett, 2000). Thus, adolescence is a critical time for the beginning of identity development, moving towards "accepting responsibility for one's self and making independent decisions" (Arnett, 2000, p. 473).

Of Canadians living with a mental illness, 70% stated their symptoms began during adolescence or young adulthood (Government of Canada, 2006). The Ontario Student Drug Use and Health Survey reported that 34% of adolescents had experienced symptoms of anxiety or depression in the past month, and 12% have experienced suicidal ideation in the past year (Boak et al., 2016). Mental illnesses also significantly impact adolescents' abilities to learn, work, and achieve their full potential (APA, 2018). Subsequently, having a mental illness at a young age can negatively impact housing, education, and legal outcomes in adulthood (Copeland et al., 2015). Failure to recognize and care for the mental health needs of adolescents can result in mental illness persisting into adulthood (Boak et al., 2016). Moreover, it is known that the experiences adolescents have with health care services at this formative time can impact their attitudes towards service providers and choices about health care in the future (Klein et al., 1993; Rickwood et al., 2005).

#### **Purpose of the Thesis**

The primary purpose of this thesis was to explore the perceptions of adolescents, living in Hamilton, Ontario, with an anxiety or mood disorder, of accessing primary care for mental health services. Perceptions regarding the role of primary care nurses in facilitating access was also explored. The age group of 14 to 18 years was chosen to allow for an exploration of the perceptions of adolescents who were of high school age. The health care professionals described within this study include primary care practitioners (i.e., physicians, nurse

practitioners) as well as primary care nurses, and primary health care professionals (e.g., dieticians, social workers, physiotherapists).

Multiple dimensions of access were examined (Penchansky & Thomas, 1981; Saurman, 2016) to explore the fit between the needs of adolescents with anxiety or mood disorders, and mental health services delivered by primary care. These access dimensions include: availability, accessibility, accommodation, affordability, acceptability, and awareness (see Appendix A for access dimensions and definitions). The ecological model (McLeroy et al., 1988) was also used to explore the influence of individual, social, and environmental factors on health (see Appendix B for image of the ecological model). Together, the access framework and ecological model were applied to analyze the inter-relationships between different dimensions of access to primary care and the levels of influence on adolescents' perceptions of their mental illnesses and access to mental health services. The different levels identified within the ecological model include individual, interpersonal, community, organizational, and policy level influences (McLeroy et al., 1988). A secondary aim of this research was to understand the role of primary care nurses in facilitating access to primary care for mental health services for adolescents experiencing an anxiety or mood disorder. Nurses working within interdisciplinary primary care teams were of particular interest, as they are one of the most prominent health care professions in this setting in Ontario after physicians and nurse practitioners (Health Quality Ontario, 2015). Therefore, the findings of this study can inform primary care practitioners,

primary care nurses, and other primary health care professionals about strategies to improve services and access for adolescents experiencing anxiety or mood disorders.

#### **CHAPTER TWO: LITERATURE REVIEW**

The purpose of this literature review was to examine the context of mental health services in Canada, appraise the existing evidence regarding access to primary care mental health services for adolescents experiencing an anxiety or mood disorder, and identify knowledge gaps in this body of evidence. The first literature review section will provide background information regarding: a) access to health care, and b) primary care mental health services in Ontario. Then, evidence identified through a targeted search to explore access to primary care mental health for adolescents with an anxiety or mood disorder will be presented using a conceptual framework of six dimensions of access (i.e., availability, accessibility, accommodation, affordability, acceptability, and awareness) (Penchansky & Thomas, 1981; Saurman, 2016), nested within the ecological model as relevant at the individual, interpersonal, organizational, community, and policy levels (McLeroy et al., 1988).

#### Access to Health Care

The Canada Health Act includes accessibility as one of its five main principles, stating that Canadians should have reasonable access to health care (Health Canada, 2015) but does not fully elaborate on the meaning of this term. Access to health care is often defined in the literature as one of two concepts: the potential to receive services or the actual entry of a person or group of people in the health care system (Canadian Medical Association, 2012; Gullford et al., 2002). Penchansky and Thomas (1981) have argued for access to be defined as

the fit between the health care service user and the services. This definition can be helpful in conceptualizing access, as the authors suggest that there is a dynamic relationship between health care service providers and service users (Levesque et al., 2013). Penchansky and Thomas (1981) distinguish five dimensions as follows. *Availability* refers to the amount of services available for a person's needs, such as the supply of health care providers. *Accessibility* describes the ability for a service user to physically get to the services, considering factors including transportation resources and travel time. *Accommodation* is the relationship between how services are delivered and if they are offered in a way which enables the service user to receive them, such as office hours and appointment times. *Affordability* describes the finances involved with care for service users, such as health insurance and out-of-pocket costs. *Acceptability* refers to the attitudes and beliefs a service user holds about the characteristics of the service provider, subsequently impacting their perception of services.

A sixth dimension of access, *awareness*, was proposed by Saurman (2016). Saurman (2016) noted that "this sixth dimension is necessary to demonstrate that the service is accessible and to determine ways for improving access" (p. 38). *Awareness* is a dimension which conceptualizes the knowledge and understanding a service user has about the services and what they offer (Saurman, 2016). Taken together, these six dimensions are well suited to explore the complex factors influencing access to health care from the perspective of the service user and have the potential to expand beyond general barriers and

facilitators which are often discussed in the literature (Penchansky & Thomas, 1981; Saurman, 2016).

#### Access to Health Care When Experiencing a Mental Illness

The context of access to health care is different for those experiencing a mental illness compared to a physical illness. First there are issues of *availability*, since mental illness accounts for 10% of illness burden in Ontario yet only 7% of health care dollars are allotted to mental health services (Centre for Addictions and Mental Health, 2018). This has resulted in lengthy wait times for adolescents under age 18 accessing specialized mental health treatment and services, and can require waiting a minimum of 9 weeks or up to 2.5 years (Children's Mental Health Ontario, 2020). Accessibility of mental health services has been limited due to the inequity of services available within different geographical regions (Children's Mental Health Ontario, 2020). There are also several *affordability* barriers as a result of system under-funding of mental health services in Canada, whereby some treatments or services essential to recovery are not publicly funded, such as prescription medications and psychological therapies (Mulvale & Hurley, 2008). Acceptability of services has been impacted by stigma and discrimination by primary care providers, and has limited the opportunity to access health care for those with mental health problems (Centre for Addictions and Mental Health, 2016). A lack of awareness of where to receive mental health services has also limited uptake of services (Vallance et al., 2011). Finally, although mental illness affects all populations equally, there is growing evidence

that unfavourable socioeconomic and environmental factors may be associated with an increased risk of developing a mental illness in children and adolescents (WHO, 2014). This may have a significant impact on those experiencing a mental illness, because people from marginalized/underserved groups (e.g., low-income, inadequate housing) are less likely to access the health care they need (Canadian Medical Association, 2012; CMHA, 2014). Thus, there are several factors that limit access to mental health services and are important to consider in understanding the context for access to care in Ontario.

#### **Primary Care and Mental Health Services**

Over 90% of Ontarians have a primary care practitioner (i.e., physician or nurse practitioner) who offers community-based care for various health conditions, including common minor health problems, health promotion interventions, and chronic disease prevention and management (Canadian Nurses Association [CNA], 2015; CIHI, 2018; Statistics Canada, 2016a). The settings in which primary care has been delivered in Ontario include solo physician practices, nurse practitioner-led clinics, and different team-based models such as Community Health Centres and Family Health Groups (Cappelli & Leon, 2017; Ontario Medical Association, 2015). Recent legislation in Ontario has mandated the creation of Ontario Health Teams, with the aim of enabling more comprehensive and connected care, which will include primary care and other care providers (Government of Ontario, 2019; Ontario Ministry of Health and Long-Term Care, 2019). At the time of this study, the role of primary care in Ontario Health Teams was to provide leadership and allow for more seamless care between sectors, such as hospital and home care (Ontario Ministry of Health and Long-Term Care, n.d.). Additionally, an important goal of this new model is to provide more integrated care that can address a person's mental and physical health needs concurrently (Ontario Ministry of Health and Long-Term Care, n.d.).

Multiple health professionals provide services in primary care, including a most responsible primary care practitioner who oversees a patient's care, such as a physician or nurse practitioner, alongside an interdisciplinary team such as primary care nurses (which may be Registered Nurses or Registered Practical Nurses), social workers, pharmacists, and dieticians (Glazier et al., 2012). As previously stated, nurses are one of the most common health professionals present in primary care (Health Quality Ontario, 2015). Primary care nurses provide many clinical interventions including screening, preventative care, education, case management, and system navigation (CNA, 2013). One of their most important roles is to provide a continuity of care over time, and to establish trusting relationships with clients to understand all aspects of their health (CNA, 2014).

Longitudinality is a central dimension of primary care, whereby a person stays with their primary care practitioners across their lifespan (Haggerty et al., 2007; Starfield, 1994). As long-standing care providers in a person's life, primary care practitioners and their interdisciplinary team can offer continuity and holistic care for all health needs (Eapen & Jairam, 2009; Leahy et al., 2013). Primary care also acts as the main point of entry into the health care system and ideally is the first sector to address a person's health care concerns before referral to specialty care (Ontario Medical Association, 2015; Statistics Canada, 2016a). Primary care professionals work to facilitate coordinated, equitable, and timely access to health care services (CNA, 2015). As primary care professionals address physical health concerns, it is essential they address mental health concerns as well, because physical and mental health are closely related (WHO, 2008).

Mental health services are one of the vital services offered by primary care (WHO, 2008). In primary care, these services include early intervention, diagnosis, treatment, and rehabilitation for persons experiencing mental illnesses (WHO, 2008). Once care is accessed, obtaining mental health services in the primary care setting has been shown to be effective for addressing mood disorders and other mental health concerns in adolescents (The National Infant, Child and Youth Mental Health Consortium Advisory, 2010). The WHO (2008) reports that the most feasible way to decrease gaps in mental health care is to improve access to primary care mental health services. Comprehensively examining the concept of access may assist in analyzing the different aspects of primary care mental health services beyond only *availability* of services, which is most commonly examined (Canadian Medical Association, 2012), in order to improve access for adolescents with anxiety or mood disorders.

### Critical Appraisal of Literature on Access to Primary Care for Mental Health Services for Adolescents Experiencing an Anxiety or Mood Disorder

The following sections will describe and appraise the quality of existing evidence related to the six access dimensions for adolescents with anxiety and mood disorders in the primary care setting. The review applied a targeted search focused on access to primary care for mental health services for adolescents with anxiety or mood disorders. The evidence will be organized within the levels of influence in the ecological model (i.e., individual, interpersonal, organizational, community, and policy), with access dimensions nested within them as relevant (i.e., availability, accessibility, accommodation, affordability, acceptability, and awareness). Appendix C provides a table that includes the references of all included studies organized under the conceptual framework and model.

The search strategy was developed in collaboration with a health sciences librarian, utilizing the databases CINAHL, Medline, Embase, PsychINFO, Cochrane Library, Web of Science, and Google Scholar. Search terms with variations included the following: *adolescent, primary care, access,* and *mental health services* (see Appendix D for the targeted search strategy). Search language was adapted based on the appropriate Boolean phrasing, MeSH headings, and keyword phrases for each database. Hand searching reference lists of relevant studies was also conducted. Articles were included if they discussed access to primary care mental health services specifically, for adolescents with anxiety or mood disorders, or unspecified mental health concerns. Studies which described mild to moderate mental illness, without specifying specific illnesses, were included due to the limited evidence base specifically focused on anxiety or mood

disorders. Publication dates of January 2008 to January 2020 were chosen to align with the release of the WHO (2008) document "Integrating mental health into primary care: a global perspective". Finally, a limit of English language and publication in Western-world countries was also applied (World Atlas, 2019). These high-income countries were selected for their similarity to Canada with respect to the delivery of health care.

Of 2397 studies identified in the search, six qualitative studies, one mixedmethods, one case-control, one observational cross-sectional, one cohort study and one systematic review met inclusion critera and are described below (n=11)(see Appendix E for study selection flowchart). These studies examined aspects of access from the perspective of parents (n=2) and adolescents (n=5). Six studies also explored the perceptions of access to primary care for mental health services from primary care practitioners (i.e., physicians, nurse practitioners) and primary care professionals (i.e., nurses, social workers, occupational therapists), or other community-based providers (e.g., social workers, counsellors, youth workers). Regarding the adolescent mental health concerns examined, five studies discussed depression, one included anxiety disorders, and six were unspecified or included general mental health concerns. Countries of origin included the United Kingdom (n=4), United States (n=3), Ireland (n=3), and Australia (n=1). Quality appraisals of the articles were conducted using the Critical Appraisal Skills Programme (2018) worksheets for qualitative, case-control and systematic review studies, the Mixed Methods Appraisal Tool (Pluye et al., 2011), and the Appraisal tool for

Cross-Sectional Studies (Downes et al., 2016). Overall, four studies were rated as strong, six were moderate, and one was of weak methodological strength (see Appendix F & G for study characteristics and appraisals). Finally, as each study utilized different terms to denote primary care practitioners and adolescent ages, the terms used from each study will also be used in the review. The term "mental health concerns" will be utilized as a broad term for symptoms of anxiety and mood disorders, as well as for studies which did not specify a specific mental illness focus.

#### Individual Level Influences

The individual level of the ecological model refers to the characteristics of an individual which influence behaviour (McLeroy et al., 1988). Some of these characteristics may include personal attitudes, knowledge, gender, ethnicity, and culture (UNICEF, 2009). The next section will explore evidence found within the individual level of influence.

*Awareness* was one access dimension implicated at the individual level of the ecological model within the literature. A mixed-methods study by Leahy and colleagues (2018) in Ireland sought to understand the role of general practitioners in providing early intervention and treatment for youth mental health concerns. In this study, they interviewed primary care, secondary care, and community-based health professionals (n=37) and young people age 11 to 25 years (n=20), as well as surveyed primary care physicians (n=137). This study was found to be of moderate strength, due to a limited description of the qualitative analysis process

(see Appendix G for study appraisals). However, a significant strength was its inclusion of perspectives from service providers outside of primary care. In this study, young people reported they did not perceive that their general practitioner provided care for mental health issues. This reflected a lack of *awareness* and was identified as a barrier to seeking help in primary care (Leahy et al., 2018).

Availability was another access dimension implicated at the individual level. Meredith and colleagues (2009) conducted a large cohort study in the United States of 368 teenagers between ages 13 to 17 years who were experiencing depression to understand their perceptions of barriers to primary care mental health services. In this moderate quality study, an important strength was matching adolescents with depression to non-depressed controls to examine and compare their perceptions (see Appendix G). However, the authors based their assessment questions from previous studies of adults in primary care and these questions may not be as relevant for adolescents. It was found that when experiencing depression, adolescents may not believe that high-quality mental health care is available to them (Meredith at el., 2009). Together, this international evidence from Leahy and colleagues (2018) and Meredith and colleagues (2009) highlights an issue related to awareness and availability of services: young people either did not know that mental health services were offered or questioned the quality of services available.

Three studies reported findings which did not fit within the access dimensions but can be categorized under the individual level of influence. The

first was a case-control study conducted by Ferrin and colleagues (2009) in England, which examined demographic factors that can influence attendance at primary care for mental health services for teenagers, between ages 13 to 17 years, who attended primary care (n=156) compared to those who did not (n=120). This study was found to be methodologically weak, as it employed a small sample size and the authors did not discuss how they controlled for the effect of cofounding variables (see Appendix G). Despite these limitations, the study was the only one that described how demographic factors and attitudes towards care can impact adolescents' perceptions and experiences of accessing primary care mental health services. Ferrin and colleagues (2009) observed that teenagers with depressive disorders who are of lower socioeconomic status, non-Caucasian ethnicity, and experiencing family conflict are more likely to attend primary care for help. This study also found that gender impacted the way adolescents presented to primary care and how they perceived getting help for their mental health concern. Specifically, males who attended primary care expressed more physical symptoms of depression than females and may be more hesitant to discuss emotional difficulties. The authors noted that females were more likely than males to believe that primary care physicians were interested in mental health concerns. This evidence is important, despite its lack of fit within the access dimensions, as it depicts the relationship between individual adolescent client characteristics and their relationship to access.

The second study was a methodologically strong qualitative study by Leahy and colleagues (2013) conducted in Ireland. This study also reported findings that did not explicitly fit within the access framework. The researchers interviewed primary care, secondary care, and community-based health professionals (n=37) to understand their perceptions and attitudes toward screening and early intervention for youth mental health concerns. A significant strength of this study, which utilized inductive thematic analysis, was its rigorous description of the data analysis process and inclusion of perspectives from health care professionals across different sectors (see Appendix G). Leahy and colleagues (2013) reported that adolescents' attitudes towards mental health and receiving treatment can be a significant barrier or facilitator to accessing primary care. Specifically, health care professionals in this study perceived a youth's inherent motivation as an enabler, and reluctance to engage in any type of counselling as a barrier to receiving care.

Finally, an important finding in the previously described moderate quality cohort study by Meredith and colleagues (2009) was related to adolescent concerns regarding stigmatization. Again, this was found to fall under the individual level of influence but did not fit within the six access dimensions. This study identified that adolescents' fears regarding stigma is an important care consideration, as it was found that they worried about how others may perceive them if they discuss their mental health concerns. They also reported worrying

about their family members' perceptions of mental illnesses, which created a barrier to accessing primary care (Meredith et al., 2009).

In summary, considering adolescents' knowledge of primary care mental health services, concerns about stigma, and demographic characteristics (e.g., gender, socioeconomic status) may be important for primary care practitioners and other health care professionals in facilitating improved access to mental health services. Specifically, this literature highlights the need to address adolescents' *awareness*, which may include improving their knowledge of mental health services available in primary care, and the perception that high-quality mental health services are not available to them. Primary care practitioners should also consider other factors that may impact access, such as individual demographics and perceptions of stigma, to facilitate access to primary care mental health services.

#### Interpersonal Level Influences

The interpersonal level of the ecological model describes the formal and informal relationships between persons and the subsequent impact these relationships have on influencing behaviour (McLeroy et al., 1988). Interpersonal level relations may include those between family, friends, coworkers, health care practitioners, and religious communities (UNICEF, 2009).

Within the interpersonal level of the ecological model, the literature provided evidence for the dimension of *acceptability*. In the previously mentioned

methodologically strong study by Leahy and colleagues (2013) of 37 primary care, secondary care, and community-based health professionals, the authors state that primary care providers may experience uneasiness surrounding the limitations of confidentiality and parent involvement because of the age of this population. They reported this was a barrier to identifying mental health concerns, as primary care providers reported involving parents, and the legal issues surrounding confidentiality, may be "restricting" (Leahy et al., 2013, p. 6).

Some facilitators to identifying mental health concerns were described in a moderate strength observational cross-sectional study by Schaffalitzky and colleagues (2014) in Ireland that surveyed 17 primary and secondary care health professionals to identify priorities for general practices to better address youth mental health concerns. A strength of this study was its clear description of the Delphi procedure; however, there was a risk of sampling bias given the small sample size of individuals identified by the study's steering committee (see Appendix G). They reported the importance of general practitioners stating their limitations of maintaining confidentiality, such as who they must disclose to and when, as this transparency was identified as a facilitator to adolescent-friendly mental health services. A moderate strength qualitative study by Graham and colleagues (2014) discussed difficulties surrounding disclosure of mental health concerns from the perspective of young people. In this study, fifty young people between ages 16 to 25 years in England were interviewed about their views and experiences of seeking help in primary care for their mental health concerns to

create quality standards. Although the authors did not specify how they validated the quality standards, a strength of the study was its inclusion of young people from primary care and several community settings (see Appendix G). To ensure that youth feel comfortable discussing their mental health, participants emphasized the need for primary care physicians to outline a strict confidentiality policy before delving into a mental health consultation to ensure there will not be unwanted disclosure to parents and family (Graham et al., 2014).

Another aspect of *acceptability* was identified in Schaffalitsky and colleagues' (2014) study. In this study, health care professionals emphasized the importance of not assuming the knowledge level of youth in relation to their understanding of mental illnesses in their interactions with clients. Additionally, Schaffalitsky and colleagues (2014) and Graham and colleagues (2014) both identified the need for primary care practitioners to decrease stigma through normalizing and discussing the prevalence of mental illness during adolescents' appointments.

Furthering the description of *acceptability*, as part of a more holistic health assessment, general practitioners should form a better understanding of the personal life and needs of an adolescent (Schaffalitzky et al., 2014). Adolescents stated they would like primary care practitioners to learn more about their personal relationships and support networks, and to discuss ways they can improve their mental well-being (Graham et al., 2014). Meredith and colleagues (2009) reported that primary care clinicians should be aware of the perceptions and attitudes adolescents hold regarding accessing care for mental health concerns, and appropriately address these with adolescents and their family. In meeting the health needs of adolescents, general practitioners should provide preventative interventions for mental health (Schaffalitzky et al., 2014), such as discussing positive mental health, lifestyle modification, and educating parents about preventative actions to improve mental health. To improve adolescents' understanding and autonomy in decision making, primary care practitioners and clinicians should also discuss other treatment options before prescribing medication (Graham et al., 2014; Meredith et al., 2009). Furthermore, if being referred to another service, adolescents want information from their primary care practitioners about what they can expect at their first appointment (Graham et al., 2014).

Relevant literature has also highlighted the importance of *acceptability* regarding the relationship between adolescents' parents and primary care practitioners. In a study to develop quality standards for adolescent mental health services in primary care in England, Sayal and colleagues (2012) interviewed 34 parents and 55 primary, secondary, and community-based health professionals. This qualitative study was found to be of moderate strength as it provided a clear description of the development of quality standards, although it did not specify the qualitative methodology that was used (see Appendix G). Parents identified that they would like general practitioners to provide education regarding the management of and how to cope with, their child's mental illness. Additionally,

parents stated that they wanted general practitioners to educate parents and adolescents equally, including explaining the referral process and wait times. If unable to sufficiently address a child's health concern, parents want their general practitioners to make a prompt referral to more appropriate services. Another moderate strength qualitative study by Sayal and colleagues (2010) in England explored the experiences of parents (n=30) who sought help for their children's mental health concerns from primary care. Similar to the previous study by Sayal and colleagues (2012), the authors provided a thorough description of the analysis process but did not specify the qualitative methodology used (see Appendix G). Findings showed that parents valued when their general practitioner showed interest in their child and family, as this was a facilitator to relationship building. Some parents reported that their general practitioner did not take their concerns seriously, which resulted in parents considering whether to access primary care again for their child's concerns (Sayal et al., 2012).

Furthering the evidence for the dimension of *acceptability*, a methodologically strong qualitative study explored the experiences of 26 Australian adolescents between age 13 to 17 years with depression and their satisfaction in receiving primary care mental health services (McCann & Lubman, 2012). This study employed interpretive phenomenological analysis, providing a clear description of the analysis process and how rigor was established (see Appendix G). Findings pointed to the importance of primary care clinicians being adolescent-friendly. Engagement of adolescents in care occurred when they felt

respected and heard by the clinician, and when they could talk openly about their situation. Leahy and colleagues (2018) found that a pre-existing positive relationship with their provider could also facilitate improved access to services, however adolescents may feel uncomfortable disclosing their mental health concerns to a primary care physician whom they know well.

Several studies were found that addressed the influence of parents on adolescents' access to primary care for mental health concerns. A methodologically strong qualitative study was conducted in the United States involving 15 primary care providers (Radovic et al., 2014). Strengths included an in-depth description of the qualitative analysis process and use of analyst triangulation (see Appendix G). The study identified interpersonal level factors that influenced primary care access which did not fit explicitly within the access dimensions. Results underlined the role of parents in adolescent depression care in primary care and found that primary care providers believe parents play a pivotal role in accessing services. Primary care providers reported that access to services was improved if the parent desired treatment for their child, as they provide transportation, motivation, and financial resources (Radovic et al., 2014). Sayal and colleagues (2010) also found that parents sometimes feared the stigma of having their child diagnosed and appearing to be a "bad parent" to their general practitioner (Sayal et al., 2010). Like adolescents, parents reported that a longstanding relationship with their general practitioner facilitates seeking

primary care for mental health services for their child, yet they also feared their concern may be downplayed by them (Sayal et al., 2010).

A methodologically strong systematic review by O'Brien and colleagues (2016) described the important relationship between parents of adolescents and primary care practitioners (see Appendix G for quality appraisal). This review, conducted in England, included 43 primary studies from countries including the United Kingdom, United States, Australia, and Canada, and aimed to understand primary care practitioners' perceptions of barriers to the treatment of adolescent mental health problems. The authors found that primary care practitioners believe parents may be more likely to access primary care services for their children if they have a longstanding relationship with their physician. Similarly, Sayal and colleagues (2010) found two main facilitators to accessing care for adolescents: parents who had established a previous positive, trusting relationship with their primary care physician, and continuity of care. Parental factors influencing access included time, accepting the adolescent's illness, feeling overwhelmed, and conflict in the home (Radovic et al., 2014). Positive family support facilitated better access and improved support at home for adolescents (Radovic et al., 2014). Overall, this evidence shows that parents play important roles in adolescents' care seeking and access to primary care mental health services.

Ultimately, the literature has highlighted several important interpersonal relationships which impact the dimension of *acceptability*: relationships between primary care and adolescents, parents as important influencers of access, and the

relationship between primary care and parents. Those working in primary care must improve their understanding of the individual, their context, and their needs, to offer more holistic and adolescent-centered mental health services. Additionally, a recognition of specific considerations of adolescents, such as confidentiality and disclosure to parents, should be accounted for in providing care.

#### **Organizational Level Influences**

The organizational level of the ecological model identifies the policies and rules, which can be formal or informal, that govern within an organization or institution (McLeroy et al., 1988). For example, the structure of work, guidelines or regulations, and management (McLeroy et al., 1988).

Existing relevant literature explored the access dimensions of *accommodation* and *awareness*. Regarding *accommodation*, some adolescents reported that finding time to access primary care for mental health services can be difficult due to school commitments, recreational activities, work, and appointment hours (Meredith et al., 2009). Another consideration to accommodate adolescents in care delivery was to improve adolescent engagement in services by incorporating technology-based interventions such as text message appointment reminders (McCann & Lubman, 2013). This evidence within the organizational level suggests that more can be done to ensure primary care mental health services are delivered in ways that facilitate engagement with adolescents.

A potential solution to address *awareness* was identified by Graham and colleagues (2014). One strategy to improve the perception that primary care can address mental health concerns was to advertise that general practitioners can help with these problems. Another recommendation was for primary care physicians to assess adolescents' understanding of mental health and primary care mental health services as part of routine care (Meredith et al. 2009). Thus, some evidence was presented which discussed considerations at the organizational level of the ecological model, involving *accommodation* and *awareness*, to improve the structure of how services are delivered and increase adolescents' knowledge about primary care mental health services.

#### **Community Level Influences**

Within the ecological model, the community level refers to "relationships among organizations, institutions, and informal networks within defined boundaries" (McLeroy et al., 1988, p. 363). Thus, community includes local networks of relationships, relationship between service providers, organizations or institutions, and geographic boundaries (McLeroy et al., 1988).

Literature that reported on the community level of influence was found in the access dimension *awareness*. O'Brien and colleagues (2016) found that primary care practitioners were often unsure about where to refer adolescents and felt uncertain about what other services they could offer their clients. They found that wait times created barriers to access, as they may inhibit primary care practitioners from making referrals to specialty care. Additionally, a lack of
communication between primary care and other services was perceived to have caused a large disconnect among care providers in relation to adolescent mental health services (O'Brien et al., 2016). To allow for seamless collaboration and referrals, general practitioners should have information about other services onhand (Schaffalitzky et al., 2014). Adolescents reported that primary care practitioners should be equipped with up-to-date knowledge of available resources in the community (Graham et al., 2014). Overall, at the community level, there is a need for strengthened relationships between primary care and other communitybased organizations or services which are important in an adolescent's recovery. Thus, improvements in access can be facilitated through improved knowledge of other mental health services available to adolescents.

Describing aspects of *awareness*, some studies explored the role of other service providers or organizations within an adolescent's life. Health care professionals in the study by Leahy and colleagues (2013) highlighted the importance of primary care maintaining constant communication with other services within an adolescents' circle of care, such as addictions or mental health therapy services. Schools have also been recognized by primary care physicians as important stakeholders in inter-agency collaboration, which could be beneficial in reaching adolescents (Schaffalitzky et al., 2014). Schools may be suitable sites as the first point of contact to initiate early identification of mental health concerns, and subsequently to prevent worsening of mental illnesses (Schaffalitzky et al., 2014). This evidence focused on *awareness* within the

community level of influence including the importance of primary care's knowledge of and relationships with local services and care providers to improve access for adolescents.

### **Policy Level Influences**

The policy level of the ecological model refers to local, provincial, or federal public policies which influence access to health care (McLeroy et al., 1988). In Canada, this could include larger-scale provincial/territorial policies which influence health care funding and service delivery, or local governing authority decisions regarding how health care services are organized.

Within this body of evidence, policy level influences on the access dimensions of *accommodation* and *availability* were identified. Regarding *accommodation* (i.e., how resources are organized to accept patients and clients' perceptions of their appropriateness), primary care practitioners identified that limited time for consultations creates a barrier to exploring and addressing adolescent mental health concerns (Schaffalitzky et al., 2014; O'Brien et al., 2016). Although primary health care professionals stated they would like more time to offer improved mental health services, limited funding has resulted in staffing shortages and has posed significant barriers (Leahy et al., 2013). Resource limitations in primary care services were among the most frequently stated barriers to the delivery of adolescent mental health services (O'Brien et al., 2016). These findings relate to the policy level as they describe considerations for

governing authorities determining funding structures which impact the organization of service delivery for primary care.

Primary care practitioners have reported they feel they do not have adequate knowledge and skills needed to address adolescent mental illnesses, therefore limiting availability of services (Leahy et al., 2018; O'Brien et al., 2016; Schaffalitzky et al., 2014). Again, this finding relates to policy level influences as guidelines for educational training and continuing professional development are set by governing bodies of health care professions. Both studies found that primary care practitioners may not engage in conversation with clients about mental health concerns, and subsequently fail to identify these concerns, due to a lack of confidence in their ability to discuss mental health problems with adolescents (Leahy et al., 2018; O'Brien et al., 2016). Additionally, parents emphasized the importance of general practitioners remaining current on their knowledge of adolescent mental health concerns (Sayal et al., 2010). Thus, primary care providers may require more knowledge and skills to engage with adolescents who are experiencing mental health concerns. Continuing medical education and training for primary care physicians to improve their skills in adolescent mental health is a high priority to facilitate access to care (Leahy et al., 2018; O'Brien et al., 2016; Schaffalitzky et al., 2014). Some primary care and other service providers reported perceiving that a consequence of lack of knowledge and expertise to provide early intervention is that adolescents with acute mental distress are taking precedence over those with mild to moderate

mental illness who also need care (Leahy et al., 2013). This is a significant because it suggests the need for improved recognition and management strategies which prevent worsening mental illness.

A further policy level issue related to *availability* reported by primary care practitioners was the perception that there is a shortage of appropriate specialized services for adolescents with mental illnesses (O'Brien et al., 2016). A consequence of this perceived shortage can be a hesitancy to refer and could result in the adolescent waiting even longer to access appropriate care (Leahy et al., 2018). Regarding *accessibility*, adolescents have also stated they would like to access other services, such as specialty mental health services, at the same site where they access primary care (Graham et al., 2014).

Overall, this evidence highlights policy level access barriers related to a lack of appropriate pre- and post-licensure training, skills, and understanding of adolescent mental health concerns, as well as resource limitations which have impacted access to primary care mental health services. Understanding the broader context for primary care mental health services, and how policy can impact *availability, accommodation,* and *accessibility* is imperative to delivering interventions which improve access.

#### **Summary of Literature Review**

In this literature review, access to primary care for adolescents was shaped by a complex combination of many different factors which influence each level of

the ecological model. A large proportion of the evidence was found to be within the interpersonal level, under the access dimension of *acceptability*. There are several needs of adolescents and parents which must be met by primary care professionals to enable improved access. Adolescents and primary care professionals have discussed the necessity for service provision to be adolescentfriendly. Some of these considerations include: feeling comfortable and respected (Leahy et al., 2018; McCann & Lubman, 2012), emphasizing the confidentiality policy (Graham et al., 2014; Schaffalitzky et al., 2014), decreasing stigma (Graham et al., 2014; Schaffalitzky et al., 2014), and gaining a holistic understanding of an adolescent's life (Graham et al., 2014; Schaffalitzky et al., 2014). Enabling autonomy in decision making, specifically when discussing prescribing medication and other treatment options, was another important care consideration (Graham et al., 2014; Meredith et al., 2009). Finally, parents' perceptions of what is acceptable care provided by primary care professionals also can influence access for adolescents (Sayal et al., 2010; Sayal et al., 2012).

*Awareness* was the second most described concept of access in the literature. Within the individual level of influence, adolescent's lack of knowledge regarding primary care mental health services was a significant barrier to accessing care (Leahy et al., 2018). A potential solution to this was described on the organizational level; primary care should advertise that they offer mental health services (Graham et al., 2014). *Awareness* was further described within the community level of influence, as primary care practitioners lacked knowledge

regarding other relevant mental health services in the community which caused a hesitancy to refer (Graham et al., 2014; O'Brien et al., 2016; Schaffalitzky et al., 2014). As there is a need for primary care to improve their collaboration with other organizations providing services to adolescents (Leahy et al., 2013), primary care should also be improving its relationship with schools to enable early identification of mental health concerns (Schaffalitzky et al., 2014).

The access dimension availability was described within the individual and policy level of influence. When experiencing a mental illness, adolescents may not believe that high-quality care is available to them (Meredith et al., 2009). Several studies reported the perception that primary care professionals do not have adequate knowledge or skills required to address adolescents' mental health concerns, therefore limiting the amount of services available for adolescents' needs (Leahy et al., 2018; O'Brien et al., 2016; Schaffalitzky et al., 2014). Accessibility was described by one study on the policy level, whereby adolescents reported co-location of specialty services with primary care can improve access (Graham et al., 2014). Accommodation was briefly discussed on the organizational level. To improve access, a consideration of adolescents' school and other commitments should be taken into account when booking appointments (Meredith et al., 2009). Within the policy level, *accommodation* was implicated as primary care professionals reported that the amount of time provided during appointments was a limitation to exploring adolescents' mental health concerns (O'Brien et al., 2016; Schaffalitzky et al., 2014).

An important consideration that did not fit within the access dimensions was the influence of adolescents' and parents' characteristics on access. Some characteristics of adolescents which may influence their likelihood of seeking help in primary care included: low socioeconomic status, non-Caucasian ethnicity, family conflict (Ferrin et al., 2009), and personal motivation (Leahy et al., 2013). Perceptions of stigma and how other people may perceive them was also an important consideration when adolescents considered accessing care (Meredith et al., 2009). The relationship between adolescents' parents and primary care professionals was reported as important to consider in facilitating access (Leahy et al., 2018; O'Brien et al., 2016; Sayal et al., 2010). As such, primary care professionals perceived the need for positive relationships with parents (O'Brien et al., 2016; Sayal et al., 2010), as well as recognition of parental factors which influence access such as their knowledge of mental illnesses, and availability of personal resources such as time and finances (Radovic et al., 2014). Lastly, four articles included nurse practitioners and nurses who provide mental health services to adolescents (Leahy et al., 2013; Leahy et al., 2018; Radovic et al., 2013; Schaffalitsky et al., 2014); however, their perceptions of adolescent's access to primary care were not reported separately.

#### Gaps in the Literature

There are several gaps in this literature which highlight a need for further investigation. None of the primary studies in the review were conducted in Canada, limiting the transferability of the findings. Only four of the total 43

studies in the systematic review (O'Brien et al., 2016) were from Canada. Another critical weakness of this body of literature was the lack of definition of access, as none of the research articles included a concrete definition of access or any of the access dimensions. This literature review found that the term access has not been adequately or consistently conceptualized, which has also been reported by other bodies of work (Levesque et al., 2013; Ontario Centre of Excellence for Child and Youth Mental Health, 2015). This is problematic because it was difficult to explicitly distinguish which dimensions of access have been considered in the research. Although studies in the review have discussed access barriers and facilitators (Leahy et al., 2013; Leahy at al., 2018; Meredith et al., 2009; O'Brien et al., 2016; Radovic et al., 2015; Sayal et al., 2010; Sayal et al., 2012), these two concepts alone may not comprehensively delve into the multiple dimensions of access that adolescents perceive when attempting to receive appropriate care.

There was little evidence depicting adolescents' perceptions of *availability* and *accessibility*, and none regarding *affordability*. The existing evidence investigated perspectives of access from different stakeholders, such as primary care professionals, secondary and community care providers; parents; and adolescents. That said, the role of primary care nurses in the delivery of primary care mental health services – including adolescents' perspectives – was not explored at all in the literature. Primary care nurses are important in facilitating continuity of care over time and can play an important role in delivering mental health services to adolescents in primary care (CNA, 2014; 2015).

In examining the life stage of adolescence in the literature, only one study specifically included participants between the ages of 14 to 18 years (Leahy at al., 2018), while other studies spanned the ages of childhood or adolescence to young adulthood. This shows that not enough attention has been given to understanding the life stage of adolescence, specifically high school age adolescents experiencing an anxiety or mood disorder. Additionally, only one of the studies discussed anxiety disorders, despite it being one of the most prevalent adolescent mental illnesses in Ontario (Office of the Auditor General of Ontario, 2016). Several authors have also identified the need to examine specific illnesses and populations in primary care, such as adolescents with anxiety or mood disorders (Leahy et al., 2013; O'Brien et al., 2016). A further gap in literature to note is that only one study discussed the impact of demographic factors which influence adolescent access to primary care mental health services (Ferrin et al., 2009). Existing evidence has not explored how determinants of health, such as race/ethnicity and gender, can influence access to primary care mental health services for high-school age adolescents.

Currently, much of the mental health policy focus in Ontario has been on assisting transitional-age youth, approximately between ages 16 to 25 years, entering the adult mental health system (Centre for Addictions and Mental Health Provincial System Support Program, 2016). A specific focus on access to primary care mental health services from the perspective of adolescents could improve early intervention and prevent the need for more specialized mental health

services, and additionally ensure a continuity of care throughout this transitional period (Canadian Association of Pediatric Health Centres, 2016; Sayal et al., 2010). There were no studies identified in this review that examined the adolescent perspective of access in the Canadian context. The age span of 14 to 18 years is a critical time for the emergence of mental health concerns, as the majority of young adults report that their symptoms began during adolescence (Government of Canada, 2006). Exploring the perceptions of adolescents with anxiety or mood disorders who have accessed primary care mental health services will assist in understanding how access to service occurs and support improved access to care. Finally, as the majority of evidence in this literature review was within the interpersonal level of influence and described the access dimension *acceptability*, there is a critical need for research which investigates access across different dimensions and levels of influences on adolescents.

# **Study Aims**

The primary aim of this study is to explore the experiences of high-school age adolescents, with anxiety or mood disorders, who have accessed primary care mental health services in Ontario. A secondary aim of this research is to examine the role of primary care nurses in facilitating access to primary care mental health services for adolescents. As the role of primary care nurses is not well understood, this research study will provide insights to inform the role of primary care nurses and begin to address access and quality gaps within primary care as identified by Lukewich and colleagues (2018).

# **Research Questions**

This study will address the following primary and secondary research questions:

# Primary research question:

 What are the perceptions of adolescents, between 14 and 18 years of age, living in Hamilton, with an anxiety or mood disorder, of accessing primary care for mental health services?

# Secondary research question:

2. How do primary care nurses facilitate access to primary care mental for health services for adolescents with anxiety or mood disorders?

# **CHAPTER THREE: METHODOLOGY**

## **Research Tradition**

The qualitative research methodology employed in this study was interpretive description. This methodology was first described in 1997 by Sally Thorne as a strategy for investigating a real-world problem identified by experience, and to provide an answer that is relevant to clinical practice (Hunt, 2009; Thorne et al., 1997). These methods allow for naturalistic inquiry, in which a phenomenon can be studied and analyzed within the context in which it occurs (Thorne et al., 2015). Moving beyond descriptive methods alone and incorporating interpretation through this methodology enables researchers to explore underlying meanings, relationships, or processes present across individuals' subjective experiences (Hunt, 2009; Thorne, 2016). Subsequently, the process of inquiry in interpretive description is congruent with clinical reasoning present in applied health disciplines, specifically nursing (Thorne, 2016). The decision to utilize this methodology supported the study aim of capturing the nature of experiences of adolescents, within the context of accessing primary care for mental health services as a person experiencing an anxiety or mood disorder.

Interpretive description does not require the researcher to separate themselves from their experiences and knowledge, but to use this knowledge as part of the theoretical scaffold (Hunt, 2009; Thorne, 2016). Positioning the researcher in the project is an important part of embarking on a study utilizing interpretive description (Thorne, 2016). My personal and professional nursing

knowledge has led me to this research question and, as such, interpretive description has allowed me to honor the ideas that I hold as a person with lived experience of mental illness as a teenager, as well as my experiences delivering mental health care as a Registered Nurse.

This study utilized the previously described six dimensions of access described by Penchansky and Thomas (1981) and Saurman (2016) as a guiding conceptual framework. Scaffolding a study on a framework and using what is already known about the topic is important to orienting the research study (Thorne et al., 1997). The works by Penchansky and Thomas (1981) and Saurman (2016) outlined access dimensions specifically for health service utilization through examining patient satisfaction. A second model used in the study to understand the experiences of adolescents was the ecological model. As noted previously, this model was first described by McLeroy and colleagues (1988) to explain the influence of individual, social, and environmental factors on health behaviours. The ecological model consequently assisted in understanding the multiple levels of influence, including individual, interpersonal, organizational, community, and policy, on an adolescent's experience in accessing services (Centers for Disease Control and Prevention, 2013). The six dimensions of access conceptual framework and the ecological model therefore acted synergistically as a scaffold to explore the personal experiences and broader health care context impacting adolescents accessing primary care mental health services. Another critical piece in scaffolding this interpretive descriptive study was conducting a thorough

literature search to determine what is known and what aspects of the phenomenon of interest have yet to be explored (Hunt, 2009; Thorne, 2016).

#### About the Researcher

I graduated from the Mohawk/McMaster Collaborative Bachelor of Science in Nursing program in 2017 and am now completing my Master of Science in Nursing at McMaster University. I am a Registered Nurse, currently practicing as a mental health nurse in an outpatient clinic at St. Joseph's Healthcare Hamilton. It has been a combination of my professonal nursing experiences and personal experience of accessing mental health services in primary care which has led me to my current research endeavour. When I worked with adolescents in various nursing roles I gained insight into the unique difficulties that adolescents had in accessing health care services because of their age. In providing nursing care, I have witnessed access gaps within the system that made accessing services even more difficult for a person experiencing a mental illness. Throughout these professional experiences, I have also carried my personal experiences. As a person with lived experience, I have my own perspective on the experience of accessing help for a mental illness. I thoughtfully recognize we each have unique experiences and perspectives, and each individual's unique insight and experiences are equally important. Together, this has inspired a passion to work with young people and advocate for those who are struggling with mental illnesses through research focused on the stories of adolescents accessing the mental health services they need.

# Sampling

## Setting and Participants

The study occurred in Hamilton, Ontario. Hamilton is a city in Southern Ontario with a population of 536,917 (Statistics Canada, 2016b). In Hamilton, about one in five people are non-Caucasian, excluding those who are Indigenous Peoples of Canada (Statistics Canada, 2016b). There are over 12,000 Indigenous Peoples of Canada residing in Hamilton (Statistics Canada, 2016b). Additionally, approximately 15% of all residents and over 20% of children and adolescents are living in poverty (Social Planning and Research Council of Hamilton, 2017). Within the total population, there are 61,620 young people between the ages of 10 to 19 years (Statistics Canada, 2016b).

Inclusion criteria for this study included the following: (a) aged 14 to 18 years, (b) currently residing in the city of Hamilton, including residents of Ancaster, Dundas, Flamborough, Glanbrook, and Stoney Creek, (c) self-reported anxiety disorder and/or mood disorder, (d) has a primary care practitioner such as a physician or nurse practitioner, (e) has visited their primary care practitioner within the past 12 months for a mental health concern related to anxiety or mood, and (f) has the ability to speak English (as I am only fluent in this language). Exclusion criteria for participants were: (a) non-English speaking, and (b) actively experiencing acute mental health distress, including active suicidal ideation, thoughts of self-harm, thoughts of harming another person, or any combination of these considerations which could impact safety and ability to give informed

consent. A further exclusion criterion was having an existing or previous patientnurse relationship with me, to prevent crossing the boundary between health care provider and researcher.

#### Sample Size

In interpretive description, there is no set sample size required for a research study; rather, a sample size is chosen based on finding a common understanding of the experience across participants and gaining insight into the problem in the clinical practice setting (Thorne, 2016). Accordingly, an appropriate size for this study was reasoned to be between eight to twelve participants. This sample size was also deemed manageable for a novice researcher completing a Master's thesis within academic time constraints. After discussing the preliminary findings with my thesis committee, a final sample size of ten participants was thought to be sufficient as the narrative emerging from my analysis displayed an appropriate level of comprehension and "generalizable scholarship" (Thorne, 2016, p.108; Thorne et al., 2004).

# Sampling Strategy

The primary sampling technique chosen was purposive sampling (Lavrakas, 2008). I attempted to recruit adolescents who identified their gender as male, female, or non-binary, in order to avoid overrepresentation of one gender. This criterion was meant to allow for examination of the experiences of accessing primary care mental health services across genders, as this was noted in the literature as a potential area of difference (Ferrin et al., 2009). This was done

through initial screening of potential participants where I asked about their gender and attempted to enroll an equal number from each group depending on recruitment. I also employed snowball sampling by asking participants if they knew other adolescents who experience anxiety or mood disorders and may be interested in participating. This method was useful for the study because the topic is of a sensitive nature, and adolescents often discuss their personal concerns with their closest friends (Rickwood et al., 2007; Shaghaghi et al., 2011). Furthermore, because people living with mental illnesses can be considered a hard to reach population, snowball sampling was appropriate (Merriam, 2009).

#### Recruitment

Two strategies were employed to recruit participants: advertising with flyers at various public, social service or health care sites in Hamilton, and online using the social media platforms Facebook and Instagram. The purpose of using these two methods was to increase the opportunity to reach adolescents experiencing mental illnesses who were not currently receiving mental health services. Flyers included: an overview of the research study, participant inclusion criteria, a short description of study activities, and contact information for further details (see Appendix H for recruitment flyer).

Several recruitment sites in Hamilton were selected for flyers to be posted. They included Child and Adolescent Services at Hamilton Public Health Services, Ngen Youth Centre, Hamilton YMCAs, Hamilton Public Libraries, Starbucks, McMaster Family Health Team, Living Rock Youth Ministries, Aboriginal Health Centre, and Urban Core Community Health Centre (see Appendix I for recruitment sites). After receiving ethics board approval, I contacted managerial staff at these organizations to inform them of the study's purpose, potential benefits and risks, request that they post recruitment flyers, expected time commitment from the site, how results would be reported, and potential benefits to the site and participants (Creswell & Poth, 2018). Recruitment of participants began in August 2019 (see Appendix J for study timeline). Flyers were posted in waiting rooms or public areas. At Child and Adolescent Services, McMaster Family Health Team, and the Urban Core, I requested that managers inform health care practitioners of the information on the flyer and to ask potential participants to contact me, if interested.

Advertisements on social media contained the same content as the flyer. These advertisements were posted on a Facebook and Instagram account dedicated to the study. I utilized paid advertisements to target adolescents in Hamilton on these websites. Advertisements posted on Instagram linked to the posts on the Facebook page. These social media pages did not allow viewers to post or comment on advertisements. Potential participants were able to send direct messages on the page to ask for further details about the study. This strategy aimed to target the most popularly used methods of social media by adolescents and provided an opportunity to participate for those not currently receiving mental health services (Amon et al., 2014; Pew Research Center, 2018).

The method of recruitment was tracked based on each strategy used. Of the ten total participants, three participants were identified through word-ofmouth by colleagues, three were from the website Reddit on the Hamilton page where a participant shared the recruitment flyer, two were from community organizations, and two were identified from snowball sampling. When a potential participant expressed interest through social media, voicemail, email, or text message, they were informed that they would be contacted by phone or text message to assess whether they fit the study's inclusion criteria (see Appendix K for recruitment script and assessment questions). The purpose of the research study was explained in detail, and those who were interested were given the opportunity to ask questions. Potential participants were informed that the study required a minimum of two and a maximum of three face-to-face meetings. The first session was to receive instructions and sign a consent form. This required about 30 minutes. The second meeting was for a 60- to 90-minute interview. I informed participants that I might request to meet a third time, or talk over the phone, to clarify any statements made during the previous interview if required. I set a mutually convenient date and time for the interview with participants who met inclusion criteria and wished to participate.

# **Data Collection**

Five methods of data collection were included in this study: a participant demographic survey, photovoice, semi-structured interviews, field notes, and reflexive journaling. The demographic survey (see Appendix L) consisted of eight

questions related to age, gender, race/ethnicity, and socioeconomic status. The second method, called photovoice or photo-elicitation, is a type of data collection which enabled participants to represent their experiences through photos, and allowed for more meaningful engagement with the research study (Catalani & Minkler, 2010). This method of data collection is considered an arts-based approach, which is specifically helpful for communicating health issues that face stigma such as mental illness (Woodgate et al., 2017). Additionally, this was chosen to reinforce to adolescents that they are "experts on their own lives" (Wang et al., 2004, p. 911) through taking photos and providing their interpretation of their meaning. This method is also useful in engaging persons with lived experiences of mental illness in research (Kristy, 2017).

In the semi-structured interviews, I employed open-ended questions to guide the participant into dialogue related to the study topic (Brinkmann, 2018). This is also where participants were given an opportunity to describe their photos and their meaning in representing their perceptions. Participants were still able to participate in the interviews if they were unable or chose not to take photos.

Field notes were comprised of my initial thoughts and observations immediately after a session and were used to help analyze my interpretation of interview data. To include this as part of my data collection strategy, I took 30 minutes after each interview to record these ideas. For example, I recorded my observations regarding key discussion points and the participant's non-verbal communication during the interview. I engaged in reflexive journaling within 48

hours after an interview session was completed. Reflexive journaling allowed me to acknowledge my subjectivity and how my personal experiences shaped the interpretation of the data (Ortlipp, 2008; Thorne, 2016). For example, I reflected on how my experiences as a Registered Nurse providing care to adults experiencing mental illnesses influenced my perception of what is important in relation to accessing mental health services, and the influence of nurses in accessing care.

**Procedures.** Data collection began after the first participant was recruited. Participants opted to meet with me in public areas close to where they live and where there were no other people close enough to hear our conversations, such as at a public park or a local restaurant. These meetings took place on the weekends or evenings to accommodate their school and work schedules. They were permitted to bring a caregiver or friend as a support person to the sessions if they chose, and were informed that this person's responses would not be part of the research. Although the presence of another person could prevent the participant from freely discussing their perspective (Thorne, 2016), it was expected to be beneficial for some participants to have a person with them for comfort. One participant chose to have a support person (a friend) with them during the interview.

**Session one.** The first session involved meeting with the participant to: introduce myself as the researcher, outline the research project, discuss confidentiality, obtain consent, complete the demographic survey, and describe

the photovoice methods. Considering the sensitive nature of discussing mental illness, I began the session with outlining confidentiality and ensured the participants understood that the sessions were a safe space to discuss their experiences. I also explained the limitations of confidentiality (i.e., legal obligation to disclose potential risk of harm). Participants were informed that this session was not audio recorded. I built rapport with the participants by introducing myself and providing a brief overview of my personal and professional experiences providing care to individuals experiencing mental illnesses. To assist in creating a safe space for discussion of mental health concerns, I utilized appropriate language in communicating with participants. For example, I ensured I followed the adolescent's personal preference for person-first or identity-first language (Mental Health Commission of Canada [MHCC], n.d.) when discussing their mental illness (e.g., a person with depression or a depressed person).

In describing the purpose of the study, participants were informed that the goal of this project was to understand their perceptions of getting help or trying to get help from their primary care doctor or nurse practitioner for a mental health problem. They were asked to use a cell phone, tablet, or digital camera to take photos. I reviewed with participants some things to consider when taking their photos. For example, participants were asked to take photos of things that directly or indirectly represented something that made it harder or easier for them to get help from their primary care doctor or nurse practitioner. Participants were given a handout to reinforce the instructions for taking photos (see Appendix M for

participant instructions). These instructions included ensuring there was no confidential information present in the photos. Participants were also provided with caption sheets to be used for creating a short caption for their photo. As part of the research, participants were asked to submit their photos to MacDrop, a secure online server hosted through McMaster University, dedicated to the study and only accessible by me (see Appendix N for submission form). I provided an encrypted USB drive to upload the photo files, if needed. We then planned a time to meet for session two.

Most participants used the USB drive to share their photos; only two decided to use the MacDrop folder. Ultimately, participants found the caption sheets to be redundant; instead, they chose to describe their intended meaning of the photos during the interviews. As such, the caption sheets were not completed by any participant. To mitigate adolescents potentially dropping out of the study, I contacted participants for session reminders the day before a session by email, text message, or phone according to their preference. After the first session, I contacted participants within three days to ask if they needed assistance with the photo project, such as support to submit the photos to MacDrop.

**Session two.** Session two was scheduled within one week of the first session. During session two, I followed a semi-structured interview guide to ask participants about their experiences and their photos (see Appendix O for interview guide). This session was audio recorded. This was where they had an opportunity to describe their photos, provide a caption, and discuss how the

photos relate to their perceptions of accessing primary care mental health services. I conducted a pretest of the instructions and interview guide with the first participant. Based on their experience in working through the photo project and responding to the interview questions, I refined the instructions and interview guide to improve clarity for subsequent participants. For example, initially I planned to guide the participants by introducing each access dimension. I noted that the first participant described access dimensions throughout recounting their experiences. Thus, for subsequent interviews I allowed the participant to lead with their personal story and asked questions regarding access dimensions as they naturally emerged. As there was potential for the dialogue to result in emotional responses, I regularly checked-in with participants throughout the interview to assess if they wanted to continue, take a break, or stop the interview (Morrison & Stomski, 2014). Based on what was described in the interview, participants were informed that they may be contacted for a third session if needed to clarify their interview responses. However, there were no instances where a third session was required.

#### **Data Analysis**

In keeping with qualitative research methodology, data analysis began immediately after the first interview and continued concurrently with subsequent data collection in order to build relational findings (Thorne, 2016; Thorne et al., 2004). This allowed me to identify areas of the research which needed more investigation. For example, parent influences on access appeared to be a recurring

theme from the early interviews, and was included in questions for interviews with subsequent participants. I listened to the audio recordings of sessions and transcribed them verbatim into a Word document, including comments regarding tone of voice and humor. After completing four transcriptions, a transcriptionist was hired for the subsequent interviews. I reviewed all of the transcripts against the audio recordings to ensure accuracy.

I began my analysis by immersing myself in the data. Thorne and colleagues (1997) emphasize the importance of immersion as the researcher comes to know each piece of data intimately and can recognize the important themes from the data. I did this by reviewing the transcripts of the interviews while listening to the recordings. Alongside analyzing my field notes and reflexive journaling, I made notes on the margins of the transcripts to highlight pieces of data to assist me in understanding how this information fit into the larger context (Thorne, 2016) of access to primary care mental health services. I used the software by QSR International (n.d.) NVivo 12 to organize the data and create nodes. Photos were also entered into NVivo with their caption from the interview and descriptions for coding. As captions were linked to their subsequent photos in NVivo, this allowed for seamless integration of the photos and their meaning with the participants perceptions of access. To support analysis, I printed all photos and examined them amongst each other to find similar ideas or patterns.

The next step after becoming immersed in the data was to organize the initial findings. I utilized open coding as identified through my notes and

highlights to pull apart separate pieces of information in the data and begin to build them into categories (Thorne, 2016). After I initially coded the transcripts, I used deductive analysis to categorize my codes within the framework of the six dimensions of access, nested within the relevant levels of the ecological model. Coding outside of this also occurred where emerging categories (groups of similar codes) did not fit the framework or model. To better understand the data, I asked myself the following questions: "What is happening here?" and "What does this tell me about this experience as a whole?" (Thorne, 2016; Thorne et al., 2004). After analyzing participant data separately, I began by looking at which categories and themes frequently emerged across interviews. At this point in the analysis process, several instances where findings did not fit within the access dimensions framework were noted.

I then employed inductive reasoning to search for explanations of findings outside of the access dimensions framework (Thorne, 2016). Morse (1994) describes this step as theorizing explanations for findings in the data. This required me to use my observations of each individual interview session and what the participant had said to make a broader generalization about what this information meant to the overall experience of access (Thorne, 2016). For example, as participants described their perceptions of access, some of their ideas did not fit within the access dimensions framework. I continued to practice reflexive journaling to examine how my initial assumptions about the topic were shaping my interpretation of the findings (Thorne, et al., 2004). I examined the

relationship between codes organized by the access dimensions and ecological model and was able to uncover themes. I then tested several options of interpretations by asking myself questions such as "What happens if I group what I have in this way versus the other?" (Thorne, 2016, p. 187). To do this, I utilized visual models which could depict the sequential process of access described by adolescents in the study.

The final phase of data analysis was to recontextualize the findings (Thorne et al., 1997). To create knowledge that was relevant to clinical practice for primary care providers working with the participant population and to answer the research questions (Thorne et al., 2004), I asked myself: "What is it like to access primary care mental health services for adolescents with anxiety or mood disorders? How can we better facilitate access that is relevant to the needs of adolescents experiencing anxiety or mood disorders?" I also looked to draw conclusions regarding the future role of nurses in primary care mental health services.

# Rigor

To establish rigor in this research study, I employed the four criteria for rigor in naturalistic inquiry outlined by Lincoln & Guba (1985) which include credibility, transferability, dependability, and confirmability. These criteria for rigor follow methodological congruence with interpretive description as one of the underpinnings for this methodology is that the study is conducted in a naturalistic context (Thorne, 2016).

First, credibility requires that it is evident how the findings of the study came to be (Guba, 1981). Thorne (2016) also states that interpretive descriptive studies must display "representative credibility" (p. 234), such that the findings are consistent with how the phenomenon of interest was studied. I performed this through source and analyst triangulation (Lincoln & Guba, 1985). To meet the requirement of source triangulation, I examined the five different data sources in the study to assess consistency across findings (Patton, 1999). For example, I inspected participant photos and their captions alongside my field notes from the interviews to maintain stability throughout the analysis process. I engaged my supervisory committee in throughout the data collection and analysis process to assist in analyst triangulation. Analyst triangulation allowed me to see the data and conclusions from perspectives outside of my own (Patton, 1999).

The second criterion of transferability refers to how the research may be relevant to other similar contexts (Guba, 1981). As this study involves naturalistic inquiry, there are limitations to transferability because the context for the research is highly related to the findings (Krefting, 1991). Guba (1981) suggests that it is the responsibility of those interpreting the study to assess the degree of fit between the study context and an external one. Therefore, I have endeavored to provide rich contextual data (e.g., community setting and participant demographics) that enables the reader to draw their own conclusions about whether the findings might be transferrable to their own context.

Third, dependability refers to the concept that the research findings are reliable and consistent (Guba, 1981). Thorne (2016) describes this aspect as "analytic logic that makes explicit the reasoning of the researcher" (p. 234). This criterion involves having descriptions of how data were collected, analyzed, and interpreted (Krefting, 1991). One method I employed to fulfill dependability is keeping an audit trail describing how I have made various decisions in the study. Although analyst triangulation was previously mentioned, this strategy is also beneficial in assessing stability in analysis over time (Krefting, 1991). Additionally, I utilized constant comparison between pieces of data to assist in stability when theorizing relationships during the analysis process (Thorne, 2016).

The final criterion to be fulfilled was confirmability, which refers to the findings of the study being produced through the data and not entirely through assumptions of the researcher (Krefting, 1991; Guba, 1981). The previously mentioned strategies of analyst and source triangulation, as well as audit trails are methods that support the confirmability of the research (Krefting, 1991). Utilizing reflexive journaling was another important strategy to improve transparency in the findings, and to illustrate how the researcher's assumptions could shape the research findings (Guba, 1981; Moon et al., 2016). An example of how I met this criterion was through engaging my supervisory committee throughout the analysis process which included sharing and ideas about the data captured through reflexive journaling.

## **Ethics Approval**

# Consent

This thesis study was approved by the Hamilton Integrated Research Ethics Board (HiREB) in June 2019. In considering the age of the population being studied it may have been appropriate to obtain consent, or assent and consent (Cohn, 2010). Although there is no stated age of consent specified by the Government of Canada (2018) in the Tri-Council Policy Statement 2, maturity and understanding must be assessed. HiREB recommends that participants aged 15 years and under give assent, with consent provided from their parents. When studying this population, it was important to consider that adolescents' parents may not be aware of their mental health concerns, or they could have stigmatizing attitudes towards mental illnesses (Mukolo et al., 2011). Therefore, for participants under age 16 who did not want their parents involved. I assessed their maturity and understanding. To accurately judge if participants were able to understand the nature of the research and the risks involved, after I described the study, I asked them to tell me in their own words what the study was about, what the risks were, and why they wanted to be involved. This assisted in helping assess competence by displaying understanding, retention of information, and freedom of choice (Larcher, 2005). None of the participants in the study required assent or parent/guardian consent as they were either age 16 or older, or they were able to convey their understanding of the study and provide informed consent (see Appendix P for participant consent form).

# Confidentiality and Safety

All data were kept in password protected files, on a computer which was used in a private setting and locked. The audio-recorder and cell phone were kept in a locked cabinet in a locked room, when not in use. Consents and demographic forms were kept in a locked cabinet in the locked room. Participants were made aware that their name and identifying information would not be shared along with the findings of the research. Additionally, they were informed that the information shared with me would not be shared with anyone else, and I highlighted that their parents and primary care practitioner would not be informed of their participation. As a cell phone was used to contact participants and send them session reminders, the phone was only be used by me and did not contain any confidential participant information.

Although participants were screened for suicidal ideation prior to study enrollment, participants were also informed of confidentiality limitations such as being at risk of harming themselves, another person, or if they disclosed information which suggested they or another young person under the age of 16 was at physical or emotional risk by a third party. In compliance with duty to report legislation in Ontario, I planned to inform the Children's Aid Society if a participant under age 16 years disclosed information that suggest they were in need of protection (Provincial Advocate for Children and Youth, 2016). In case a participant experienced acute distress during or after an interview, I provided all participants with a list of community and emergency resources at the beginning of

our first interview (see Appendix Q for mental health and community crisis supports resource sheet). As I was acting in the role of researcher and not as a nurse, I planned to contact crisis support (i.e., calling 911) if there was an immediate risk of harm. All study participants screened negative during the initial recruitment screening, and no acute mental health concerns arose during the interviews.

#### *Compensation*

A monetary incentive of a \$20 gift card per session was offered for participation, as this was previously identified as an appropriate honorarium for the target population (Seymour, 2012). Depending on method of transportation, each participant was given two bus tickets or a parking pass, if necessary, to recover their travel costs. As locations were chosen by participants and often geographically close to where they lived, bus tickets were given to a few participants; none required parking passes. Additionally, as the research involved the use of photos, participants were paid \$1 for each of their photos, up to a maximum of \$5, and were asked to sign a photographer release form (see Appendix R). This allowed me to reproduce any photographs (without any identifiable images of people in them) to support the reporting of the results.

## **CHAPTER FOUR: FINDINGS**

This chapter of the thesis outline the results of the study, beginning with a description of the participant demographics and their participation in the data collection process. To answer the primary and secondary research questions, the subsequent sections present the main findings and subthemes. Participant quotes are presented using gender-neutral pseudonyms to protect their identities. Additionally, the term "mental health concerns" is used as a general term to denote symptoms of anxiety or mood disorders.

# **Participant Demographics**

Ten participants were recruited to participate in the study. Participants reported on their gender, identity as LGBTQ2S+ (Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Two-Spirit, plus), ethnicity, diagnosed mental illness, and if they or their family is receiving social assistance. They also reported on their access to mental health care entry point, and use of primary care services. Table 1 on the following page presents demographic details of the participants.

None of the participants recruited dropped out of the study. Four adolescents participated in interviews but did not take photos. Three participants were unable to take photos due to personal time constraints from school and work demands, while one participant was not interested.

# Table 1

# Participant demographics and service use

Variables	Ν	Percent of total (%)
Age		
14	0	0
15	2	20
16	1	10
17	4	40
18	3	30
Gender		
Female	6	60
Male	2	20
Non-binary	2	20
LGBTQS2+		
Yes	3	30
No	7	70
Ethnicity		
Caucasian	9	90
Non-Caucasian	1	10
Self-reported mental illness*		
Anxiety disorder	5	50
Depressive disorder	1	10
Bipolar disorder	1	10
Obsessive compulsive disorder	1	10
Anxiety and depressive disorder	3	30
Receiving social assistance		
Yes	4	40
No	5	50
Unsure	1	10
Entry point to access mental health care		
Primary care	5	50
Therapy or counselling	3	30
Acute care	1	10
School	1	10
Last visit to primary care		
Three months or less	5	50
Three to six months	2	20
Eight to eleven months	3	30

\*Categories not mutually exclusive

Table 1 (	continued)
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Variables	Ν	Percent of total (%)
Frequency of visits to primary care		
Monthly	2	20
Bimonthly	2	20
Quarterly	2	20
Semi-annual	3	30
Changes based on need	1	10
Other health care professionals		
providing mental health services*		
Therapists	7	70
Psychiatrists	2	20
Occupational therapist	1	10
Dietician	1	10
None	3	30

\*Categories not mutually exclusive

# **Main Findings**

This study found that several external and contextual factors influenced the process of accessing mental health services from primary care for adolescents experiencing an anxiety or mood disorder. While some of these findings aligned with the access dimensions outlined by Penchansky and Thomas (1981) and Saurman (2016), many did not, suggesting factors outside of the dimensions often discussed in the literature. Further, these factors both operated and were influenced by considerations at multiple levels of influence within the ecological model (McLeroy et al., 1988). Additionally, it is important to note that participants reported their perceptions using language that did not necessarily coincide with the access dimensions and levels of influence conceptualized in the guiding framework and model, and reflected conceptualizations of the adolescents themselves. The analysis process led to identification of one overarching theme *"It's not about the end – it's about the road"*, as well as three main themes and several subthemes. To introduce the themes, each is briefly defined, including a description of how the theme is depicted in a proposed conceptual framework, and a participant photograph to support the theme. Detailed results for each theme and subtheme follow.

Adolescents in the study perceived accessing primary care mental health services as a process, using terms such as "journey", "path", "long", and "road to recovery" to describe their experiences. The overarching theme "*It's not about the end – it's about the road*", stated by participant Blake, encompasses adolescents' perceptions of access overall, and describes the path involved in arriving at primary care. This process involved three phases as part of the access journey: "*It was all in my head*", "*I needed help*", and "*I wanted to be seen as a person*". Figure 1 on the following page displays a proposed conceptual framework illustrating an adolescent's journey through this process of access using these themes and their subthemes.

The image of the valley and hills was chosen to align with participants' perceptions that accessing primary care for mental health services is a personal journey leading towards recovery of a meaningful life that can be challenging and does not necessarily have a set endpoint in terms of what is traditionally thought of as clinical recovery. The path used in the framework is shown to descend between hills and valleys, depicting adolescents' perceptions that the process of moving towards accessing primary care can be difficult, and each phase presents
# Figure 1

The process of access to primary care for mental health services: "It's not about the end - it's about the road"



its own challenges. Blake described this as: "It's a long journey. And black and white, it's just kind of, it's moody and it's not easy". Harper also provided an encompassing statement about this difficult process, stating: "When you're in the office, it means you've managed to get somewhere and are taking a steppingstone to getting better." These participants took photographs of paths to represent their perceptions of their access experiences, displayed in Figure 2 on the following page.

# Figure 2

Photos by Blake and Harper depicting the process of access as a road or path



The first major theme "*It was all in my head*" refers to adolescents' perceptions of the internalized process where they initially reported: feeling uncertain about their mental illness symptoms and the need to access help, a knowledge gap regarding what services for mental health were offered in primary care, and fears about stigmatization or hospitalization if they decided to seek help. This theme is depicted as a valley in the figure because adolescents perceived this phase as being challenging; they reported feeling alone in their experiences of mental illnesses and felt unsure about what to do. Simran stated: "Mental health is really isolating ... I thought it was just me alone, going crazy." Quin took a photo (Figure 3 on the following page) symbolizing this idea, stating: "The dark brown flower amongst the green ones is to me a symbol of loneliness or being out casted as different and not really fitting in anywhere, because of what you're feeling

## inside."

# Figure 3

Photo by Quinn depicting their perceptions of loneliness



The second major theme "*I needed help*" refers to: adolescents coming to recognize the need to obtain help for their concerns and subsequently externalizing their concerns with parents, family, or friends; using the Internet to learn about other people's experiences of mental illnesses; and seeking advice from others in their life or online to decide how to access help for their mental health concerns. A hill represented this theme, as it depicts an upward process of overcoming obstacles and obtaining motivation as adolescents decided to move towards seeking help in primary care through support from other people.

The final major theme "*I wanted to be seen as a person*" involves obtaining help for their mental health concerns in primary care including perceptions of entering the primary care environment, and interacting with their primary care professionals. This was also depicted as a hill in the model, which displays the upward process and the notion that there can be continued challenges in receiving mental health services. The last shaded hill in the background depicts access as a continuing process on their recovery journey, as adolescents reported that they either were referred to other speciality services or continued to access mental health services in primary care over time.

The following sections will describe these stages in detail. The first three themes each have four subthemes and the third theme has three subthemes, which are further broken down into characteristics that provide a rich description of the subtheme. Some of these characteristics are presented in other subthemes indicating their cross-cutting nature. For example, the subtheme Supporting Development during Adolescents' Emerging Adulthood is present throughout several subthemes in the major theme "*I wanted to be seen as a person*". For ease of reference, cross-cutting subthemes and characteristics were organized by best fit according to adolescents' descriptions of their access journey. Each major theme is also organized under the ecological model and access dimensions where applicable. These categories do not always represent a perfect fit but were helpful in organizing the data under concepts in the guiding framework and model. A

summary of themes and subthemes organized by the guiding framework and model can be found in Appendix S.

## Theme One: "It was all in my head"

Adolescents in the study described several important factors that impacted the process of access which is reflected in the theme "*It was all in my head*". Overall, this theme was described as a difficult internalized process early in their access journey which involved identifying their: a) mental health concerns and the need to obtain help for them, b) knowledge of what primary care could offer for mental health concerns, c) fear of stigmatization, and d) fear of hospitalization. This theme's four subthemes all fall under the ecological level of the individual. One subtheme fit the access dimension – awareness – and involved not knowing about primary care mental health services, while the other three subthemes were precursors to accessing services and represented factors outside of the access framework. Each subtheme is presented below.

1a) Uncertainty of Mental Illness Symptoms and the Need to Access Help (Individual level: factor outside access framework). Most participants reported that although they felt something was wrong, they did not know that they were experiencing a mental illness. The uncertainty of mental illness symptoms resulted in some participants reporting that they questioned what they were experiencing. Reflecting on their experiences, Simran stated: "I didn't understand what any mental illnesses were to be honest .... And because of stigma, part of me thought maybe this wasn't even real." Some participants stated they did not know if their concerns warranted help, for example Quinn stated: "I had like a lot of difficulty getting help. Cause, I wasn't sure if I actually needed it or if it was all in my head."

#### 1b) Not Knowing Primary Care Offered Mental Health Services

(**Individual level: awareness**). Prior to getting help, all participants noted that they were unaware that primary care offered mental health services. Further, they did not know where to access help for their concerns. Some believed that to receive mental health services they would need to go directly to a psychiatrist, therapist, or hospital, and that primary care only managed physical health concerns. As Simran stated:

I had no idea the level of what they could do there. I thought maybe I could get sent straight to a psychiatrist or straight to the hospital. Because I thought you go to the family doctor if your nose is runny or something.

Similarly, Alex discussed: "I didn't think you went to your doctor's, I thought you went straight to a therapist... I thought it was just for [physical] sickness."

## 1c) Fear of Stigmatization (Individual level: factor outside access

**framework).** Most participants discussed having a fear of stigmatization if they were to access help for their concerns. Although the notion of stigma of mental illnesses was raised at different points in the access process, adolescents predominately described fears of stigmatization through the first major theme. As such, this finding has been expanded on here. Within this subtheme, adolescent's

expressed their fears of how others would judge them or react, which could cause a hesitancy to seek help. For example, Quin stated: "Telling people how you feel or what's going on in your head is like 'How are they going to react? Are they going to see me any different? Are they going to treat me any different?" Most participants described feelings of vulnerability if they were to talk to someone about their mental health. This sentiment was depicted in Figure 4 in which Blake described vulnerability as: "You're locked up you have to open and tell people all your dark secrets right? .... It's kinda like your guarded secrets of your mental health and you have to be honest about things."

# Figure 4

Photo by Blake depicting their perceptions of vulnerability when discussing mental health concerns



#### 1d) Fear of Hospitalization (Individual level: factor outside access

**framework**). Within this final subtheme, some participants described fears of hospitalization when they were deciding if they should access help and discuss their mental health concerns. Blake stated: "A lot of people are kind of scared of being hospitalized involuntarily .... Like, how honest can you be before you're sent away?" To explain the root of this uncertainty and fear of hospitalization, Simran discussed: "A lot of media consumption led me to believe I'd be put in a mental ward right away. So, I was really nervous to start talking about what exactly was wrong."

In summary, the theme of "*It was all in my head*" aligned with the individual level of the ecological model and incorporated the dimension of awareness and factors outside of the access framework. Adolescents expressed not knowing that primary care offered mental health services, demonstrating a lack of awareness. They also discussed difficulty in identifying the symptoms of their mental illness and if they required help for these concerns. Finally, adolescents reported perceptions of their fear of stigmatization and the potential of being hospitalized if they choose to access help for their mental health concerns. Therefore, the first access process of "*It was all in my head*" involved several aspects of examining internal knowledge of mental health concerns and available mental health services. This also included overcoming personal fears to begin the process of receiving help.

## Theme Two: "I needed help"

There were multiple factors participants described which related to the second theme *"I needed help"*. This theme describes initiating the second phase of seeking help on their recovery journey which involved taking action on their mental health concerns by obtaining support from other people, and learning that they can access help from primary care. This theme has four subthemes which all fit the interpersonal level of influence, and three described factors outside of the access framework. One subtheme described the access dimension of awareness. These subthemes included: a) parent role in enabling accessing, b) encouragement from friends, c) family perceptions of mental health concerns, and d) researching online about mental illnesses and others' experiences.

2a) Parent Role in Enabling Access (Interpersonal level: factor outside access framework). Most participants reported that their parents played an important role in helping them in deciding to access services. They reported their parents helped push them to seek care and took action to assist in obtaining help for their child's mental health concerns through booking appointments and providing transportation. Teagan discussed the importance of parents in this role, stating:

I can't remember if it was my mom or my dad, but it was one of them who called and it was one of them who dragged me to the appointment because I really didn't want to go .... I never considered [going to the doctor's] myself until my parents kinda forced me to. Additionally, some participants perceived that their parents had an understanding of what type of mental health services they needed from primary care. As Harper stated: "I needed help and I went to my mom … when she found out there were options to put me on certain antidepressants that would help fix the issues I was having, she took me to the family doctor." This reflected the idea that parents may take an active role in deciding which services are needed to assist with their adolescent's mental health concerns.

**2b)** Encouragement from Friends (Interpersonal level: factor outside access framework). A common subtheme among participants was the role of their friends in providing encouragement to access help for their mental health concerns. Quinn stated: "Friends are a big part of support for, like, when you're having a mental disorder or mental issues. So, they do play a big part in getting to that step of getting help." Some participants also reported that their friends had suggested they seek help for their concerns through primary care. For example, Ryley shared: "I have a friend that has anxiety and she told me that she went to the doctors and they diagnosed her. It really helped. So, I thought that would be good for me."

**2c)** Family Perceptions of Mental Health Concerns (Interpersonal level: factor outside of access framework). Some participants described how their family's perceptions of mental health concerns could positively or negatively influence their own perceptions of accessing help. A few participants reported their family members were understanding and encouraging of receiving help for their mental health concerns, as Simran stated about their mother: "She was 100% supportive ... she struggled when she was a kid too. And my dad did too, like I said, it's in the family." Conversely, a few participants reported that their family members perpetuated stigma surrounding mental health concerns, making it difficult to access help. Jamie stated, "My dad, he's like, 'Stop being a pussy, you're not actually depressed.' Or with my grandparents ... they think mental health is a myth."

# 2d) Researching Online about Mental Illnesses and Others' Experiences (Interpersonal level: awareness). A few adolescents reported that they researched on the Internet information about mental illnesses and other people's experiences with them. Participants reported that they utilized the Internet to learn about how other people had obtained help for mental health concerns. This subsequently helped inform them that primary care offers help for mental health concerns. Blake took a photo describing this (Figure 5 on the following page), and shared:

There's a lot of stories [online]. There's people's success stories or people who are depressed, but it was motivational to hear that things can get better... By looking at the internet and success stories I was like, "well might as well [try to get help]" right?

In summary, the second subtheme "*I needed help*" described the interpersonal level of influence, factors outside of the access framework, and the access

## Figure 5

Photo by Blake depicting researching online about other people's experiences

of mental illnesses



dimension awareness which contributed to adolescents motivation to move towards receiving care. This theme discussed the importance of recognizing the need for and receiving help or support from other people, which assisted adolescents to initiate the process of taking action to access primary care. This included the positive or negative influences parents, family, and friends, and researching the Internet.

# Theme Three: "I wanted to be seen as a person"

The final major theme which adolescents identified as an important stage in the process of accessing primary care for mental health services was *"I wanted to be seen as a person"* which consisted of three subthemes: a) the relationship between primary care practitioners, adolescents and parents, b) primary care process and structures, and c) influences extending beyond primary care. Within this theme, subthemes addressed the interpersonal, organizational, community, and policy levels of influence. All access dimensions were discussed in this theme including: acceptability, accommodation, accessibility, awareness, affordability, and availability.

**3a)** The Relationship among Primary Care Practitioners, Adolescents and Parents. This subtheme involved three characteristics including: i) patient-centred care considerations, ii) supporting development during adolescents' emerging adulthood, and iii) relationships between primary care practitioners and parents.

## 3ai) Patient-centred care considerations (Interpersonal level: acceptability).

All participants reported several important patient-centred care considerations for their primary care practitioners when delivering mental health services. Most participants reported that having a supportive primary care practitioner was essential, as Quinn stated: "When I have anxiety, I show it. I like fidget and stuff. So, she was patient and understanding and I think that's very important." Having a practitioner who is non-judgmental was another important characteristic, as Jamie described their practitioner: "I have never felt judged by her." However, some adolescents reported being judged by their primary care practitioners about their mental health concerns, as Blake discussed: "They mostly are judgemental ... they're like 'oh, everyone experiences this' and they downplay your actual issues."

Another patient-centred care consideration reported by all adolescents was the importance of primary care practitioners focusing on adolescents' needs when communicating with them. This included providing adequate time during appointments, education, and validation of their concerns. Most reported the need to feel that they have enough time to discuss their concerns and not be rushed. Adolescents reported that feeling they had enough time during appointments enabled them to describe their concerns to their practitioners. Additionally, half of the participants stated they want their primary care practitioner to educate them about the symptoms of mental illnesses and their causes, as well as how to maintain positive mental health. Teagan shared: "She did tell me that there are people with chemical imbalances, and that made a lot more sense to me." An additional important communication strategy reported by some of the participants was validation, as Jamie stated: "Just accept what they're feeling. And don't downplay or invalidate their emotion or how they're feeling. Just because you can't see, doesn't mean it's not there."

Finally, most participants acknowledged the importance of building a relationship with their practitioner over time to improve trust. Jamie stated when discussing adolescent mental health concerns: "If you talk to somebody you've been seeing since you were 3 years old, of course you would be okay with it, and you're comfortable with that person." However, a few adolescents in the study reported an opposing view, expressing some discomfort in discussing concerns

with someone they know. As Simran stated: "Because I've known her for so long, I didn't want her to think of me in a bad way .... I didn't want to disappoint her".

#### 3aii) Supporting Development during Adolescents' Emerging Adulthood

(Interpersonal level: acceptability). The importance of supporting development during adolescents' emerging adulthood when primary care practitioners interact with adolescents was reported by all participants. This characteristics details the specific features of patient-centred care that were distinctive to the developmental age and stage of adolescence. Most adolescents perceived the need for primary care practitioners to support development through emerging adulthood by giving them choices, believing them, and treating them as an equal. A few adolescents reported perceptions of how adults view them, as Jaelyn stated: "I think there's always a stigma about teenagers where people just kind of don't take them seriously." Further, when it comes to practitioners providing mental health care to adolescents, Teagan stated:

She always said, "You know best because it's how you are feeling" and that was really important for me because she always took me seriously, she never said, "Are you sure that's how you are feeling?" She never made it seem like she didn't believe what I was saying, and that's very important.

Harper also discussed their perceptions regarding this in describing their photo (Figure 6 on the following page):

# Figure 6

Photo by Harper depicting their perceptions of wanting to be seen as a person



I wanted to be treated like I wasn't just a kid. The tree represents how I feel as a person, that I'm kind of the same as everyone else. I'm not trying to be a basket case. I wanted to be seen as a person instead of a person who has anxiety or a person who has depression.

Two practical considerations to assist in supporting development during their emerging adulthood included facilitating appropriate referrals and providing choices when discussing treatment options, specifically medication. Most adolescents reported the need for their primary care practitioners to facilitate appropriate referrals to other services through having knowledge of the services, explaining the purpose of the referral, and following up on referral status. Adolescents wanted practitioners to have a full understanding of adolescents' needs before they made referrals to other services. As Amal stated: "Sometimes when they recommend things it's like either you don't know enough about the program to know I'm not 18, or you don't know enough about me." Further, to facilitate this collaborative process, Teagan shared their experiences stating:

It was very important for me not to feel like [the practitioner] was trying to pass me off to someone else when she gave me referrals. She wasn't saying 'Here you go, don't talk to me about this again.' It was 'We are going to make an appointment a couple days after you go and see this person and you are going to tell me how it went.'

Most adolescents reported the importance of being provided choices when discussing treatment options, specifically medication. Although some participants perceived they were enabled to make decisions about medications, some reported they were not. For example, Simran stated: "She pretty much said I have to take it ... I felt like if they have all these options, why can't I choose what I want?"

Finally, most participants noted the critical need for and enforcement of policies related to confidentiality. This finding highlights the importance of supporting adolescents as they develop their personal identity and begin to take responsibility for their health. Some felt assured that their confidentiality would be maintained, while others felt uncertain. Blake stated: "If you don't say 'I'm

saying this within confidentiality then they will tell your parents when you're younger ... it should just be known that they shouldn't say it."

3aiii) Primary Care Practitioner Relationships with Parents (Interpersonal *level: acceptability*). A few participants whose parents were involved in their care perceived that the relationship between primary care practitioners and parents was important. This included parental involvement in assessment and determining a plan of care. Some participants reported it was helpful that their parents communicated adolescents' needs to practitioners during the first appointment. In Teagan's experience: "It was a really hard conversation for me to have with [my doctor]. I didn't even do most of the talking, my mom kind of told her most of it and I sat there." Further, Harper stated: "He was asking my mom questions about me so that he could find out how to help me." Additionally, a few adolescents perceived that their parents needed to approve of the plan of care, reflecting their developmental need for support from parents. For example, Quinn shared that this support from their mother was beneficial: "We changed doctors after she prescribed me a medication that my mom was like not approval of .... My mom felt like she didn't know what she was talking about." Jamie furthered the notion of parental approval, stating: "My doctor's acceptable, but that's because I don't think my mom would let me go to a doctor that wasn't." There were no instances where participants perceived their parents had too much input into or control over their care plan.

**3b) Primary Care Processes and Structures.** This second subtheme within *"I wanted to be seen as a person"* involved the processes and structures of primary care and how services were organized. There were four characteristics related to process and structural considerations: i) clinic organization: staffing, scheduling, and layout; ii) marketing of primary care mental health services to adolescents; and iii) location of primary care practice.

#### 3bi) Clinic Organization: Staffing, Scheduling, and Layout (Organizational

*level: accommodation).* Adolescents noted several considerations for primary care clinic organization in providing mental health services. These included staffing, scheduling, and clinic layout. This characteristic depicted the access dimension accommodation, as it described how primary care resources are organized to suit adolescents' needs. Firstly, most adolescents reported the importance of continuity of care providers. Harper shared:

When you're just seeing the same doctor over and over again you can build a connection and build trust. Changing the doctor and changing the regimen so much, it throws off the balance completely. You have to make a new connection to that doctor and build trust ... if I need to make an appointment and the doctor I prefer isn't there then it's kinda scary thinking like 'I am going to go and tell a complete stranger that I am having a relapse.'

Second, the need for convenient office hours for booking appointments was recommended by many participants. As Jamie stated: "On weekends, or on

evenings, they should prioritize the teenagers." Some adolescents reported their primary care office did offer weekend or evening hours, which were perceived as more convenient times to schedule appointments.

Finally, some adolescents discussed their perceptions of feeling uncomfortable waiting in the waiting area. They discussed their discomfort being around several other clients, as Alex stated: "I'm kind of just nervous because there's other people. And then I'm scared for when the doctor calls me because then I have to walk in front of all those people." Similarly, Quinn took a photo to represent their waiting room experiences (Figure 7), stating: "The chair would be facing you. Like, no matter where you stand it's always facing you. So, I took that in retrospect of how I felt like everyone was staring at me when I was in the waiting room."

# Figure 7

Photo by Quinn depicting their perceptions of feeling uncomfortable in the waiting room



*3bii) Marketing of Primary Care Mental Health Services to Adolescents* (*Organizational level: awareness*). Most participants perceived the need for improved marketing of primary care mental health services to adolescents. As discussed previously, adolescents perceived they did not know they could access primary care for mental health services. Jamie discussed that primary care practitioners should: "Tell the patients that it's a possibility to come talk to them for help, even if the patients haven't shown any signs of mental depression." Simran's suggestion to facilitate this was:

More advertisements ... or even little pamphlets, or posters. Maybe just for doctors to like, reach out themselves rather than wait. Like, if you go there for something and they could just say, 'Oh, just in case you need it, we have services for mental health.'

Jamie discussed the need for advertising outside of primary care as well:

It's most important to put it in school and somewhere where kids go. Because you don't really know until somebody tells you. And everybody goes to school for the most part, and even the place where kids go. 'This is a possibility for you, if you need help, you can go get it. It's not as hard as you think it will be, to go get help.'

# *3biii) Location of Practice (Organizational level: accessibility).* All

adolescents reported on the accessibility of the physical location of their primary care practice, with nearly half reporting that they perceived the location as a far

distance to travel. This required them to take multiple buses or be driven by their parents. Subsequently, participants also stated it can be difficult to access their primary care practice, as Blake stated: "If you don't drive I don't know how you would get there 'cause I wouldn't be able to get to my doctors' by bus." A few participants perceived their practice location as geographically close and reported that it was easily accessible by one bus route or walking. Additionally, a few participants stated they were able to access individual and group psychotherapy services at their primary care office, improving their opportunities to access these services. As Simran stated: "They can give you groups for all over - if you're all the way up in the mountain or you live far away, they know these people that have groups here."

#### 3c) Influences Extending Beyond Primary Care.

The final subtheme within "*I wanted to be seen as a person*" describes the access influences extending beyond primary care. This included three characteristics: i) the need for improved collaboration to meet adolescents' multiple individual needs, ii) the need for updated mental health knowledge for primary care practitioners to understand illness during emerging adulthood, and iii) the cost of mental health care as potentially prohibitive to adolescents.

*3ci) The Need for Improved Collaboration to Meet Adolescents' Multiple Individual Needs (Community level: awareness).* A few adolescents reported the need for improved collaboration between primary care and other organizations or

service providers, in order to meet adolescents' care needs. Specifically, these organizations included schools and mental health care providers. Teagan described the positive experience they had when their community mental health care provider worked in collaboration with their primary care practitioner, stating: "[When] I was diagnosed I think it was a group effort between the two of them; they were working together." The idea that adolescents could receive interprofessional collaboration in care when their service providers worked together was also described by Amal. They stated:

My psychiatrist is big on working as a team so, my family doctor can't prescribe me meds without conferring with them .... Before it was like they were learning from me. So, it's helpful for family doctors to like actively work with your other care.

In regard to the importance of collaboration between primary care and schools, Simran shared their experiences: "I started having a lot of trouble in school, and the principal took notice and got me help. Then I went straight to my doctor .... I kind of wish that they would work more with the schools." Jamie described the benefit of a teamwork approach between the two, stating:

"I think for kids my age, it's most important to put [information about primary care] in school and somewhere where kids go ... because [school is] the most accessible for kids right now, because not everybody can go to a therapist and not everybody can go see a doctor right away."

These findings highlight the importance of primary care having an awareness of other community organizations or service providers in adolescents' lives, and working collaboratively with them in order to meet adolescents' mental health needs.

*3cii) The Need for Updated Mental Health Knowledge for Primary Care Practitioners to Understand Illness during Emerging Adulthood (Policy level: acceptability).* A few participants perceived the need for primary care practitioners to have updated knowledge of mental health concerns to support *acceptable* service provision. Participants' statements reflected a policy level consideration, as the governing bodies of health care professions set guidelines for education and professional development which must be current with new understandings of adolescent mental health concerns and their emerging adulthood. Amal discussed: "It's like their perspective and what they've been taught, however long ago that was." Ryley also reflected on their perception of the need for improved knowledge, stating: "I think my doctor's office isn't educated on mental illness enough, that they don't understand it. So, I feel like as much as they tried to, they couldn't for the life of them."

*3ciii) Cost of Accessing Mental Health Care (Political level, affordability).* The final characteristic of the subtheme Influences Extending Beyond Primary Care described adolescents' financial concerns about access to primary care for mental health services. This characteristic fit the political level in the ecological model, as it is influenced by publicly funded primary care remuneration policies. Most adolescents perceived they did not have any financial concerns because either their parents had a health benefit plan, or the treatment their primary care practitioner recommended to them did not incur an out-of-pocket cost to them because of universal coverage through the provincial health insurance plan. Harper stated: "If there ever was a cost [for medication] then he changed [it] to accommodate it for me." In contrast, a few participants reported they had financial concerns, given that some medications were not covered through public or private medication coverage. For example, Simran stated: "The reason I'm not on medication right now is because the last one they recommended me cost. And it wasn't even that much money .... We just didn't have it."

#### **Secondary Research Question: Primary Care Nurses**

When asked about the role of nurses in facilitating access to primary care for mental health services, most participants reported they had interacted with a nurse at their primary care practice, but in a negligible way. Some reported that nurses called them in from the waiting room and conducted an initial assessment. Adolescents perceived that the role of nurses in primary care was minor, as Jaelyn discussed: "There might be nurses that will put you in the room, but like I don't really see them do too much." Further, most participants reported that the role of the primary care nurse was primarily to provide physical care, such as administering vaccines, checking vital signs, or taking their height and weight. Teagan shared their experiences: [Nurses] do take my height and weight. And if I need to get any physical tests done, like if I need to, um, like they will check my blood pressure and all that stuff but they don't talk to me too often about my mental health.

To further this idea that adolescents did not perceive providing mental health care to be part of a primary care nurses' role, Alex stated: "They're not really there for mental health." One final finding of note was that most participants were unsure of the designation of the nurse providing care to them (i.e., Nurse Practitioner, Registered Nurse, or Registered Practical Nurse). For example, Quin noted: "I normally don't see doctors I just see the nurses ... she was like 'We're gonna put you on this medication' and she prescribed me the medication." Based on the actions described in this encounter (i.e., prescribing medication), Quin appears to have received care from a Nurse Practitioner; however, Quin stated they were not aware of this provider's designation.

#### **Summary of Findings**

In summary, the findings of this study were generated from interpreting the perspectives of adolescents, age 14 to 18, living in Hamilton, with an anxiety or mood disorder, of accessing primary care for mental health services. This analysis was guided by the access framework by Penchansky and Thomas (1981), augmented by Saurman (2016), and the ecological model by McLeroy and colleagues (1988). The process was depicted as a complex and difficult journey, which was influenced by multiple access dimensions (Penchansky & Thomas,

1981; Saurman, 2016) and occurred at multiple levels of influence (McLeroy et al., 1988) when accessing primary care for mental health services. The overarching process of access - "It's not about the end – it's about the road" - for adolescents was comprised of three stages (major themes): "It was all in my head", "I needed help" and "I wanted to be seen as a person". These three themes are depicted in the proposed conceptual framework developed from the results of this study. It displays the process of access as a path, with a valley and hills to depict the challenges and movement towards accessing care. However, a critical finding was that adolescent described several important aspects of their access journey which did not fit within the access dimensions framework. Although each participant's experiences of access were different, all highlighted the influence of external and contextual access factors prior to accessing primary care described in the first two stages of access "It was all in my head" and "I needed help". These external and contextual factors fell outside of the access dimensions framework.

Most of the findings fit within the dimension of acceptability in the access framework and at the interpersonal level in the ecological model, particularly within the major theme "*I wanted to be seen as a person*". This theme described adolescents' perceptions of interactions with primary care practitioners when receiving care. The interpersonal level of influence was also described in adolescent's experiences of receiving help and support from others in order to seek care in the major theme "*I needed help*". Awareness was the only access

dimension which appeared across all three major themes which were related to adolescent's awareness of primary care services, and primary care practitioners' knowledge of other mental health support and services.

The findings of this study have also provided some insight into the role of primary care nurses in facilitating access to primary care for mental health services for adolescents. From the perspective of adolescents, they reported primary care nurses did not play a major role in their access despite having interacted with them. Adolescents were also unaware of the professional designation of the nurse providing care to them and did not perceive that providing mental health services was within the role of the nurse.

## **CHAPTER FIVE: DISCUSSION**

The purpose of this thesis study was to obtain an understanding of the perceptions of adolescents experiencing an anxiety or mood disorder of accessing primary care for mental health services. A secondary aim was to learn about the role of primary care nurses in facilitating access to primary care for mental health services from the perspective of adolescents as the service user. The key finding of this research study was that adolescents perceive accessing primary care for mental health services as a difficult and complex process that involves several access dimensions independent of and involving primary care which included multiple levels of influences (i.e., individual, interpersonal, organizational, community, political). Building on the thorough literature search conducted in this thesis, these findings contribute new evidence to the current body of knowledge on the topic. The first section of the discussion will discuss the use of the guiding framework and model used in this study. Subsequently, the overarching theme, major themes, and subthemes will be discussed, highlighting new knowledge that this study contributes to the field, and study findings that align with previous literature. The final section will discuss strengths and limitations, and implications of the study.

#### **Guiding Framework and Model**

In this thesis, a conceptual framework and an ecological model were utilized to guide the research study and assist in contextualizing the findings. These included the access framework described by Penchansky and Thomas

(1981), augmented by Saurman (2016), and the ecological model by McLeroy and colleagues (1988). Adolescents were asked about their perceptions of accessing primary care for mental health services, which provided them with an opportunity to describe their personal story and experiences of accessing help. What emerged was a rich description of how adolescents perceived access as a process that began before entering primary care and involved external influences outside of primary care. Therefore, their experiences of access spanned further than the six access dimensions of the framework used (Penchansky & Thomas, 1981; Saurman, 2016). This section will discuss how employing the guiding framework and model assisted in the development of the results and, as a consequence of evident gaps in the existing framework, a new conceptual framework was created to represent adolescents' journey of access.

The guiding framework used to examine the concept of access was defined by Penchansky & Thomas (1981) and augmented by Saurman (2016). A significant strength of the work by Penchansky & Thomas was that they tested the validity of their proposed five dimensions and found that they are relevant to the concept of access when examining patient satisfaction in adults. They also provided clear definitions of access dimensions which allowed for the current study to apply them. Additionally, the idea of access as a "fit" between the service user and the service which they described was useful in examining the connection between adolescents and primary care. These dimensions of access have been used in other works to evaluate access to primary care for Indigenous Peoples in

Australia and adult asylum and refugee seekers in the United Kingdom (Davy et al., 2016; Kang et al., 2019).

The ecological model was chosen as it was thought to assist in exploring the multiple levels of influence within and outside of adolescents' control which impact access. The ecological model has been more frequently used in public health prevention or promotion contexts to examine health behaviours (McLeroy et al., 1988; Cramer & Kapusta, 2017). However, recent literature has supported the use of ecological models in examining mental illnesses (Reupert, 2017), as it allows for exploration of the relationships and interconnectedness present within different levels of influence on an individual (Price-Roberston et al., 2017). Ecological models may be even more pertinent when examining pediatric issues as they allow for a multi-factored systems approach, instead of an individual focus (Logan & King, 2001), considering young people often rely on caregivers to access health services. Utilizing this model to examine access in the current study was therefore found to be useful as it allowed for consideration of internal and external forces which can shape an adolescents' perceptions and experiences of access. These included family, health care professionals, organizations, and policies.

The current study found the access framework by Penchansky and Thomas (1981) and Saurman (2016) to be constraining when applied to analysing adolescents' perspectives of accessing primary care for mental health services. Although not all aspects described by adolescents were directly related to primary

care, they were critical in adolescents arriving at primary care. Adolescents' perceptions within the first two major themes – "It was all in my head" and "I needed help" – depicted factors influencing access to services which were outside of the access framework. Since the framework could not account for these factors, it was important to carefully consider where these access factors occurred during an adolescent's access journey, and the relationship between these factors. Addressing these constraints resulted in the developmental of a proposed conceptual framework depicting a process of access prior to entering, and while receiving, mental health services in primary care. This framework is further described in the next major section "Overarching Theme: "It's not about the end – it's about the road". Only the final third major theme "I wanted to be seen as a person" and its' subthemes were well aligned with the definition of access and its' dimensions outlined by Penchansky and Thomas (1981) and Saurman (2016), as it depicted adolescents' experiences receiving mental health services.

Given that factors outside of the primary care context were raised by all participants in relation to accessing care (e.g., uncertainty of mental illness symptoms and the need to access help, parent role in enabling access), it is important to consider other models or concepts which discuss the process in which a person decides to access health care. One of these concepts frequently discussed in the literature is help-seeking behaviour (Magaard et al., 2017). Helpseeking behaviour is a concept which describes an "intentional action to solve a problem that challenges personal abilities" (Cornally & McCarthy, 2011, p. 286).

It can involve communicating with informal supports such as family, and formal supports such as mental health professionals to receive help for a problem (van de Toren et al., 2020). One narrative review, which appears to be based on the authors' otherwise unpublished research, described help-seeking behaviours for mental health concerns among youth aged 14 to 25 years in Australia (Rickwood et al., 2005). Rickwood and colleagues described help-seeking as a process which begins in the personal domain of experiencing a mental health concern, leading to the interpersonal domain of seeking help. Stages in the process of help-seeking included: awareness and evaluation of concerns, expression of symptoms and need for support, availability of help, and willingness to seek help (Rickwood et al., 2005). Although primary care was included in the review, it was not the focus. Despite this, the review aligns with the findings of the current study which also assert that adolescents perceive access as a process, starting with the internalized process of questioning their mental health concerns and fears about receiving help. Subsequently, this leads to the externalization of their mental health concerns by talking with others in the initial action phase, and then finally entering the primary care setting to obtain mental health services. The current study expands the concept of help-seeking behaviours, which focuses primarily on actions of the individual, and allows for consideration of access using the interface between services and the service user. What the current study adds is qualitative evidence on the perceptions of adolescents seeking help for mental health concerns in primary care in the Canadian context.

The main finding of the current study highlights that access to primary care for mental health services by adolescents experiencing an anxiety or mood disorder is a process which incorporates aspects of help-seeking behaviour and several dimensions of access. These processes occur before entry into the health care system, and when receiving care. Utilization of the definitions provided by Penchansky & Thomas (1981) and Saurman (2016) was initially helpful to allow for an understanding of multiple dimensions of access to primary care for mental health services. However, the access framework was limited in its ability to account for individuals' external and contextual factors outside of primary care influencing access. As a result of these limitations, a conceptual framework depicting the process of access for adolescents was created. Therefore, a consideration of help-seeking behaviours integrated with Penchansky & Thomas' (1981) and Saurman's (2016) access dimensions is important to gain a comprehensive understanding of access and the delivery of primary care mental health services. Finally, the ecological model was useful in guiding the exploration of broader contextual influences such as individual, organizational, and system level factors that could impact an individual's access to services. Specifically, the model assisted in examining the relationship between levels of influence on access for adolescents whose health behaviours are affected by their parents, primary care practitioners, and broader health care policies. As the purpose of this study was to allow for an improved understanding of an issue relevant to clinical practice, in combination, this proposed conceptual framework

and (unchanged) ecological model have enabled a holistic understanding from the adolescents' perspective of accessing primary care as "*It's not about the end – it's about the road*" and the major themes - "*It was all in my head*", "*I needed help*", and "*I wanted to be seen as a person*."

#### Overarching Theme "It's not about the end – it's about the road"

This overarching theme "It's not about the end – it's about the road" described adolescents' perceptions of accessing primary care for mental health services as a difficult and complex process. This process was described as a "journey", "path", or "road" and is depicted in the proposed conceptual framework (Figure 1). Adolescents reported there are different challenges faced with each stage of the access process, beginning with the initial challenging phase "It was all in my head", represented as a valley. This was an internalized process in which adolescents reflected on their level of mental health literacy and fears about seeking help. The consequence of their lack of knowledge about mental illnesses, where to seek help, and perceptions of stigma was experienced as feelings of loneliness and isolation. As adolescents chose to externalize their concerns, they moved along the road towards seeking care during the phase "I *needed help*". This is depicted in the proposed framework as moving on the path toward the first hill, which involved obtaining support and help from parents, friends, and family, as well as by seeking out information on the Internet. Finally, the third hill, illustrating the third major theme "I wanted to be seen as a person",

reflects the unique needs of adolescent in receiving primary care and how they interact with their practitioners.

The proposed conceptual framework and findings of this study parallel several important principles and guidelines for recovery-oriented practice outlined by the Mental Health Commission of Canada (2015). Recovery-oriented approaches to care recognize that recovery is an individual process through which people recover a meaningful life following a diagnosis of mental illness and is not the same as a cure (MHCC, 2015). The MHCC (2015) states "recovery is personal" and is a non-linear journey that occurs within the context of an individual's own life. As such, a consideration of the process of access for adolescents as a journey or path assists in understanding the personal experiences of individuals as they move through this developmental stage and receive primary care mental health services. The conceptual framework depicts the findings as a valley and three hills, to illustrate the notion of continued difficulty and personal challenges faced when embarking on the recovery journey while moving closer to accessing care. Recognizing the many challenges individuals with mental illnesses face during their recovery is an important aspect of fostering hope and optimism (MHCC, 2015). Regarding the main findings, the first two themes "It was all in my head" and "I needed help" were described as two imperative aspects of the access journey, yet both occurred prior to accessing primary care for help. The MHCC (2015) identifies that "most of a person's recovery journey occurs outside the mental health system" (p. 16) and within an individual's
personal context, including their social supports, local community, and schools, which supports the findings from the current study. The third theme "*I wanted to be seen as a person*" highlights the importance of person-centred care through empowerment, which in turn supports adolescents during their emerging adulthood. Empowerment is a key principle within recovery-oriented practice, which enables self-determination, decision-making, and opportunities for personal growth (MHCC, 2015). Therefore, the findings of this research align with the priorities stated by the MHCC's (2013) Youth Council, which include improving the mental health skills of primary care providers to deliver and integrate a recovery-oriented approach in care. These contextual findings about adolescents' perceptions and journey of access are important to inform and improve primary care practitioner's competence in providing recovery-oriented care.

A systematic review and narrative synthesis by Leamy and colleagues (2011) sought to combine existing evidence about the concept of personal recovery in mental health. Their review included studies from the United States, United Kingdom, Australia, and Canada. They identified that characteristics of a person's recovery journey can include notions that recovery is an active, individual, and difficult process. Although their work was not specifically adolescent or youth-focused, the authors highlight aspects of the recovery journey nested within the transtheoretical model of change which aligns well with what adolescents reported about their path within access. The pre-contemplation phase is described with words such as "stuck" and "overwhelmed" (Leamy et al., 2011,

p. 449) which reflects some of what adolescents described during the internalized process within "*It was all in my head*". In the contemplation and preparation phase, Leamy and colleagues (2011) utilize the terms "accepting of help", "igniting a spark of hope", and "turning points" (p. 449). These two phases also align well with what adolescents perceived during "*I needed help*" as they externalized their concerns and sought informal support, in order to access primary care. Finally, the final major theme "*I wanted to be seen as a person*", which describes receiving mental health services in primary care, may build on what Leamy and colleagues (2011) describe within the action phase, as "learning" and "moving forward". Thus, the findings of the current study support Leamy and colleagues (2011) characteristics of recovery journeys within the transtheoretical model of change for an adolescent population.

Tilleczek and colleagues (2017) conducted a literature review to examine what is known about recovery journeys specifically in youth mental health; primary studies in the review were conducted in Canada, Italy, Eastern Europe, and New Zealand. They identified that youth journeys in mental health care are non-linear, with multiple different individual and systemic issues. An important finding of their work which also is consistent with results of the current study is that access journeys begin "long before they receive formal care from a primary health care provider" (Tilleczek et al., 2017, p. 153). This supports the current study's finding that access began before receiving services and included many factors outside of the primary care setting. However, specific evidence on

adolescent perceptions of access journeys and recovery focused on primary care does not appear to be well represented in the literature. The current study therefore adds the unique perspectives of adolescents experiencing anxiety or mood disorders. Thus, a new contribution to the literature from this study was an understanding of adolescents' perceptions of access as a journey specifically in the context of accessing primary care in an urban setting in Canada.

#### **Major Themes and Subthemes**

This section of the chapter will discuss the findings in relation to the three major themes – "*It was all in my head*", "*I needed help*", and "*I wanted to be seen as a person*" – highlighting research that aligns with these results, and noting new contributions made to the field.

# Theme One: "It was all in my head"

The internalized process of access depicted in the theme "*It was all in my head*" included the perceptions of adolescents in feeling uncertain of their mental illness symptoms and the need to access help, not knowing primary care offered mental health services, and fears about stigmatization and hospitalization. This major theme was found to reflect the individual level of influence, as adolescents reported an internalized process where they reflected on their mental health concerns and fears of accessing help. Adolescents in the study reported that they feared how people would view them and the potential for discrimination if they disclosed that they were experiencing a mental health concern. This aligns with previous evidence which discussed adolescents' fears about how people will

perceive them if they access primary care for mental health services (Meredith et al., 2009). Similarly, a systematic review of international literature examined help-seeking behaviours for mental health concerns in young people aged 12 to 25 years and reported that one of the largest barriers to seeking help for adolescents and youth is worry about how people will perceive them, including their health care providers (Gulliver et al., 2010). Gulliver and colleagues' (2010) review similarly mirrors the current study's finding that adolescents do not perceive that primary care can offer help for mental health concerns. Adolescents in the current study reported they were unaware of mental health services offered by primary care, which was also reported by Leahy and colleagues (2018).

It was evident in the current study that adolescents have a narrow understanding of mental illnesses and their symptoms, as well as appropriate avenues to receive help. This reflected a low level of mental health literacy. Mental health literacy is defined as "knowledge about mental health disorders that is associated with their recognition, management, and prevention" (Furnham & Swami, 2018, p.240). Insufficient knowledge about mental illnesses in adolescents was also reported in the systematic review by Gulliver and colleagues (2010) and by Coles and colleagues (2015) in a survey of high school studies between ages 14 to 19 years in the United States. Specifically, adolescents may lack knowledge in the areas of illness recognition and beliefs about treatment (Reavely & Jorm, 2011).

The current study also found that adolescents' inability to recognize symptoms of mental illnesses and the need to receive help for these concerns was compounded by their lack of knowledge of primary care mental health services. Since adolescents were unable to recognize they were experiencing a mental illness, they were subsequently unable to identify the need to access health care. Low mental health literacy was also reported as a barrier to seeking professional help in narrative review of youth in Australia (Rickwood et al., 2007). Another layer of complexity was their fear of stigmatization by others, and the potential for hospitalization. The fear of being hospitalized was not previously found in the literature as a barrier to accessing primary care for mental health services. Furthermore, the current study adds qualitative evidence on how fears of stigmatization and hospitalization, and inadequate mental health literacy, contributed to feelings of isolation and uncertainty in adolescents experiencing an anxiety or mood disorder.

In conclusion, through the process depicted in "*It was all in my head*", the current study further builds on the understanding of how adolescents must consolidate their knowledge about their concerns and fears to examine how to begin getting help. This all occurs within the individual domain and is an internalized process that influenced their health behavior of seeking mental health services. These factors represent aspects of help-seeking, as adolescents began to examine their beliefs about their mental health concern, fears of the consequences of discussing their concerns with others, and their understanding of potential

options for help. The findings in this theme contribute important contextual information regarding access barriers for adolescents at this stage due to being uncertain of their symptoms of their mental illness and questioning if they need help for these concerns.

# Theme Two: "I needed help"

Adolescents perceived the access process of "*I needed help*" as the stage in which they initiated receiving help by discussing their concerns with parents, friends, and family. This stage describes the turning point in which an adolescent moves from problem recognition, to seeking informal support and deciding an appropriate course of action. Additionally, adolescents identified the influence of their family's perceptions of mental health concerns on their decision to seek help from primary care. Leahy and colleagues (2013) reported that adolescents' inherent motivation to seek primary care was an important factor in access. This major theme "*I needed help*" describes that motivation is influenced by various factors in adolescents' lives which contribute to their decision to seek care. Once adolescents perceive they have a mental health problem for which they need help, they will obtain informal support from trusted people in their lives who may encourage them to seek mental health services.

Adolescents in the current study depicted their parents as important enablers to accessing care. The role of parents is important in access for adolescents and can range from recognizing problems and seeking help (Reid et al., 2011) to decision-making in care (Aarthun et al., 2019). As adolescents

transition from relying on their parents to achieving autonomy and independence through this life stage, the role of parents in facilitating access to health care can diminish with increasing age (American Academy of Child and Adolescent Psychiatry, 2015). Parents in the current study were described as organizers in their role of helping their adolescent access primary care. They would offer emotional support when initially seeking help, as well as instrumental support through booking appointments and providing transportation. Parents also helped adolescents choose to access help from primary care and would ensure they received services. These findings support what has been previously reported in the literature. Radovic and colleagues (2014) noted that opportunities to access primary care were improved when parents were involved. Similarly, Sayal and colleagues (2010) found that access to primary care for mental health services can be dependent on the knowledge parents have about primary care services. Anderson and Lowen (2010) conducted a systematic review to identify different models of health care delivery which enable youth ages 12 to 25 years to access mental health care. Their findings mirror the current study's finding that parents can have an important role in supporting adolescents to obtain help by helping them identify mental health concerns and in decision making to seek care.

Adolescents in the current study perceived the positive and negative impact family and friends can have on their decisions to seek help from primary care. Starting with family, adolescents reported that their family's perceptions of mental health problems impacted how they felt about seeking help. Some

adolescents perceived that their parents were supportive, and, for others, learning their parents had experienced mental illnesses was validating for the adolescents. However, some adolescents also felt that their families perpetuated stigma in society which worsened their fears of being judged, creating a barrier to accessing help. Moses (2010) conducted a cross-sectional study in the United States of adolescents between ages 12 to 18 years to examine their experiences of stigma towards mental illnesses. Moses (2010) found that adolescents perceive their family as less judgmental than other people. However, they also argue that negative perceptions of mental illnesses in families may be difficult to observe and have not been extensively investigated (Moses, 2010).

Adolescents in the current study perceived friends as important supports, who may recommend seeking primary care for mental health services based on their own experiences. A literature review by Wilson and colleagues (2011) from Australia has also reiterated the importance of friends helping young people recognize their mental health concerns and the need for help. Rickwood and colleagues (2007) also conducted a literature review and found that as adolescents become older, they may rely more on friends to confide in and obtain support. In a previously described study by Rickwood and colleagues (2005) examining helpseeking behaviours, the authors described friends as an important informal source of support. However, they found that it was unclear if this informal support was helpful as friends may not be well equipped to provide help. In contrast, the current study found that friends either suggested accessing help or had their own

experiences of accessing help from primary care and therefore recommended obtaining services, illustrating the importance of the influence of friends.

One final element in this subtheme was adolescents' use of the Internet to research information about how to receive help and learning about other people's experiences with mental illnesses. A cross-sectional study by Wetterlin and colleagues (2014) conducted in British Columbia, Canada, examined youth ages 17 to 24 years experiences of online mental health resources. Similar to the current study, they also reported that young people utilize the Internet to seek out information about what they were experiencing. The current study adds that adolescents may feel motivated to seek care by utilizing the Internet to learn about positive experiences of others related to seeking help for mental health concerns. However, there are some limitations to utilizing the Internet such as the risk of accessing unreliable sources, and privacy considerations (Pretorius et al., 2019).

In summary, the access process depicted in *"I needed help"* describes the need for adolescents to consolidate their knowledge about having a mental health concern which requires help, and identify that receiving mental health services from primary care is an option. How adolescents identified they could access primary care was through discussions about their concerns with family and friends or researching how to get help online. An important contribution of the current study is that adolescents can be motivated to seek care when learning about other people's positive experiences through their friends or online platforms.

# Theme Three: "I wanted to be seen as a person"

The final major theme "*I wanted to be seen as a person*" described the process of receiving mental health services in primary care. Adolescents perceived several important care considerations for primary care practitioners which were organized into three characteristics: the relationship between primary care practitioners, adolescents, and parents; primary care processes and structures; and influences external to primary care. This theme represented five access dimensions (i.e., acceptability, accommodation, affordability, accessibility, awareness), and ecological levels of influence: interpersonal, organizational, community, and political.

Several findings in this theme align with important considerations found in the literature for engagement in primary care through patient-centred care strategies. Adolescents reported important characteristics of their primary care practitioner such as being supportive, non-judgmental, and friendly, which improved their level of comfort in disclosing their concerns. They also valued having enough time during appointments to discuss their concerns and having their concerns validated by their primary care practitioners. A systematic review of youth-friendly health care strategies found these aspects included: staff attitude such as being respectful, honest, and listening actively; supporting autonomy; and enabling involvement in care (Ambresin et al., 2012). In the context of primary care, the importance of adolescent-friendly strategies, where adolescents feel engaged, was previously reported by McCann and Lubman (2012) and Leahy and

colleagues (2018). Finally, adolescents perceived the importance of a positive relationship between their parents and their primary care practitioner, as was previously described by O'Brien and colleagues (2016) and Sayal and colleagues (2010). These findings describe the importance of a patient-centred approach in care, which includes a respect for patients' preferences and the importance of caregiver involvement (Picker Institute, 2020).

Adolescents in the current study also reported the importance of care that was specifically tailored to their developmental age and life stage. Supporting adolescents during emerging adulthood in the delivery of primary care mental health services was echoed by several participants in this study. This included supporting their developing autonomy by treating adolescents as equals and involving them in the decision-making of their plan of care (e.g., medications, referrals to other mental health services). Learning to make independent decisions is critical during emerging adulthood (Arnett, 2000), and shared decision-making practices are important at this life stage to support adolescents' capability to plan for their future (Registered Nurses' Association of Ontario [RNAO], 2010). Adolescents also wanted primary care practitioners not to treat them "like a kid" through supporting their need to be seen as independent and capable. Developing this therapeutic relationship was reported to be something that occurred over time and through multiple interactions with the same practitioner. Another important concern raised by adolescents in developing therapeutic relationships was outlining the confidentiality policies and what information could be disclosed to

their parents. A review of confidentiality policies was previously reported as a crucial care consideration by others (Graham et al., 2014; Leah et al., 2013; Schaffalitzky et al., 2014). Evidence in the current study parallels the importance of recovery orientation when providing mental health services to adolescents. Recovery-oriented mental health care, as previously discussed, includes the principles of "enabling choice, encouraging responsibility and promoting dignity and respect... Taking into account their developmental stage" (MHCC, 2015, p. 16). Recovery-oriented practices also respect an individual's right to privacy and confidentiality (MHCC, 2013). The targeted literature search in this thesis did not identify any studies which emphasized the importance of adolescent's specific developmental needs in care in order to facilitate access. This finding represents a new contribution to the current body of literature describing adolescents'

There were several considerations for primary care organizational policies and structures that adolescents perceived as important in their experiences of access, and if improved upon, could enable enhanced access. Firstly, adolescents perceived that specialty services would be more accessible if available in the primary care setting. The need for further collaboration between primary care and specialty care, as well as co-location of these services, has been reported by Graham and colleagues (2014). The American Academy of Pediatrics (Cheung et al., 2018) also recognized collaborative care models between primary and speciality care as a key recommendation in the treatment of adolescents

experiencing depression. Secondly, adolescents stated that they would have accessed services sooner if primary care had better advertised that they provide their mental health services. Improved awareness of primary care mental health services to facilitate access was also reported by Graham and colleagues (2014). Adolescents in the current study perceived that primary care practitioners require updated knowledge of mental health concerns to better serve their pediatric clients. Leahy and colleagues (2018), O'Brien and colleagues (2016), and Schaffalitzky and colleagues (2014) also reported that primary care practitioners need more training to improve their comfort in discussing mental health concerns with adolescents. Additionally, the need for appropriate training was recommended in the American Academy of Pediatrics (Zuckerbrot et al., 2018) guideline as a method of improving identification of adolescents with depression.

In summary, although the theme "*I wanted to be seen as a person*" reiterated many care considerations which have been reported previously, this study displays that person-centred and recovery-oriented care in primary care has still not been fully enacted. What the current study also adds is the understanding that adolescents require mental health services which are tailored to their developmental age and stage. Finally, an important new contribution made by this study is understanding the unique needs of adolescents when obtaining mental health care. Improving primary care mental health services through meeting the needs of adolescents has the potential to improve their overall satisfaction with

primary care and can be associated with improved recovery outcomes (MHCC, 2015).

### **Nurses in Primary Care**

Client perspectives, particularly of adolescents' views, of primary care nurses in delivering mental health services have not been well-developed in the literature. There is a paucity of evidence regarding the role of primary care nurses in delivering mental health services (McLeod & Simpson, 2017), especially in Canadian contexts (Akeroyd et al., 2009). This study highlights that primary care nurses appear to be underutilized in the delivery of mental health services. Adolescents reported perceiving that nurses primarily conduct initial assessments and address physical health concerns. Although most participants had interacted with primary care nurses, they did not perceive that nurses had a role in delivering mental health services. The national competencies for Registered Nurses working in primary care by the Canadian Family Practice Nurses Association (2019) state that it is within nurses' scope of practice to provide mental health services, including: early intervention, management of psychological and social issues, and facilitate empowering approaches in care. Based on the current study's findings, it appears that primary care nurses may not be practicing to this full scope in delivering mental health care.

# Strengths and Limitations of the Thesis Study

This study has several strengths, beginning with the methodological approach. Utilizing interpretive description to undertake this research study was

appropriate to assist in aligning the findings with recommendations for clinical practice. Additionally, applying a qualitative methodology through semistructured interviews and photo-elicitation enabled a deeper investigation into the perspectives of adolescents with lived-experience of anxiety or mood disorders – a research need identified by the MHCC Youth Council (2013). From the outset, this study employed a clear definition of access and its' dimensions to enable greater transferability of the findings. Finally, this study is one of the first conducted in an urban setting in Ontario which examined adolescents' perceptions of accessing primary care for mental health services.

This study also had some limitations. First, a potential limitation was that it only included participants who have accessed primary care for mental health service in Hamilton, Ontario, which limits transferability of the findings to adolescents who have not accessed primary care and those outside of a Canadian urban centre. All adolescents in the study reported the involvement of their parents to some extent, potentially limiting the understanding of access perceptions by adolescents who have not had parental involvement. Although an inclusion criterion was that adolescents were aged between ages 14 to 18 years, no adolescent's age 14 years participated in the study. A potential reason that younger adolescents did not volunteer for the study is that they may rely more on their parents, and may only consider being involved if their parents were informed of the study. The recruitment strategy did not include advertising to parents.

Finally, only one participant identified themselves as non-Caucasian, limiting the transferability of these findings to adolescents who are non-Caucasian.

#### Implications

This final section describes the practice, education, research, and policy implications of this work. This can guide future directions in these fields.

# **Practice Implications**

This research study has shed light on adolescents' processes of access as a "road", "journey", or "path" that involves several stages with different valleys and hills to climb along the way. As such, primary care practitioners should consider the beginning stages of this process whereby adolescents struggle with identifying their mental health concerns and knowing where to access help. To support early intervention, primary care practitioners must provide information to adolescents about mental health concerns and services offered in primary care for these concerns during routine interactions. Routinely assessing for mental health concerns would also support early intervention. When determining a plan of care, practitioners should implement an individualized and person-centred approach that acknowledges adolescents' unique access journeys, helps cultivates their emerging adulthood, and supports their personal motivating factors to seeking care. It is important to consider their developmental age and stage, as well as the finding that adolescents may require more support in the earlier stages of access. They also require opportunities to make shared decisions and want their input to be valued as they develop independence and autonomy. An additional

consideration when discussing treatment options is for practitioners to consider any out-of-pocket costs which may be incurred before recommending treatment.

Primary care practitioners should also seek to develop improved relationships with parents, as parents can play an important role in enabling access to the mental health care system for adolescents. Many adolescents have the same primary care practitioners as their parents, and as such, practitioners can educate parents on signs and symptoms of mental illnesses in their children, and when to seek care. Regarding the geographic location of the primary care practice, practitioners should be aware that parents often provide transportation. Finally, primary care should consider improving the layout of their office space to be more adolescent-friendly, such as changing the layout of the chairs.

In considering the findings of the secondary research questions, an important practice implication in the primary care setting is to optimize the role of primary care nurses in facilitating access to primary care for mental health services for adolescents. It is within nurses' scope of practice to deliver several aspects of mental health services, such as mental health and risk assessments, and provide one-to-one patient education and counselling (RNAO, 2012). Additionally, Registered Nurses can provide interventions that assist patients in navigating the health system and facilitate long-term care planning that integrates a variety of care options (RNAO, 2012; College of Nurses of Ontario, 2018). There must be organizational support from primary care practices to ensure nurses are enabled to provide these interventions, which can assist in facilitating

improved access to primary care for mental health services. Enabling nurses to play a more active role in the delivery of mental health services could assist in creating more integrative and comprehensive care. Finally, an important practice implication is for nurses to improve client education regarding differences between Registered Nurses, Nurse Practitioners, and Registered Practical Nurses, who work in primary care.

## **Education Implications**

Governing bodies of health care professionals, such as the College of Physicians and Surgeons of Ontario and the College of Nurses of Ontario, should include mental health education in their quality assurance programs. This can include specific modules or programs for continuing education that target concerns raised by adolescents, such as stigma in society and stigma experienced by adolescents when accessing care. In considering that mental health is too often treated as a separate entity from physical health concerns, undergraduate or professional training programs must ensure their curriculum explores how to provide integrative care for these concerns in primary care. This training must include a focus on identification to support early intervention for adolescents when attending primary care for routine visits, or physical health concerns. Specific education should also be provided on how to develop therapeutic relationships with adolescents. Some of these considerations include being perceived as supportive by adolescents, believing them, and reinforcing confidentiality policies. An improved knowledge of adolescent mental health

concerns can support early intervention, as primary care practitioners improve their comfort levels and abilities to provide mental health services in primary care.

Regarding school-based education for adolescents, there is a need for mental health literacy curriculum to expand beyond general information and on to illness recognition and types of support adolescents can obtain for these concerns. Specific school-based education that supports early identification could help mitigate the perceived feelings of loneliness and isolation adolescents experience when feeling uncertain about their concerns or how to receive help. This curriculum can also serve to challenge stigma in society by normalizing mental illnesses and describe the prevalence of these concerns in adolescents and youth. There is also a need for teachers and school support staff to learn about the role of primary care in adolescent mental health, and how they can help guide adolescents to access primary care. As in Hamilton each secondary school is connected with a Public Health Nurse (City of Hamilton, 2020), there can be a role for these nurses in educating school staff about how to improve adolescents' access to primary care for mental health services.

# **Research Implications**

There are several implications for future research studies. Firstly, there is a need for more qualitative research examining the perceptions of specific populations, such as adolescents living in rural settings. Adolescents who are non-binary or male, and adolescents who identify as LGBTQ2S+ have been underrepresented and their perceptions need to be further explored (Clark et al.,

2018). Three participants in the study were recruited through an online posting of the study flyer, two of which were male. As such, future studies should consider a more fulsome online advertising strategy utilizing different social media platforms to recruit a more varied sample. The inclusion of diverse cultures and ethnicities is also important to investigate perceptions of access, as there can be differences in beliefs about mental illnesses and seeking help, as well as inequities in the ability to access appropriate mental health care services (Jimenez et al., 2012; CMHA 2014). As adolescent ages can be divided into early, mid, and late stages (RNAO, 2010), future studies can investigate the different care considerations for these age groups. There is also a need to explore the perceptions of adolescents experiencing other mental illnesses (e.g. schizophrenia, obsessive-compulsive disorder) as well as concurrent disorders (e.g., substance use and mood disorder). Although this study's findings have provided information about access prior to entering primary care, studying the perceptions of adolescents who have not accessed primary care for mental health concerns could provide further insight into barriers to access. Finally, future studies should also seek information regarding how adolescents perceive a greater nursing role in delivering primary care mental health services.

Studies investigating perceptions of access should continue to provide a clear definition of access and how it will be employed in the study to improve knowledge gained in this field. Researchers should consider utilizing an access framework along with a conceptual model that accounts for individuals' factors

and motivations for obtaining help, such as help-seeking behaviours. Although the current study was initially guided by a framework and model, following the adolescents' perceptions and stories was critical to understanding access beyond what is currently known in the literature. To enable a broader understanding of the needs of adolescents at all stages in their access journey and how to implement the implications into practice, youth-led participatory action research projects which include adolescents should be considered (Ozer & Akemi Piatt, 2017). One method to be used in future studies is experienced-based co-design which enables young people, the service users, to be involved in quality improvement research through sharing their perceptions (Hackett et al., 2018). Utilizing photovoice, an arts-based approach, provided compelling evidence for the internalized processes perceived by adolescents in this study. Future studies should consider employing arts-based approaches in their methodology when studying adolescent mental illness, as it allows for a medium that can convey difficult to express emotions or information (Woodgate et al., 2017).

In addition to the scant amount of qualitative evidence in this area, there is also little quantitative evidence examining access for this population in primary care. Future quantitative studies could examine adolescents' access to primary care through developing and testing new models of care. Components of a new model could include the findings of this study, such as the understanding of access as a "road", "journey", or "path", as well as adolescent and primary care practitioner participation through co-design methods. As adolescents wanted

improved advertising of primary care mental health services, future quantitative studies could measure the impact of providing this information during routine or physical health visits. Finally, more research is needed to examine the effect of improved training programs for health care professionals regarding mental health on early identification, and how this can impact adolescents' perceptions of access and early intervention.

## **Policy Implications**

On a policy level, there are implications for primary care and other community organizations, such as schools and specialty care. Adolescents highlighted that there can be more opportunities for early identification and intervention if primary care and schools improved their collaboration. Primary care practices should form relationships with local high schools/school boards to share information about their services and provide guidance about when adolescents should seek help from primary care for mental health concerns. As Ontario Health Teams continue to form with the goal of providing more connected care across sectors, they are planning to serve a geographic catchment area (Ontario Ministry of Health and Long-Term Care, n.d.). Considering this, policies guiding the work of Ontario Health Teams must include a focus on how to develop collaborative relationships with local schools and/or school boards. Collaborating with a local public health unit is useful way to facilitate linkages between schools and primary care. School boards must also create policies regarding how to link adolescents with primary care when a mental health

concern is recognized. At the time of this study, based on the policies available online for the largest school board in Hamilton, the Hamilton Wentworth District School Board (2020) did not appear to have any procedures describing how to support early identification and intervention for adolescent mental health concerns in school.

Another important area for collaboration is between primary care and specialty mental health services. Although transitions from pediatric to adult specialty care services was not specifically examined in this study, it is currently an important topic in policy research for youth. When adolescents are engaged in primary care services, they can experience improved outcomes through having a stable care provider when they transition from pediatric to adult specialty care services (Bhawra et al., 2016; Children's Mental Health Ontario, 2020). Kates and colleagues (2019) suggest that collaboration should be the forefront from the planning stages, and this is one of the goals of the forming Ontario Health Teams. Policies guiding collaboration should require primary care to clarify who is responsible for different aspects of care with specialty care or other communitybased mental health service providers (Kates et al., 2019). As pediatric and adult services and primary care work together to prevent gaps in care during transitions, emerging adults must be supported in taking more responsibility for their health care (Randall et al., 2016). Therefore, an improvement in collaboration between primary care and other care organizations through governing policies mandating these relationships could assist in improving transitions from the pediatric to adult

health care system. Additionally, adolescents described the benefit of specialty care services being co-located with primary care to improve accessibility. Providing more funding for primary care to hire health care professionals trained in mental health would improve access to these services. Another method of improving collaboration and co-location can be through further provincial policy and funding for primary care models which enable inter-professional collaboration, such as capitation-based models which fund Family Health Teams (Ministry of Health and Long-Term Care, 2020; HealthForceOntario, 2019).

# Conclusion

In conclusion, this study addressed the primary and secondary research questions: "What are the perceptions of adolescents, between age 14 and 18 years of age, living in Hamilton, with an anxiety or mood disorder, of accessing primary care for mental health services?" and "How do primary care nurses facilitate access to primary care mental for health services for adolescents with anxiety or mood disorders?" This thesis found that access to primary care for mental health services for adolescents is a difficult and complex process that involves different stages. These stages can be described in the overarching theme "*It's not about the end – it's about the road*". The three major themes and stages within access that emerged were "*It was all in my head*", "*I needed help*" and "*I wanted to be seen as a person*". These stages represent how adolescents moved from an internalized process of feeling uncertain about their mental illness and if they need help, to

discussing their concerns with their support network or by searching the internet, adolescents decided to access primary care for mental health services. Adolescents also reported on their perceptions of several important care considerations for primary care practitioners.

Although this project was initially guided by an access framework (Penchansky & Thomas 1981) and ecological model (McLeroy, 1988), what emerged was the key finding that access to services cannot be examined without looking at the external and contextual factors that occur before an adolescent enters the primary care setting. Subsequently, a new proposed access framework was created. Implications of this work for primary care practitioners include ensuring care is adolescent-centred and aims to foster their emerging adulthood by providing opportunities for shared decision-making and viewing adolescents as capable and independent. Primary care practitioners should improve adolescent and parental knowledge of adolescents' mental health concerns and when to seek help from primary care to improve early identification of mental illnesses. Primary care must improve its' collaboration with speciality care, schools, and other community-based mental health organizations to facilitate improved care transitions and early identification and intervention. Finally, the role of the primary care nurse is underutilized and needs to be supported organizationally by primary care practices to enable nurses to contribute to the delivery of adolescentcentred mental health services.

# REFERENCES

- Aarthun, A., Oymar, K.A., & Akerjordet, K. (2019). Parental involvement in decision-making about their child's health care at the hospital.
   *NursingOpen*, 6(1), 50-58. https://doi.org/10.1002%2Fnop2.180
- Akeroyd, J., Oandasan, I., Alsaffar, A., Whitehead, C., & Lingard, L. (2009).
  Perceptions of the Role of the Registered Nurse in an Urban
  Interprofessional Academic Family Practice Setting. *Nursing Leadership*, 22(2), 73-84. doi: 10.12927/cjnl.2009.20800
- Ambresin, A.E., Bennett, K., Patton, G.C., Sanci, L.A., & Sawyer, S.M. (2013).
  Assessment of Youth-Friendly Health Care: A Systematic Review of Indicators Drawn from Young People's Perspectives. *Journal of Adolescent Health, 52*, 670-681.

http://dx.doi.org/10.1016/j.jadohealth.2012.12.014

American Academy of Child and Adolescent Psychiatry. (2015). Parenting:

Preparing for Adolescence. Retrieved from

https://www.aacap.org/AACAP/Families\_and\_Youth/Facts\_for\_Families/

FFF-Guide/Parenting-Preparing-For-Adolescence-056.aspx

American Psychological Association (APA). (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC: Author.

- American Psychological Association (APA). (2018). Children's Mental Health. Retrieved from <u>https://www.apa.org/pi/families/children-mental-</u> health.aspx
- Amon, K.L., Campbell, A.J., Hawke, C., & Steinbeck, K. (2014). Facebook as a Recruitment Tool for Adolescent Health Research: A Systematic Review. *Academic Pediatrics*, 14(6), 439-447.

https://doi.org/10.1016/j.acap.2014.05.049

- Anderson, J.E., & Lowen, C.A. (2010). Connecting youth with health services. *Canadian Family Physician*, 56(8), 778-784.
- Arnett, J.J. (2000). Emerging Adulthood: A Theory of Development from the Late Teens Through the Twenties. *American Psychologist*, 55(5), 269-480. doi: 10.1037//0003-066X.55.5.469
- Bandurraga, A., & Gowen, L.K. & The Finding Our Way Team. (2013). "I Bloomed Here": A Guide for Conducting Photovoice with Youth Receiving Culturally- and Community-based Services. Retrieved from <u>https://www.pathwaysrtc.pdx.edu/pdf/proj5-photovoice.pdf</u>
- Bhwara, J., Toulany, A., Cohen, E., Hepburn, C.M., & Guttmann, A. (2016).
  Primary care interventions to improve transition of youth with chronic health conditions from paediatric to adult healthcare: a systematic review. *BMJ Open, 6*(e011871). doi: 10.1136/ bmjopen-2016-011871

- Boak, A., Hamilton, H.A., Adlaf, E.M., Henderson, J.L., & Mann, R.E. (2016). *The mental health and well-being of Ontario students, 1991-2015: Detailed OSDUHS findings.* (CAMH Research Document Series No. 43).
  Toronto: Centre for Addiction and Mental Health.
- Brinkmann, S. (2018). The Interview. In N.K. Denzin & Y.S. Lincoln (Eds). *The* SAGE Handbook of Qualitative Research (5th ed) (pp. 576-599).
  Thousand Oaks, CA: SAGE.

Canadian Association of Pediatric Health Centres. (2016). A Guideline for Transition from Paediatric to Adult Health Care for Youth with Special Health Care Needs: A National Approach. Retrieved from <u>http://www.cheo.on.ca/uploads/Transition%20Program/2016%2006%202</u> <u>9%20%20CAPHC%20Transition%20YSHCN%20Guideline.pdf</u>

Canadian Family Practice Nurses Association. (2019). National Competencies for Registered Nurses in Primary Care. Retrieved from https://www.cfpna.ca/national-core-competencies

Canadian Institute for Health Information (CIHI). (2015). Care for Children and Youth with Mental Disorders. Retrieved from <u>https://secure.cihi.ca/free\_products/CIHI%20CYMH%20Final%20for%20</u> <u>pubs\_EN\_web.pdf</u>

Canadian Institute for Health Information (CIHI). (2018). Primary Health Care. Retrieved from <u>https://www.cihi.ca/en/primary-health-care</u> Canadian Medical Association. (2012). CMA Position Statement: Ensuring Equitable Access to Care: Strategies for Governments, Health System Planners, and the Medical Profession. Retrieved from <u>https://www.cma.ca/Assets/assets-library/document/en/advocacy/PD14-</u> 04-e.pdf

Canadian Mental Health Association (CMHA). (2014). Housing and Mental Health. Retrieved from <u>https://ontario.cmha.ca/wp-</u> <u>content/uploads/2014/03/CMHA-Ontario-Mental-Health-and-Housing-</u> <u>Backgrounder\_April12014FINAL-APPROVED-2.pdf</u> Canadian Mental Health Association (CMHA). (2018). Child and Youth – Access

to Mental Health Promotion and Mental Health Care. Retrieved from <u>https://cmha.ca/documents/child-youth-access-mental-health-promotion-</u> <u>mental-health-care</u>

Canadian Mental Health Association British Columbia Division. (2013). Mood Disorders. Retrieved from <u>https://cmha.bc.ca/documents/mood-disorders-</u> 2/

Canadian Nurses Association. (2013). Registered Nurses: Stepping up to transform health care. Retrieved from: <u>https://www.cna-</u> <u>aiic.ca/~/media/cna/files/en/registered\_nurses\_stepping\_up\_to\_transform\_</u> <u>health\_care\_e.pdf</u> Canadian Nurses Association. (2014). Optimizing the Role of Nurses in Primary Care in Canada. Retrieved from <u>https://www.cna-aiic.ca/-/media/cna/pagecontent/pdf-en/optimizing-the-role-of-nurses-in-primary-care-incanada.pdf?la=en&hash=693D3580BA0B5F401E126EF0D4194615BB6 A04F9</u>

Canadian Nurses Association. (2015). Position Statement: Primary Health Care. Retrieved from <u>https://www.cna-aiic.ca/-/media/cna/page-content/pdf-</u> en/primary-health-care-positionstatement.pdf?la=en&hash=611712E3AAC033BF0C4E94FB3F07F30866 <u>F6B692</u>

Cappelli, M., & Leon, S.L. (2017). Paving the path to connected care: Strengthening the interface between primary care and community-based child and youth mental health services. Retrieved from <u>http://www.excellenceforchildandyouth.ca/resource-hub/paving-path-</u> <u>connected-care-strengthening-interface-between-primary-care-and-</u> <u>community</u>

Catalani, C., & Minkler, M. (2010). Photovoice: A Review of the Literature in
Health and Public Health. *Health Education & Behaviour*, *37*(3), 424-451.
doi: 10.1177/1090198109342084

Centre for Addictions and Mental Health. (2016). Mental Health and Primary Care Policy Framework. Retrieved from https://www.camh.ca/- /media/files/pdfs---public-policy-

submissions/primarycarepolicyframework\_march2016-pdf.pdf

- Centre for Addictions and Mental Health. (2018). Mental Illness and Addiction: Facts and Statistics. Retrieved from <u>https://www.camh.ca/en/driving-</u> <u>change/the-crisis-is-real/mental-health-statistics</u>
- Centre for Addictions and Mental Health Provincial System Support Program. (2016). Transition-Age Youth Evidence Brief. Retrieved from <u>https://eenet.ca/sites/default/files/pdfs/TAYEnglish\_EENetEvidenceBrief\_Final.pdf</u>

Centers for Disease Control and Prevention (CDC). (2013). Social Ecological Model. Retrieved from <u>https://www.cdc.gov/cancer/nbccedp/sem.htm</u>

Cheung, A.H., Zuckerbrot, R.A., Jensen, P.S., Laraque, D., Stein, R.E.K., &
GLAD-PC Steering Group. (2018). Guidelines for Adolescent Depression
in Primary Care (GLADPC): Part II. Treatment and Ongoing
Management. *Pediatrics*, 141(3):e20174082

Children's Mental Health Ontario. (2020). Kids Can't Wait : 2020 Report on Wait Lists and Times for Child and Youth Mental Health Care in Ontario. Retrieved from <u>https://cmho.org/wp-content/uploads/CMHO-Report-</u> <u>WaitTimes-2020.pdf</u>

- Christie, D., & Viner, R. (2005). Adolescent development. *BMJ*, 5(330), 301-304. https://dx.doi.org/10.1136%2Fbmj.330.7486.301
- City of Hamilton. (2020). Public Health Nurses in School. Retrieved from <u>https://www.hamilton.ca/educational-programming-teachers/healthy-</u> <u>schools/public-health-nurses-in-schools</u>
- Clark, B.A., Veale, J.F., Greyson, D., & Saewyc, E. (2018). Primary care access and forgone care: a survey of transgender adolescents and young adults. *Family Practice*, 35(3), 302-306. doi:10.1093/fampra/cmx112
- Cohn, T.C. (2010). Assent. In *Encyclopedia of Research Design*. https://dx.doi.org/10.4135/9781412961288

Coles, M.E., Ravid, A., Gibb, B., George-Denn, D., Bronstein, L.R., & McLeod,
S. (2015). Adolescent Mental Health Literacy: Young People's
Knowledge of Depression and Social Anxiety Disorder. *Journal of Adolescent Health*, 58(1), 57-62.

https://doi.org/10.1016/j.jadohealth.2015.09.017

Colleges of Nurses of Ontario. (2018). RN and RPN Practice: The Client, the Nurse and the Environment. Retrieved from

https://www.cno.org/globalassets/docs/prac/41062.pdf

Copeland, W.E., Wolke, D., Shanahan, L., & Costello, E. (2015). Adult functional outcomes of common childhood psychiatric problems: A prospective,

longitudinal study. *JAMA Psychiatry*, 72(9), 892-899. doi: 10.1001/jamapsychiatry.2015.0730

- Cornally, N., & McCarthy, G. (2011). Help-seeking behaviour: A concept analysis. *International Journal of Nursing Practice*, *17*, 280-288. doi: doi:10.1111/j.1440-172X.2011.01936.x
- Cramer, R.J., & Kapusta, N.D. (2017). A Social-Ecological Framework of Theory, Assessment, and Prevention of Suicide. *Frontiers in Psychology*, 8(1756). doi: 10.3389/fpsyg.2017.01756
- Creswell, J. W., & Poth, C.N. (2018b). Chapter 7. Data Collection. In Qualitative Inquiry and Research Design: Choosing Among Five Approaches (4th ed.) (pp 147-180). Thousand Oaks, CA: Sage Publications.
- Critical Appraisal Skills Programme. (2018). CASP Appraisal Checklists. Retrieved from <u>https://casp-uk.net/casp-tools-checklists/</u>
- Davy, C., Harfield, S., McArthur, A., Munn, Z., & Brown, A. (2016). Access to primary health care services for Indigenous peoples: A framework synthesis. *International Journal for Equity in Health*, 15(163), 1-9. doi: 10.1186/s12939-016-0450-5
- Downes, M.J., Brennan, M.L., Williams, H.C., et al. (2016). Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open, 6*(e011458). doi: 10.1136/bmjopen-2016-011458

Eapen, V., & Jairam, R. (2009). Integration of child mental health services to primary care: challenges and opportunities. *Mental Health in Family Medicine*, 6(1), 43-48. Retrieved from <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2777591/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2777591/</a>

- Ferrin, M., Gledhill, J., Kramer, T., & Garralda, M.E. (2009). Factors influencing primary care attendance in adolescents with high levels of depressive symptoms. *Social Psychiatry and Psychiatric Epidemiology*, *44*, 825-833. doi: 10.1007/s00127-009-0004-x
- Furnham, A., & Swami, V. (2018). Mental health literacy: A review of what it is and why it matters. *International Perspectives in Psychology: Research, Practice, Consultation*, 7(4), 240–257. <u>https://doi.org/10.1037/ipp0000094</u>
- Glazier, R.H., Zagorski, B.M., & Rayner, J. (2012). Comparison of Primary Care Models in Ontario by Demographics, Case Mix and Emergency Department Use, 2008/09 to 2009/10. Retrieved from <u>https://www.ices.on.ca/Publications/Atlases-and-</u> <u>Reports/2012/Comparison-of-Primary-Care-Models</u>
- Graham, T., Rose, D., Murray, J., Ashworth, M., & Tylee, A. (2014). Usergenerated quality standards for youth mental health in primary care: a participatory research design using mixed methods. *BMJ Quality and Safety, 23,* 857-866. doi:10.1136/bmjqs-2014-002842

Government of Canada. (2006). The human face of mental health and mental illness in Canada. Retrieved from http://www.phac-

aspc.gc.ca/publicat/human-humain06/pdf/human\_face\_e.pdf

Government of Canada. (2011). Pediatric and Adolescent Care - Chapter 19 -

Adolescent Health. Retrieved from <u>https://www.canada.ca/en/indigenous-</u> <u>services-canada/services/first-nations-inuit-health/health-care-</u> <u>services/nursing/clinical-practice-guidelines-nurses-primary-</u> care/pediatric-adolescent-care/chapter-19-adolescent-health.html

Government of Canada. (2018). Consent. Retrieved from <u>http://www.pre.ethics.gc.ca/eng/policy-politique/interpretations/consent-</u> <u>consentement/</u>

Government of Ontario. (2019). Improving health care in Ontario. Retrieved from <u>https://www.ontario.ca/page/improving-health-care-ontario</u>

Guba, E.G. (1981). Criteria for Assessing the Trustworthiness of Naturalistic
 Inquiries. *Educational Communication and Technology Journal*, 29(2),
 75-91.

Gulliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech,
R., & Hudson, M. (2002). What does 'access to health care' mean?.
Journal of Health Services Research & Policy, 7(3), 186-188. doi:
10.1258/135581902760082517

- Gulliver, A., Griffiths, K.M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry*, 10(113). <u>https://doi.org/10.1186/1471-244X-10-113</u>
- Haggerty, J., Burge, F., Levesque, J.F., Pineault, R., Beaulieu, M.D., & Santos, D. (2007). Operational Definitions of Attributes of Primary Health Care:
  Consensus Among Canadian Experts. *Annals of Family Medicine*, *5*(4), 336-344. doi: 10.1370/afm.682.
- Hamilton Wentworth Catholic District School Board. (2020). Policies. Retrieved from https://www.hwdsb.on.ca/about/policies/
- Health Canada. (2015). Canada Health Act Annual Report 2014-2015. Retrieved from <u>https://www.canada.ca/content/dam/hc-sc/migration/hc-sc/migration/hc-sc/hcs-sss/alt\_formats/pdf/pubs/cha-ics/2015-cha-lcs-ar-ra-eng.pdf</u>
- HealthForceOntario. (2019). Family Medicine Compensation and Practice Models in Ontario. Retrieved from

http://www.healthforceontario.ca/UserFiles/file/PracticeOntario/FM%20C ompensation%20Practice%20Models%20EN.pdf

 Health Quality Ontario. (2015). Quality in Primary Care: Setting a Foundation for Monitoring and Reporting in Ontario. Retrieved from <a href="https://www.hqontario.ca/Portals/0/Documents/pr/theme-report-quality-in-primary-care-en.pdf">https://www.hqontario.ca/Portals/0/Documents/pr/theme-report-quality-in-primary-care-en.pdf</a>
- Hunt, M. (2009). Strengths and Challenges in the Use of Interpretive Description:
  Reflections Arising from a Study of the Moral Experience of Health
  Professionals in Humanitarian Work. *Qualitative Health Research*, 19(9),
  1284-1292. doi: 10.1177/1049732309344612
- Institute for Clinical Evaluative Sciences (ICES). (2017). The Mental Health of Children and Youth in Ontario: 2017 Scorecard. Retrieved from <u>https://www.ices.on.ca/Publication\_s/Atlases-and-Reports/2017/MHASEF</u>

Ipsos & Children's' Mental Health Ontario. (2017). Children and Youth Mental Health Survey: Getting Help in Ontario. Retrieved from <u>https://www.ipsos.com/sites/default/files/ct/news/documents/2017-</u> <u>11/Children%20and%20Youth%20Mental%20Health%20Survey%20Find</u> <u>ings\_FINAL\_Nov.pdf</u>

Jimenez, D.E., Bartels, S.J., Cardenas, V., Daliwal, S.S., & Alegria, M. (2012).
Cultural Beliefs and Mental Health Treatment Preferences of Ethnically
Diverse Older Adult Consumers in Primary Care. *American Journal of Geriatric Psychiatry*, 20(6), 533-542. doi:10.1097/JGP.0b013e318227f876

Kang, C., Tomkow, L., & Farrington, R. (2019). Access to primary health care for asylum seekers and refugees: a qualitative study of service user experiences in the UK. *British Journal of General Practice, 69*(685), e537-545. <u>https://doi.org/10.3399/bjgp19X701309</u>

- Kates, N., Arroll, B., Currie, E., Hanlon, C., Gask, L., Klasen, H., Meadows, G., Rukundo, G., Sunderji, N., Ruud, T., & Williams, M. (2019). Improving collaboration between primary care and mental health services. *The World Journal of Biological Psychiatry*, 20(10), 748-765. https://doi.org/10.1080/15622975.2018.1471218
- Klein, J.D., Slap, G.B., Elster, A.B., & Cohn, S.E. (1993). Adolescents and access to health care. *Bulletin of the New York Academy of Medicine*, 70(3), 219-235.
- Krefting, L. (1991). Rigor in Qualitative Research: The Assessment of Trustworthiness. *The American Journal of Occupational Therapy*, 45(3), 41-50.
- Kristy, B.L. (2017). RNAO Mental Health and Addiction Resource: Tips for Engaging Lived Experience. Retrieved from

http://mharesource.rnao.ca/tips-engaging-lived-experience

- Larcher, V. (2005). ABC of adolescence. *BMJ*, *330*(7487), 353-356. https://dx.doi.org/10.1136%2Fbmj.330.7487.353
- Lavrakas, P.J. (2008). Purposive Sample. In *Encyclopedia of Survey Research Methods*. https://dx.doi.org/10.4135/9781412963947.n419
- Leahy, D., Schaffalitzky, E., Armstrong, C., Bury, G., Cussen-Murphy, P., Davis, R., Dooley, B., Gavin, B., Keane, R., Keenan, E., Latham, L., Meagher,

D., McGorry, P., McNicholas, F., O'Connor, R., O'Dea, E., O'Keane, V., O'Toole, T., Reilly, E., ... Cullen, W. (2013). Primary care and youth mental health in Ireland: qualitative study in deprived urban areas. *BMC Family Practice, 14*(194). <u>http://www.biomedcentral.com/1471-</u> 2296/14/194

- Leahy, D., Schaffalitzky, E., Saunders, J., Armstrong, C., Meagher, D., Ryan, P., Dooley, B., McNicholas, F., McGorry, P., & Cullen, W. (2018). Role of the general practitioner in providing early intervention for youth mental heath: a mixed methods investigation. *Early Intervention in Psychiatry*, *12*, 202-216. doi:10.1111/eip.12303
- Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011).
  Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British Journal of Psychiatry*, *199*(6), 445-452. doi: 10.1192/bjp.bp.110.083733
- Levesque, J.F., Harris, M.F., & Russell, G. (2013). Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health, 12*(18). Retrieved from <u>http://www.equityhealthj.com/content/12/1/18</u>
- Lincoln, Y.S., & Guba, E.G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage Publications.

Logan, D.E., & King, C.A. (2001). Parental Facilitation of Adolescent Mental Health Service Utilization: A Conceptual and Empirical Review. *Clinical Psychology: Science and Practice*, 8(2), 319-333.

Lukewich, J., Taylor, S., Poitras, M.E., Martin-Misener, R. (2018). Advancing family practice nursing in Canada: An environmental scan of international literature and national efforts towards competency development. *Nursing Leadership*, *31*(2). Retrieved from <a href="https://docs.wixstatic.com/ugd/a5cbe4\_1f47f040c3854dd7bf528b49df3cd">https://docs.wixstatic.com/ugd/a5cbe4\_1f47f040c3854dd7bf528b49df3cd</a> 94e.pdf

- Magaard, J.L., Seeralan, T., Schulz, H., & Levke Brutt, A. (2017). Factors associated with help-seeking behaviour among individuals with major depression: A systematic review. *PLoS ONE*, *12*(5), e0176730.
  <a href="https://doi.org/10.1371/journal.pone.0176730">https://doi.org/10.1371/journal.pone.0176730</a>
- McCann, T., & Lubman, D.I. (2012). Young people with depression and their satisfaction with the quality of care they receive from a primary care youth mental health service: a qualitative study. *Journal of Clinical Nursing*, 21, 2179-2187. doi: 10.1111/j.1365-2702.2012.04086.x
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health education quarterly*, 15(4), 351-377.

McLeod, S. (2018). Erik Erikson's Stages of Psychosocial Development. Retrieved from <u>https://www.simplypsychology.org/Erik-Erikson.html</u>

McLeod, K., & Simpson, A. (2017). Exploring the value of mental health nurses working in primary care in England: A qualitative study. *Journal of Psychiatric Mental Health Nursing*, 24(6).
https://doi.org/10.1111/jpm.12400

Mental Health Commission of Canada (MHCC). (n.d). Language Matters.

Retrieved from <u>https://www.mhfa.ca/sites/default/files/safer\_language\_reference\_guide.pd</u> <u>f</u>

Mental Health Commission of Canada (MHCC). (2013). The Mental Health Strategy for Canada: A Youth Perspective. Retrieved from <u>https://www.mentalhealthcommission.ca/sites/default/files/2016-</u> <u>07/Youth\_Strategy\_Eng\_2016.pdf</u>

Mental Health Commission of Canada (MHCC). (2015). Guidelines for

Recovery-Oriented Practice. Retrieved from

https://www.mentalhealthcommission.ca/sites/default/files/MHCC\_Recov eryGuidelines ENG 0.pdf

Meredith, L.S., Stein, B.D., Paddock, S.M., Jaycox, L.H., Quinn, V.P., Chandra, A., & Burnam, A. (2009). Perceived Barriers to Treatment for Adolescent

Depression. Medical Care, 47(6), 677-685. doi:

10.1097/MLR.0b013e318190d46b

Merriam, S.B. (2009). Designing your study and selecting a sample. In *Qualitative Research: A Guide to Design and Implementation* (pp. 55-84).
San Francisco, CA: Jossey-Bass.

Ministry of Health and Long-Term Care. (2020). Primary Care Payment Models in Ontario. Retrieved from

http://www.health.gov.on.ca/en/pro/programs/pcpm/

Moon, K., Brewer, T., Januchowksi-Hartley, S.R., Adams, V.M., & Blackman,
 D.A. (2016). A guideline to improve qualitative social science publishing
 in ecology and conservation journals. *Ecology and Society*, 21(3), 17. 17.
 <u>http://dx.doi.org/10.5751/ES-08663-210317</u>

- Morrison, P., & Stomski, N.J. (2014). Embracing participation in mental health research: conducting authentic interviews. *Mental health research*, 47.
  Retrieved from <u>www.emeraldinsight.com/1443-9883.htm</u>
- Morse, J. M. (1994). "Emerging from the data": Cognitive processes of analysis in qualitative inquiry. In J.M. Morse (Ed). Critical issues in qualitative research methods (pp. 23-43). Thousand Oaks, CA: Sage.
- Moses, T. (2010). Being treated differently: Stigma experiences with family, peers, and school staff among adolescents with mental health disorders.

Social Science & Medicine, 70(7), 985-993. doi:

10.1016/j.socscimed.2009.12.022

- Mukolo, A., Hefling, C. A., & Wallston, K.A. (2010). The stigma of childhood mental disorders: A conceptual framework. *Journal of the American Academy of Child and Adolescent Psychiatry*, 49(2), 92-198.
- Mulvale, G., & Hurley, J. (2008). Insurance coverage and the treatment of mental illness: effect on medication and provider use. *The journal of mental health policy and economics*, *11*(4), 177-199.
- O'Brien, D., Harvey, K., Howse, J., Reardon, T., & Creswell, C. (2016). Barriers to managing child and adolescent mental health problems: a systematic review of primary care practitioners' perceptions. *British Journal of General Practice, 66*(651), e693-e707.

https://doi.org/10.3399/bjgp16X687061

Office of the Auditor General of Ontario. (2016). Annual Report. Retrieved from <a href="http://www.auditor.on.ca/en/content/annualreports/arreports/en16/2016AR">http://www.auditor.on.ca/en/content/annualreports/arreports/en16/2016AR</a> \_v1\_en\_web.pdf

Ontario. (2015). Children and youth mental health: signs and symptoms. Retrieved from <u>https://www.ontario.ca/page/children-and-youth-mental-health-signs-and-symptoms</u> Ontario Centre of Excellence for Child and Youth Mental Health. (2015).

Evidence In-Sight: Access to child and youth mental health services.

Retrieved from

Ontario Medical Association (OMA). (2015). What is primary care and how do you receive it? Retrieved <u>http://www.ontariosdoctors.com/what-is-</u> <u>primary-care-and-how-do-you-receive-it/</u>

Ontario Ministry of Health and Long-Term Care. (n.d.). Ontario Health Teams: Guidance for Health Care Providers and Organizations. Retrieved from <u>http://health.gov.on.ca/en/pro/programs/connectedcare/oht/docs/guidance\_doc\_en.pdf</u>

Ontario Ministry of Health and Long-Term Care. (2019). Newsroom: Ontario Passes Legislation That Puts Patients at the Centre of an Integrated Health Care System. Retrieved from <u>https://news.ontario.ca/mohltc/en/2019/04/ontario-passes-legislation-that-</u> puts-patients-at-the-centre-of-an-integrated-health-care-system.html

Ontario Ministry of Health and Long-Term Care. (2020). Primary Care Payment Models in Ontario. Retrieved from <u>http://www.health.gov.on.ca/en/pro/programs/pcpm/</u>

- Ortlipp, M. (2008). Keeping and Using Reflective Journals in the Qualitative Research Process. *The Qualitative Report, 13*(4), 695-705. <u>https://doi.org/10.1080/14623943.2015.1134472</u>
- Ozer, E.J., & Akemi Piatt, A. (2017). Adolescent Participation in Research: Innovation, rationale, and next steps. Retrieved from <u>https://www.unicef-</u> irc.org/adolescent-research-methods/
- Patton, M.Q. (1999). Enhancing the quality and credibility of qualitative analysis.
   HSR: Health Services Research, 34(5), 1189-1208. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089059/pdf/hsresearch0 0022-0112.pdf
- Penchansky, R., & Thomas, J.W. (1981). The Concept of Access: Definition and Relationship to Consumer Satisfaction. *Medical Care*, 19(2), 127-140. Retrieved from <u>https://www.ncbi.nlm.nih.gov/pubmed/7206846</u>
- Pew Research Center. (2018). Teens, Social Media & Technology. Retrieved from <u>http://www.pewinternet.org/2018/05/31/teens-social-media-</u> <u>technology-2018/</u>
- Picker Institute. (2020). Principles of Person Centred Care. Retrieved from https://www.picker.org/about-us/picker-principles-of-person-centred-care/
- Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P., & Rousseau, M.C. (2011). Proposal: A

mixed methods appraisal tool for systematic mixed studies reviews. Retrieved from <u>http://mixedmethodsappraisaltoolpublic.pbworks.com</u>

- Pretorius, C., Chambers, D., & Coyle, D. (2019). Young People's Online Help-Seeking and Mental Health Difficulties: Systematic Narrative Review. *Journal of Medical Internet Research*, 21(11), e13873. doi: 10.2196/13873
- Price-Robertson, R., Obradovic, A., & Morgan, B. (2017). Relational recovery: beyond individualism in the recovery approach. *Advances in Mental Health*, 15(2), 108-120. <u>https://doi.org/10.1080/18387357.2016.1243014</u>
- Prince, M. (2012). Epidemiology: Bias. Retrieved from
  <a href="https://www.sciencedirect.com/science/article/pii/B978070203397100009">https://www.sciencedirect.com/science/article/pii/B978070203397100009</a>
- Provincial Advocate for Children and Youth. (2016). Yes, You Can: Dispelling myths about sharing information with Children's Aid Societies. Retrieved from <u>http://www.oacas.org/wp-</u>

content/uploads/2016/11/7798OPACYMyths-Booklayout-Web.pdf

- QSR International. (n.d.). NVivo 12 Pro. Retrieved from https://www.gsrinternational.com/nvivo/nvivo-products/nvivo-12-pro
- Radovic, A., McCauley, H., Sucato, G., Stein, B., & Miller, E., (2014). "She thought that the girl had just made it up": Primary care provider perceptions of parental barriers to adolescent depression care. *Journal of*

Adolescent Health, 54(2), S19-20.

https://doi.org/10.1016/j.jadohealth.2013.10.053

Randall, G. E., Mulvale, G. M., Wakefield, P. A., Embrett, M. G., Barr, N. G.,

Miatello, A. M., Longo, C. J., Nguyen, T. D., Di Rezze, B. M., Vania, D.
K., & McRae, S. A. (2016). *Mapping the Policy to Practice Landscape for Youth Mental Health in Ontario: A Report from the "Youth to Adult Transitions in Health Care – the Case of Mental Health Services in Ontario" research team.* Retrieved from
https://www.researchgate.net/publication/299676766

Reavley, N.J., & Jorm, A.F. (2011). Recognition of mental disorders and beliefs about treatment and outcome: findings from an Australian National Survey of Mental Health Literacy and Stigma. *Australian and New Zealand Journal of Psychiatry*, 45(11), 947-956.

https://doi.org/10.3109/00048674.2011.621060

Registered Nurses' Association of Ontario [RNAO]. (2010). Enhancing Healthy Adolescent Development. Retrieved from <u>https://rnao.ca/sites/rnao-</u> <u>ca/files/Enhancing\_Healthy\_Adolescent\_Development.pdf</u>

Registered Nurses' Association of Ontario [RNAO]. (2012). Primary solutions for Primary Care: Primary Care Task Force. Retrieved from <u>https://rnao.ca/sites/rnao-ca/files/Primary\_Care\_Report\_2012.pdf</u>

- Reid, G.J., Cunningham, C.E., Tobon, J.I., Evans, B., Stewart, M., Brown, J.B.,
  Lent, B, Neufeld, R.W., Vingilis, E.R., Zaric, G.S., & Shanley, D.C.
  (2011). Help-Seeking for Children with Mental Health Problems: Parents'
  Efforts and Experiences. *Administration and Policy in Mental Health, 38*.
  384-397. doi: 10.1007/s10488-010-0325-9
- Reupert, A. (2017). A socio-ecological framework for mental health and wellbeing. Advances in Mental Health, 15(2), 105-107. <u>https://doi.org/10.1080/18387357.2017.1342902</u>
- Rickwood, D.J., Deane, F.P., Wilson, C.J., & Ciarrochi, J. (2005). Young people's help-seeking for mental health problem. *Australian e-Journal for the Advancement of Mental Health*, 4(3), 218-261.
  <a href="https://doi.org/10.5172/jamh.4.3.218">https://doi.org/10.5172/jamh.4.3.218</a>
- Rickwood, D.J., Deane, F.P., & Wilson, C.J. (2007). When and how do young people seek professional help for mental health problems? *Medical Journal of Australia, 187*(7), S35. Retrieved from <a href="https://www.mja.com.au/journal/2007/187/7/when-and-how-do-young-people-seek-professional-help-mental-health-problems">https://www.mja.com.au/journal/2007/187/7/when-and-how-do-young-people-seek-professional-help-mental-health-problems</a>

Saurman, E. (2016). Improving access: modifying Penchansky and Thomas's Theory of Access. *Journal of Health Services Research & Policy*, 21(1), 36-39. doi: 10.1177/1355819615600001

- Sayal, K., Amarasinghe, M., Robotham, S., Coope, C., Ashworth, M., Day, C., Tylee, A., & Simonoff, E., (2012). *Quality standards for child and adolescent mental health in primary care. BMC Family Practice*, 13(51). <u>https://dx.doi.org/10.1186%2F1471-2296-13-51</u>
- Sayal, K., Tischler, V., Coope, C., Robotham, S., Ashworth, M., Day, C., Tylee,
  A., & Siminoff, E. (2010). Parental help-seeking in primary care for child and adolescent mental health concerns: qualitative study. *The British Journal of Psychiatry*, 197, 476-481. doi: 10.1192/bjp.bp.110.081448
- Schaffalitzky, E., Leahy, D., Cullen, W., Gavin, B., Latham, L., O'Connor, R., Smyth, B.P., O'Dea, E., & Ryan, S. (2014). Youth mental health in deprived urban areas: a Delphi study on the role of the GP in early intervention. *Irish Journal of Medical Science*, *184*(4), 831-843. doi: 10.1007/s11845-014-1187-z
- Seymour, K. (2012). Using Incentives: Encouraging and recognizing participation in youth research. *Youth Studies Australia*, *31*(3), 51-59.
- Shaghaghi, A., Bhopal, R.S., & Sheikh, A. (2011). Approaches to Recruiting
  "Hard-To-Reach" Populations into Research: A Review of the Literature. *Health Promotion Perspectives*, 1(2), 86-84. doi:10.5681/hpp.2011.009
- Social Research and Planning Committee of Hamilton. (2017). Hamilton's Social Landscape Bulletin (Issue 14): Poverty among Hamilton's taxfilters. Retrieved from <u>http://www.sprc.hamilton.on.ca/wp-</u>

content/uploads/2017/04/SPRC-HSL-Bulletin-14-Poverty-of-taxfilers-April-2017.pdf

Statistics Canada. (2016a). Primary Health Care Providers, 2016. Retrieved from https://www150.statcan.gc.ca/n1/pub/82-625-x/2017001/article/54863eng.htm

Statistics Canada. (2016b). Census Profile, 2016 Census. Retrieved from https://www12.statcan.gc.ca/census-recensement/2016/dppd/prof/details/page.cfm?Lang=E&Geo1=CD&Code1=3525&Geo2=PR& Code2=35&Data=Count&SearchText=Hamilton&SearchType=Begins&S earchPR=01&B1=All&GeoLevel=PR&GeoCode=3525&TABID=1

Starfield, B. (1994). Primary care: Balancing health needs, service and technology. The Lancet, 344(8930), 1129-1133.

The National Infant, Child and Youth Mental Health Consortium Advisory (2010). Access & Wait Times in Child and Youth Mental Health: A Background Paper. Retrieved from <u>http://www.excellenceforchildandyouth.ca/sites/default/files/resource/poli</u> cy\_access\_and\_wait\_times.pdf

Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice*, 2<sup>nd</sup> ed. NY: New York.

- Thorne, S., Kirkham, S.R., & MacDonald-Emes, J. (1997). Interpretive Description: A Noncategorical Qualitative Alternative for Developing Nursing Knowledge. *Research in Nursing & Health*, 20, 169-177. <u>https://doi.org/10.1002/(SICI)1098-240X(199704)20:2<169::AID-</u> NUR9>3.0.CO;2-I
- Thorne, S., Kirkham, S.R., & O'Flynn-Magee, K. (2004). The Analytic Challenge in Interpretive Description. International Journal of Qualitative Methods, 3(1), 1-11. <u>https://doi.org/10.1177/160940690400300101</u>
- Thorne, S., Stephens, J., & Truant, T. (2015). Building qualitative study design using nursing's disciplinary epistemology. *Journal of Advanced Nursing*, 72(2), 451-460. doi: 10.1111/jan.12822
- Tilleczek, K.C., Bell, B.L., Munro, M.A., & Gallant, S.D. (2017). Canadian Journal of Community Mental Health, 36(2), 151-164. doi: :10.7870/cjcmh-2017-026

Transparent Reporting of Systematic Reviews and Meta-Analyses. (2009). PRISMA Statement. Retrieved from <u>http://prisma-</u>

statement.org/PRISMAStatement/PRISMAStatement

UNICEF. (2009). Social Ecological Model - Unicef. Retrieved from https://www.unicef.org/cbsc/files/Module\_1\_SEM-C4D.docx

- Vallance, A.K., Kramer, T., Churchill, D., & Garralda, M.E. (2011). Managing child and adolescent mental health problems in primary care: taking the leap from knowledge to practice. *Primary Health Care Research & Development, 12*, 301-309. doi:10.1017/S1463423611000338
- van de Toren, S., van Grieken, A., Lugtenberg, M., Boelens, M., & Raat, H.
  (2019). Adolescents' Views on Seeking Help for Emotional and Behavioral Problems: A Focus Group Study. *International Journal of Environmental Research and Public Health*, 17(191). doi: 10.3390/ijerph17010191
- Wang, C.C., Morrel-Samuels, S., Hutchison, P.M., Bell, L., & Pestronk, R.M.
  (2004). Flint Photovoice: Community Building Among Youths, Adults, and Policymakers. *American Journal of Public Health*, 94(6), 911-913.
  Retrieved from

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1448361/pdf/0940911.pdf

- Wetterlin, F.M., Mar, M.Y., Neilson, E.K., Werker, G.R., & Krausz, M. (2014).
  eMental Health Experiences and Expectations: A Survey of Youths' Web-Based Resource Preferences in Canada. *Journal of Medical Internet Research*, 16(12), e293. <u>https://doi.org/10.2196/jmir.3526</u>
- Wilson, C.J., Bushnell, J.A., & Caputi, P. (2011). Early access and help seeking: practice implications and new initiatives. *Early Intervention is Psychiatry*, 5(s1), 34-39. <u>https://doi.org/10.1111/j.1751-7893.2010.00238.x</u>

Woodgate, R.L., Zurba, M., & Tennet, P. (2017). A Day in the Life of a Young Person with Anxiety: Arts-Based Boundary Objects Used to Communicate the Results of Health Research. *Forum: Qualitative Social Research, 18*(3), Art 17. <u>http://dx.doi.org/10.17169/fqs-18.3.2886</u>

World Atlas. (2019). List of Western Countries. Retrieved from https://www.worldatlas.com/articles/list-of-western-countries.html

World Health Organization (WHO). (2008). Integrating mental health into primary care: A global perspective. Retrieved from <u>https://www.who.int/mental\_health/resources/mentalhealth\_PHC\_2008.pd</u> <u>f</u>

World Health Organization (WHO). (2014). Social Determinants of Mental Health. Retrieved from <u>http://apps.who.int/iris/bitstream/handle/10665/112828/9789241506809\_e</u> <u>ng.pdf;jsessionid=862AEA2547D2DD1239A4067D0CBF448F?sequence</u> =1

- World Health Organization (WHO). (2018). Adolescent mental health. Retrieved from <u>http://www.who.int/news-room/fact-sheets/detail/adolescent-mental-</u> health
- Zuckerbrot, R.A., Cheung, A., Jensen, P.S., Stein, R.E.K., Laraque, D., & GLAD-PC Steering Group. (2018). Guidelines for Adolescent Depression in

Primary Care (GLAD-PC): Part I. Practice Preparation, Identification,

Assessment, and Initial Management. Pediatrics, 141(3): e20174081

## **APPENDICES**

# **Appendix A: Access Dimensions by Penchansky and Thomas (1981)**

Access Dimension	Definition
Availability	"The relationship of the volume and type of existing services (and resources) to the client's volume and types of needs. It refers to the adequacy of the supply of physicians and other providers." (p.128)
Accessibility	"The relationship between the location of supply and the location of clients, taking account of client transportation resources and travel time, distance and cost." (p.128)
Accommodation	"The relationship between the manner in which the supply resources are organized to accept clients (including appointment systems, hours of operation, walk-in facilities, telephone services) and the clients' ability to accommodate these factors and the clients' perception of their appropriateness." (p.128)
Affordability	"The relationship of prices of services and providers' insurance or deposit requirements to the clients' income, ability to pay, and existing health insurance." (p.128)
Acceptability	"The relationship of clients' attitude about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of clients." (p. 129)
Awareness*	"A service that was aware of the local context and population needs could provide more appropriate and effective care, and patients could better access and use such services if they were simply aware of them in the first place." (p.37)*

\*Saurman (2016).



**Appendix B: Ecological Model by McLeroy and Colleagues (1988)** 

		Ferrin et al., 2009	Graham et al., 2014	Leahy et al., 2013	Leahy et al., 2018	McCann et al., 2012	Meredith et al., 2009	O' Brien et al., 2016	Radovic et al., 2014	Sayal et al., 2010	Sayal et al., 2012	Schaffalitzky et al. , 2014
	Accessibility											
	Availability						Х					
lal	Affordability											
Individual	Accommodation											
Ind	Acceptability											
	Awareness				X							
	Uncategorized	Х		Х			Х					
	Accessibility											
	Availability											
nal	Affordability											
Interpersonal	Accommodation											
Inter	Acceptability		Х	Х	Х	Х	Х			X	X	Х
	Awareness											
	Uncategorized							Х	Х	Х		
	Accessibility											
onal	Availability											
Organizational	Affordability											
rgan	Accommodation					Х	Х					
0	Acceptability											

Appendix C: Access Dimensions within Studies

# Appendix C (continued)

		Ferrin et al., 2009	Graham et al., 2014	Leahy et al., 2013	Leahy et al., 2018	McCann et al., 2012	Meredith et al., 2009	O ' Brien et al., 2016	Radovic et al., 2014	Sayal et al., 2010	Sayal et al., 2012	Schaffalitzky et al., 2014
cational	Awareness		X									
Organizational	Uncategorized											
	Accessibility											
	Availability											
nity	Affordability											
Community	Accommodation											
Con	Acceptability		Х	X				X				Х
	Awareness											
	Uncategorized											
	Accessibility											
	Availability				Х			Х		X		Х
~	Affordability											
Policy	Accommodation			X				X				Х
	Acceptability											
	Awareness											
	Uncategorized											

## **Appendix D: Targeted Search Strategy**

Medline & Cochrane

MeSH headings:

Adolescent/

Primary Health Care/ or Community Health Centers/

Embase

Subject headings:

Juvenile/ or Adolescent/

Primary medical care/ or Primary health care/ or General practice/ or Family medicine/

### Terms used for all databases:

- 1. (adolesc\* or teen\* or youth\*) and
- ((primary adj2 (care or healthcare or health care)) or (family and (medicine or physician or practice)) or general practi\* or community health centre\*) and
- (access\* or accept\* or availab\* or accommod\* or afford\* or barrier\* or facilitat\* or fit or experience\*) and
- 4. mental adj2 (service\* or care)

# Limits:

- English language literature only
- Published between 2008 and January 2020
- Western-world counties: Canada, United States, Mexico, Australia, New Zealand, Iceland, Greenland, Scotland, Ireland, England, Portugal, Spain, France, Andorra, Belgium, Netherlands, Luxemburg, Germany, Switzerland, Italy, Monaco, Croatia, Greece, Slovenia, Austria, Czech Republic, Slovakia, Poland, Norway, Sweden, Finland, Lithuania, Latvia, Estonia



#### **Appendix E: Study Selection Flowchart**

Inclusion criteria:

- Describes a concept of access
- Context of primary care mental health services
- Anxiety or mood disorders, or unspecified mental health problems, mild to moderate mental illness
- Includes adolescent age range 14-18 years

Exclusion criteria:

- Psychosis

Author & Year	Study design	Participants	Country	Type of participant	Terms used	Illness focus
Ferrin et al., 2008	Case-control	Cases (n=156) Controls (n=120)	England, U.K.	Age 13 to 17 years, attending primary care versus non- attendees	General practitioner	Depression
Graham et al., 2014	Qualitative, unspecified methodology: interviews and focus groups	Youth (n=50)	England, U.K.	Age 16 to 25 years	General practitioner	Mental health problems
Leahy et al., 2013	Qualitative, inductive thematic analysis; semi- structured interviews	Health care professionals (n=37)	Ireland	Health care professionals in primary, secondary, and community care^	General practitioner	Mental health and substance use problems
Leahy et al., 2018	Sequential qualitative design; qualitative interviews and surveys	Health care workers (n=37) Young people (n=20) General practitioners (n=175)	Ireland	Primary, secondary, and community care workers^ Youth age 11 to 25 years	General practitioner	Mental health problems
McCann et al., 2012	Qualitative, interpretive phenomenologic al analysis semi- structured interviews	Young people (n=26)	Australia	Young people, average age 18 years	Primary care clinician	Depression

Appendix	<b>F</b> :	Study	Characteristics
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^Included nurses

Author & Year	Study design	Participants	Country	Type of participant	Terms used	Illness focus
Meredith et al., 2009	Cohort	Depressed teens (n=184) Non- depressed teens (n=184) Parents (n=338)	U.S.A.	Teenagers age 13 to 17 years	Primary care clinician	Depression
O'Brien et al., 2016	Systematic review	Qualitative (n=13) Quantitative (n=30)	U.K., U.S.A., Australia Canada	Articles from the perspective of the primary care practitioner	Primary care practitioner	Anxiety, mood, other disorders
Radovic et al., 2015	Qualitative, unspecified methodology; semi- structured interviews	Primary care practitioners (n=15)	U.S.A.	Primary care practitioners^	Primary care provider	Depression
Sayal et al., 2010	Qualitative, unspecified methodology; focus groups, semi- structured interviews	Parents (n=34)	England, U.K.	Parents, from non- specialist community settings	General practitioner	Mental health problems
Sayal et al., 2012	Qualitative, unspecified methodology; focus groups	Parents (n=34) Health care professionals (n=55)	England, U.K.	Parents, and primary care and community- based professionals.	General practitioner	Mental health problems
Schaffalitzky et al., 2015	Observational cross- sectional study; Delphi survey	Health care professionals (n=17)	Ireland	Primary and secondary care <sup>^</sup>	General practitioner	Mental health problems

# Appendix F (continued)

^Included nurses

Author &	Appraisal	Strengths	Weaknesses	Transferability
Year Ferrin et	rating CASP*	- Comparison of	Small comple size	- Similar age range (13
al., 2008	case control: Weak	adolescents attending primary practice vs. control group of not attending - Compared different demographic backgrounds and non- Caucasian adolescents	<ul> <li>Small sample size</li> <li>Wide confidence intervals for several statistically significant findings</li> <li>Cofounding variables not accounted for</li> </ul>	to 17) - Examined only depressive symptoms - Does not directly discuss access
Graham et al., 2014	CASP* qualitative: Moderate	<ul> <li>Large sample of 50 youth</li> <li>Recruited youth from several community settings and primary care</li> </ul>	-Quality standards generated were not tested for validity - Recruitment strategies and participant demographics not well described	-Age range spans teen to young adult (16-25) - Does not directly discuss access - Focus on mental health concerns in general
Leahy et al., 2013	CASP* qualitative: Strong	<ul> <li>Health care workers and youth perspectives</li> <li>Rigorous data analysis methods described</li> </ul>	<ul> <li>Lack of background information about the researchers</li> <li>Lack of information on researchers relationship with participants</li> </ul>	<ul> <li>Age range spans teen to young adult (11-25)</li> <li>Discusses some access concepts</li> <li>Depression focus</li> </ul>
Leahy et al., 2018	MMAT <sup>#</sup> : Moderate	<ul> <li>Included other service providers outside of primary care</li> <li>Clear methodology and description of processes</li> </ul>	<ul> <li>Minimal description of qualitative analysis process</li> <li>No description of data management process</li> </ul>	<ul> <li>Only perspectives of health care professionals</li> <li>Does not directly discuss access</li> <li>Focus on mental health concerns in general</li> </ul>
McCann et al., 2012	CASP* qualitative: Strong	- Individual interviews - Phenomenological methodology with rigor strategies described in detail	- Participants came from a mental health focused primary care practice	<ul> <li>Age range spans teen to young adult (16-25)</li> <li>Mentions access broadly</li> <li>Depression focus</li> </ul>

# **Appendix G: Study Appraisals**

\*CASP: Critical Appraisal Skills Programme <sup>#</sup>MMAT: Mixed Methods Appraisal Tool

Author &	Appraisal	Strengths	Weaknesses	Transferability		
Year	rating					
Meredith et al., 2009	CASP* cohort: Moderate	<ul> <li>Perspectives from adolescents with depression vs. non- depressed adolescents</li> <li>Guided by the Health Belief Model</li> </ul>	<ul> <li>Utilized self-reported depressive symptoms</li> <li>Based assessment questions on studies of adults with depression in primary care</li> </ul>	<ul> <li>Age 13 to 17</li> <li>Does not directly discuss access</li> <li>Depression focus</li> </ul>		
O'Brien et al., 2016	CASP* systematic review: Strong	<ul> <li>Followed PRISMA guidelines in methodology</li> <li>Appropriate combining of quantitative and qualitative findings</li> </ul>	- Inclusion of studies from South America, Africa	<ul> <li>Age range under</li> <li>21</li> <li>Does not directly discuss access</li> <li>Examined mental health in general, not anxiety and depression specific</li> </ul>		
Radovic et al., 2015	CASP* qualitative: Strong	<ul> <li>Clear description of analysis process</li> <li>Describes analyst triangulation</li> </ul>	<ul> <li>Risk of self-selection</li> <li>bias, interviewed primary</li> <li>care practitioners who had</li> <li>enhanced access to mental</li> <li>health specialists</li> <li>Lack of background</li> <li>information about the</li> <li>researchers</li> </ul>	depression specific - Examined the parent role - Describes barriers and facilitators to access - Depression focus		
Sayal et al., 2010	CASP* qualitative: Moderate	<ul> <li>Clear description of analysis process and participant validation of findings</li> <li>Parents recruited from several different community settings</li> </ul>	<ul> <li>Unclear qualitative methodology</li> <li>Some focus groups contained less than four participants</li> </ul>	<ul> <li>Parents of children age 2 to 17 years</li> <li>Focus on mental health concerns in general</li> <li>Does not directly discuss access</li> </ul>		

# Appendix G (continued)

\*CASP: Critical Appraisal Skills Programme

Author & Year	Appraisal rating	Strengths	Weaknesses	Transferability
Sayal et al., 2012	CASP* qualitative: Moderate	<ul> <li>Clear description of focus group and quality standard development</li> <li>Utilized Delphi surveys to measure validity</li> </ul>	<ul> <li>Unclear qualitative methodology</li> <li>Lack of detailed demographic information about participants</li> </ul>	<ul> <li>Parents of children age 2 to 15 years</li> <li>Focus on mental health concerns in general</li> <li>Does not directly discuss access</li> </ul>
Schaffalitzky et al., 2015	AXIS <sup>^</sup> : Moderate	<ul> <li>Examined perspectives of primary care practitioners and secondary care providers</li> <li>Clear description of Delphi survey process</li> </ul>	<ul> <li>Risk of sampling bias; small sample size of individual identified by the steering committee of the study</li> <li>Cofounding variables not accounted for</li> </ul>	<ul> <li>Focus on mental health concerns in general</li> <li>Does not define access</li> </ul>

# Appendix G (continued)

\*CASP: Critical Appraisal Skills Programme ^AXIS: Appraisal Tool for Cross-Sectional Studies

**Appendix H: Recruitment Flyer** 



### Participants needed for research in adolescent mental illness



## Are you between 14 to 18 years of age? Do you have a mental health concern? Do you live in Hamilton?

If yes, you can help us learn about the experience of

getting help or trying to get help from your family doctor or nurse practitioner's office.

The aim of this study is to help us learn how to improve experiences accessing mental health services through the family doctor or nurse practitioner's office. If you participate, you will meet with the researcher for an interview and take photos about your experiences.

- Your participation will involve between 2 to 3 meet ups,
- One session 30 minutes, and one 60 to 90 minutes long
- You will receive a \$20 gift card for each session
- You will receive light snacks and drinks at each session
- Your travel costs may also be covered

For more information about this study, or to volunteer please contact:

Lisa De Panfilis RN, BScN Master of Science in Nursing student School of Nursing, McMaster University 365-336-1358 or Email: <u>adolpsc@mcmaster.ca</u> Facebook: <u>www.facebook.com/adolpcs</u> Instagram: @adolpcs

This study has been reviewed by the Hamilton Integrated Research Ethics Board under project #6005. Version #2 – Version Date May 23, 2019

| Call or text Lisa   |
|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
| (365)-336-1358      | (365)-336-1358      | (365)-336-1358      | (365)-336-1358      | (365)-336-1358      | (365)-336-1358      |
| Email:              | Email:              | Email:              | Email:              | Email:              | Email:              |
| adolpcs@mcmaster.ca | adolpcs@mcmaster.ca | adolpcs@mcmaster.ca | adolpcs@mcmaster.ca | adolpcs@mcmaster.ca | adolpcs@mcmaster.ca |

#### **Appendix I: Potential Recruitment Sites**

Child and Adolescent Services Hamilton Public Health Services 140 King St E, Suite 4 Hamilton 905-546-2424 ext 3678

NGen Youth Centre 24 Main Street West Hamilton 905-524-2222

McMaster Family Practice 100 Main Street West, 3<sup>rd</sup> Floor 905-546-9885

Hamilton Urban Core Community Health Centre 71 Rebecca Street 905-522-3233

De dwa da dehs nye s Aboriginal Health Centre 678 Main Street East Hamilton 905-544-4320

Hamilton Downtown Family YMCA 79 James Street South Hamilton 905-529-7102

Les Chater Family YWCA 365 Rymal Road East Hamilton 905-667-1515

YMCA Newcomer Youth Centre 211 Centennial Parkway North Stoney Creek 905-662-9400 Starbucks 151 York Boulevard 289-921-8594

Starbucks 1508 Upper James Street 905-318-5151

Central Hamilton Public Library 55 York Boulevard Hamilton 905-546-3200

Lynwood Charlton Centre 526 Upper Paradise Road Hamilton 905-389-1361

Living Rock Youth Ministries 30 Wilson Street Hamilton 905-528-7625

Carlisle Hamilton Public Library 1496 Centre Road Flamborough 905-689-8769

Central Hamilton Public Library 55 York Boulevard Hamilton 905-546-3200

Lynwood Charlton Centre 526 Upper Paradise Road Hamilton 905-389-1361

	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	June	July	Aug
Ethics approval															
Recruitment															
Data collection															
Analysis															
Thesis write- up															

Appendix J: Study Timeline 2019-2020

### **Appendix K: Script and Assessment Questions**

**E-mail subject line:** McMaster Study: Experiences of adolescents with anxiety or mood disorders of accessing primary care mental health services

Dear \_\_\_\_\_:

Thank you for emailing me about the study.

As a McMaster University Master of Science in Nursing student I am conducting research on adolescent experiences of primary care (your regular family doctor or nurse practitioner's office) mental health services.

I aim to understand the experience of adolescents between the ages of 14 to 18 years who have gotten help, or tried to get help, from family doctor or nurses practitioners' office for a mental health concern.

I would like to learn about your experiences getting help or getting to your family doctor or a nurse your family doctors' office for a mental health concern.

The study requires 2 to 3 sessions, each about one or one and a half hours long. You will be asked to:

- meet with me to learn about the study
- take a few photos that describe your experience, and
- meet with me again to answer some question and describe your photos
- potentially meet a final time to clarify previous comments or answer any new questions that come up

Your participation in this study is voluntary (volunteer). It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time.

If you are interested in being part of the research study and learning more, please reply to this email or call me at 905 525 9140 x21222

Kindly,

Lisa De Panfilis RN, BScN Master of Science in Nursing student School of Nursing McMaster University

## Appendix K (continued)

#### **Telephone script:**

Thank you for calling me about the study. My name is Lisa De Panfilis and I am a nurse and Master of Science in Nursing student at McMaster University.

I am conducting research on adolescent experiences of primary care (your regular family doctor or nurse practitioner's office) mental health services.

I aim to understand the experience of adolescents between the ages of 14 to 18 years who have gotten help, or tried to get help, from family doctor or nurses practitioners' office for a mental health concern.

I would like to learn about your experiences getting help or getting to your family doctor or a nurse your family doctors' office for a mental health concern.

The study requires 2 to 3 sessions, each about one or one and a half hours long. You will be asked to:

- meet with me to learn about the study
- take a few photos that describe your experience, and
- meet with me again to answer some question and describe your photos
- potentially meet a final time to clarify previous comments or answer any new questions that come up

Your participation in this study is voluntary (volunteer). It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time.

Do you have any questions about the study?

Are you interested in participating in the study?

If yes, I must ask you a few screening questions to make sure you are able to participate in the study.

#### **Screening questions for telephone:**

- 1. Are you between of 14 to 18 years of age?
- 2. Do you live in Hamilton? Including Ancaster, Dundas, Flamborough, Glanbrook, and Stoney Creek?
- 3. Do you identify as: male, female, non-binary, or prefer not to say?
- 4. Have you seen your family doctor or nurse practitioner in the last year for a mental health concern?
- 5. Do you have an anxiety or mood disorder?

Are you currently experiencing a worsening of your mental health symptoms?

#### Appendix K (continued)

- 6. Do you have any concerns about your safety, such as thoughts of harming yourself, suicidal thoughts, or harming another person?If yes and participant is under age 16, call Children's Aid Society.If yes and they are age 16 and above, refer them to crisis supports in Hamilton (Appendix P).
- 7. Do you have access to a phone, tablet, or camera for taking photos?
- 8. Do you have internet access?

Final questions

- 9. Do you have any questions for me?
- 10. When we meet, I will be asking you to sign a consent form to participate in the study. We will talk about the study, how you can stop participating in the study at any time, and how I will try to protect your information for your privacy. There are no specific benefits to you for being in the study, although you will be compensated for your time.
- 11. When and where should we meet for our first meeting? A private room at McMaster or a location of the Hamilton Public Library near you? At the first meeting I will describe the study in more detail and go over the consent forms.
- 12. There will be some snacks and drinks at the sessions. Do you have any allergies or food restrictions?
- 13. Do you need any bus tickets to cover your cost of getting here/there? If you plan to come to McMaster, do you need a parking pass?
- 14. Would you like text or email reminders for our meeting? If so, what is your email/cell phone number.

### **Appendix L: Demographic Data Collection Form**

Date: \_\_\_\_\_

Participant ID: \_\_\_\_\_

Study title: Experiences of adolescents with anxiety or mood disorders of accessing primary care mental health services

Please answer the following questions about yourself. The purpose of this survey is to collect information so we will be able to describe, as a group, the participants in this study.

Question	Your answer
1. What is your age?	
<ul><li>2. Do you identify with any race/ethnicities?</li><li>For example, African, Asian, First Nations, Spanish.</li></ul>	□ Yes □ No □ Prefer not to say
3. Do you identify with a sexual orientation included in LGBTQ2S+?	□ Yes □ No □ Prefer not to say
4. Who do you live with?	Specify: □ Prefer not to say
5. Are you (if living alone) or your parents on social assistance (If relevant)?	□ Yes □ No □ Prefer not to say
6. When was the last time you visited your family doctor or nurses' office for mental health concerns?	
7. How many times do you see them in a year?	
8. Have you seen anyone else there for your mental health concerns?	
8. Are you seeing anyone else for your mental health concerns?	<ul> <li>□ Yes □ No</li> <li>□ Prefer not to say</li> <li>If yes, who: (Type of care provider, e.g. therapist, counselor, pediatrician).</li> </ul>
## **Appendix M: Participant Instructions**

Goal:

The goal of this project is to understand your experiences in getting help or trying to get help from your family doctor or nurse practitioner's office for a mental health problem.

Materials:

- Camera such as your cell phone, tablet, or a digital camera
- Computer, phone, or tablet to upload your photo and fill out the caption for it
- Printed copy of the caption sheet if needed

Rules for taking photos:

- 1. Please don't include any personal information in your photo. Some things not to include are peoples' faces or names.
- 2. Don't take any photos that someone would be upset with if they knew you had that photo.
- 3. You should take at least one photo, and a maximum of five.

Some questions to think about when taking photos:

- 1. What are some things that helped or challenge me in getting help from my family doctor or nurse practitioner?
- 2. Were there any physical, personal, family, or money related factors?
- 3. Was there anything about your family doctors' office that made it easier or harder to get help?

Some things might include the location, the space, costs, getting an appointment, or the people who work there like nurses or other health care providers.

4. Was there anything about your family doctor or nurse's services that made it easier or harder to get help?

Some things might include the time you had for an appointment, if you liked or didn't like the services, if your family or parents were included, or how you knew where to go.

Adapted from Bandurraga & Gowen, 2013.

## **Appendix N: Photo Submission Form**

Picture #1 File name:

Name of Photographer:\_\_\_\_\_

\_\_\_\_\_

Some things to think about are... People who made it easier or harder to get help, something about a person which helped or made it harder, money, travel...

This picture is about:

- □ Something that helped me get help
- □ Something that made it harder to get help

This picture is of:

This picture is important because:

\_\_\_\_\_

## **Appendix O: Interview Guides**

## Session 1: Introduction to the research study guide

- 1. Thank participant for coming
- 2. Introduce self as a researcher, nurse, and student
- 3. Obtain consent (review and sign), talk about confidentiality and limitations
- 4. Consent for photo release
- 5. Collect demographic information
- 6. Talk about the research topic, such as what is primary care, who works there, and what mental health services are Talk about "access" and generally the many dimensions involved in getting help that fits a person's needs
- 7. Describe how photo-voice works, what the rules are, and how they can submit their documents. Using "Participant Instructions" (Appendix K).
- 8. Give participant their honorarium and travel reimbursement (gift cards, bus tickets, parking pass, pay them for each photo)
- 9. Plan a second time to meet

## Session 2: Semi-structured Interview guide

- 1. Introduce self again, thank them for coming
- 2. Review consent form and confidentiality within this space
- 3. Begin recording
- 4. Overview what this session will include: talking about their photos and captions, and interview questions about them
- 5. Allow time for normalizing the experience of mental illness: discuss briefly that I am a Registered Nurse who works with young people, and have worked with people with mental illnesses. Talk about that I work with young people with mental illnesses in the school setting. Talk about the purpose of the study and what it is trying to learn
- 6. Remind them this interview could take 60 minutes, maximum 90
- 7. Remind them we are able to take breaks or stop if needed

## Background

I'd like to start by getting to know you a bit and just talking about who you are.

• Tell me a bit about yourself. Do you have any hobbies or interests?

# Appendix O (continued)

As you know, this study is about your experiences trying to get help from your family doctor or nurse practitioners' office for a mental health concern. I want to know about your experiences from the first time you thought about getting help, to now. It can help us learn was has worked and what has not worked well.

• Can you tell me about your experiences so far with getting help from your family doctor or nurse practitioner? *Probe: When did you first talk to a health care professional about your mental health concerns?* 

(Consider: participant story-telling may follow their own chronological order, the following questions will therefore be asked in an order that is appropriate to following their ideas)

## **Interview questions**

Photos

• Can you tell me a little bit about this picture? Why did you take this picture? *Probe with their caption sheet* 

*Probe: was this something that helped you or made it harder to get help?* Access dimensions (may have addressed some of these in their photos)

1. Accessibility

Tell me about how easy or not easy it was to physically get to your family doctors or nurse practitioners' office for your mental health concern? What made it hard or easy? *Probe: How did you get there? How far is it from your home?* 

2. Acceptability

I want to know how you felt about the characteristics of your family doctor or nurse practitioner. What are they like? How were they when you talked about your mental health concern?

*Probe:* What was it about their personality or how they treated you that made it better or worse?

3. Affordability

Can you describe any costs for you as part of getting help for your mental health concern?

*Probe: Did it cost you anything to get help? Such taking a bus or a taxi? Did your doctor recommend anything that cost you money?* 

## **Appendix O (continued)**

### 4. Accommodation

Tell me how your family doctor or nurse/s' office made accommodations to you and what you wanted/needed? How did they change their services to meet your mental health needs?

*Probe:* How long did you have to wait to get an appointment? Did you take time away from school or work to go? Did anyone talk to you about what would happen at your appointment?

5. Availability

Do you think there were enough services offered to help you and your mental health concern? *Probe: Did you need more services? Such as...* 

6. Awareness

Tell me about how if you knew you could try to get help from your family doctor or nurse practitioner's office for your mental health concern? *Probe: What lead you to going to there for help? What would helped you know where to get help from?* 

## Nurses and other health care professionals

- Can you describe what your family doctor or nurse practitioner's office is like? Who is there besides them? How many people do you speak to when you go there?
- I am wondering if you ever saw a nurse, (besides your NP if applicable)? *Probe: Sometimes these are the people seen wearing scrubs, giving needles, or talking to you when you first get into the room.*
- If you did, do you remember what their role was? *Probe: What did they do for you? Did you talk to them?*
- Did you see or talk to any other health care professionals? How many? *Probe: Some of these people could be a counsellor, therapist, social worker, dietician, physiotherapist...*

## **Appendix O (continued)**

If not previously addressed:

Could you tell me a little bit about who else was part of you getting help for your mental health concern?

*Probe: Did anyone in your family help/parents? Friends? Teachers or people at your school?* 

If relevant, is there anything about your cultural background, gender, or about your sexual orientation that was part of your experience with getting help for your mental health concern?

And how your family doctor or nurse treated you?

Is there anything else you would like to tell me about your experiences getting help for your mental health concern?

If you had a magic wand, what would your best scenario for getting help from your family doctor, nurse practitioner, or primary care nurse for a mental health concern look like?

(Paraphrase things they have said and summarize some of their ideas).

Do you feel that what I said has described your experiences?

## Conclusion

Thank you for meeting me with again today. I really appreciate that you have shared some of your experiences with me and the research study.

If we need to meet again to go over some of your information, I will call or email you.

*Remember to give their reimbursements (gift cards, bus ticket or parking pass) and payment for each photo.* 

## **Appendix P: Consent Form**



Inspiring Innovation and Discovery

LETTER OF INFORMATION / CONSENT

# Experiences of adolescents with anxiety or mood disorders of accessing primary care mental health services

#### Investigators:

Local Principal Investigator: Dr. Ruta Valaitis School of Nursing McMaster University Hamilton, ON, Canada (905) 525-9140 ext. 22298 E-mail: valaitis@mcmaster.ca

#### **Student Investigator:**

Lisa De Panfilis School of Nursing McMaster University Hamilton, ON, Canada Phone: (905) 525 9140 ext. 21222 E-mail: depanl@mcmaster.ca

#### What is this study about?

You are invited to take part in this study on the experiences of adolescents, between the ages of 14 to 18 years, who have gotten help, or tried to get help from, their family doctors' office. This research is part of a thesis in the Master of Science program in Nursing at McMaster University.

I am hoping to learn about what this has been like for you, like what things helped and what made it harder to get help for a mental health concern.

I also hope to find out about if you have worked with, or met, any nurses when you tried to get help.

#### What will happen during the study?

In the study, we will meet or talk over the phone two to three times. The first time, I will talk to you more about what it could mean to try to get help from your family doctor's office. I will also ask you for some demographic/background information like your age and ethnicity/culture.

You will be asked to take pictures that show something that represents your experiences. You will be asked to fill out a form and give a caption to your picture using an online survey and drop box. You will be given instructions about how to do this in a way which protects your confidentiality and I will walk you through it. This session might take about 30 minutes to one hour.

Then, you will meet with me to talk about the pictures you took, and about your experiences. This session might take about 60 minutes, to one hour and a half. With your permission, I will be audio-taping (recording) the interview and taking notes. Some questions that may be in the interview are:

## **Appendix P (continued)**

- Tell me about your experience getting help or trying to get help from your family doctors' office?
- Are there any people in your life that were part of your experience?
- Did you talk with any other health professionals besides your family doctor?

We might meet or talk a third time if I have to ask a few more questions about what you have said.

#### Are there any risks to doing this study?

The risks involved in participating in this study are minimal. You may feel uneasy talking about your mental illness. You might worry about confidentiality and who will know what you have said. I describe below the steps I am taking to protect your privacy.

You do not need to answer questions that you do not want to answer, or that make you feel uncomfortable. And you can stop to take a break at any time. You can also withdraw (stop taking part) in the study at any time.

#### Are there any benefits to doing this study?

The research will not benefit you directly. I hope that what is learned as a result of this study will help us to better understand how adolescents feel about getting help from their family doctors' office. This could help to find better ways to meet adolescents' needs for mental health services.

#### **Payment or Reimbursement**

For your participation in the study, you will be given a \$20 gift card for each session you are part of. You will also be given \$1 for each picture you take for the study.

If you decide to meet with me at McMaster University or at the Hamilton Public Library, I can give you bus tickets or a parking pass.

#### Confidentiality

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me, or other members of the research team such as my professors, will know whether you participated unless you choose to tell them. Your family doctor and your parents will not know about your participation unless you choose to tell them.

I will be keeping your consent form, demographic form, and audio-recordings, in a locked cabinet or on a locked computer which only I have access to, in a locked office at McMaster. Information on the computer will be password protected.

Once the study is complete, an archive of the data, without identifying information, will be kept. Your consent and demographic forms will be destroyed after 2 years.

## **Appendix P (continued)**

#### b) Legally Required Disclosure

Although I will protect your privacy as outlined above, if the law requires it, I will have to reveal certain personal information. This can happen if you are at risk of hurting yourself or another person, or if you talk about things that suggest you or another young person is at risk.

#### What if I change my mind about being in the study?

Your participation in this study is voluntary (volunteer). It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study.

If you decide to withdraw, there will be no consequences to you. If this happens, information provided up to the point where you stop taking part will be kept unless you request that it be removed.

If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Your decision whether or not to be part of the study will not affect the help you get from your family doctors' office, or other mental health services.

#### How do I find out what was learned in this study?

I expect to have this study completed by approximately October 2019. If you would like to know about some of the results, please let me know how you would like it sent to you.

#### **Questions about the Study**

If you have questions or need more information about the study itself, please contact me at:

#### Local Principal Investigator:

Dr. Ruta Valaitis School of Nursing McMaster University Hamilton, ON, Canada (905) 525-9140 ext. 22298 E-mail: valaitis@mcmaster.ca

#### Student Investigator:

Lisa De Panfilis School of Nursing McMaster University Hamilton, ON, Canada Phone: (905) 525 9140 ext. 21222 E-mail: depanl@mcmaster.ca

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

## Appendix P (continued)

#### CONSENT

I have read the information presented in the information letter about a study being conducted by Lisa De Panfilis, of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand that if I agree to participate in this study, I may withdraw from the study at any time. I will be given a signed copy of this form. I agree to participate in the study. Appendix N (continued)

Name of Participant (Printed)	Signature	Date	
Consent form explained in person by:			
Name and	Role (Printed)		

# **Appendix Q: Resource Sheet**

# Mental health resources in Hamilton

Here are a few mental health resources that could help you if you want to find support, or if you are in a crisis:

- C.O.A.S.T. Crisis Outreach and Support Team 24-Hour Hamilton Crisis Line. 905-972-8338
- Kids Help Phone Chat one-on-one with a Kids Help Phone counsellor, online, over the phone, or download their Always There app.
   <u>www.kidshelpphone.ca</u> 1-800-668-6868
- ConnexOntario
  Information about addictions, mental health, and problem gambling services in Ontario.
   <u>www.connexontario.ca/</u> 1-866-531-2600
- Mindyourmind Tools and resources for young people about mental health and wellness.
   www.mindyourmind.ca
- Calling your family doctors or nurses' office can be a way to get help and support if you need it and if they are part of your care.

If you are at risk of harming yourself or another person, or in crisis, **please** call 911 or go to your local emergency room:

- Hamilton General Hospital, 237 Barton Street East, Hamilton
- Juravinski Hospital, 711 Concessition Street, Hamilton
- St. Joseph's Healthcare Hamilton, 50 Charlton Avenue, Hamilton

If you or a person you know is being abused or is at risk of abuse, you may call:

- The Police Crime Stoppers: 1-800-222-8477
- Children's Aid Society of Hamilton: 905-522-1151
- Catholic Children's Aid Society of Hamilton: 905-525-2012

## **Appendix R: Photographer Release Form**

THIS AGREEMENT MADE AS OF THE \_\_\_\_\_(Day) of \_\_\_\_(Month), \_\_\_\_\_(Year)

**BETWEEN:** McMaster University, a University incorporated by special act of the Province of Ontario, Canada (hereinafter referred to as "McMaster")

--and—\_\_\_\_\_,(hereinafter referred to as the "Participant")

**WHEREAS** McMaster has developed or is intending to develop an information resource product (the "Product")

**WHEREAS** McMaster intends to allow others to use, reproduce, store and distribute the Project for educational, research dissemination and non-commercial purposes;

**WHEREAS** Participant has provided or will be providing his or her services (the "Services"), which are fully described in Photographer's Guide to Photovoice, attached hereto, to McMaster to assist with the creation of the Project;

**NOW THEREFORE**, in consideration of the payment of one dollar (\$1) by each party to

each of the other parties and for other good and valuable consideration (the receipt and

sufficiency of which is hereby acknowledged by each of the parties hereto), each of the parties agree as follows:

- 1. The Participant irrevocably grants to McMaster, its successors, licensees, assigns and legal representatives all rights of any kind, whether known or becoming known, in the Series and the results of the Services and the Project;
- 2. The Participant hereby waives any moral rights or *droits d'auteur* that he or she may have in the results of the Services.
- 3. The Participant acknowledges that McMaster shall own copyright in the Project and may utilize the Project, without restriction from the Participant, for non-commercial purposes;
- 4. The Participant agrees that when reasonably requested by McMaster, he or she shall agree to execute all papers and to perform such other proper acts as McMaster may deem necessary to secure for McMaster or its designee the rights herein assigned.
- Any disputes concerning any matter under this agreement shall be submitted to McMaster's Intellectual Property Board pursuant to McMaster's Intellectual Property Policy.

## Appendix R (continued)

6. The Participant will use best efforts to ensure that the Services provided do not infringe on any third party ownership rights. Should third party ownership rights be infringed upon, the Participant hereby releases McMaster of any liabilities resulting from the claim of infringement.

**IN WITNESS WHEREOF** the parties have duly executed this Assignment Agreement:

Name (Print)	Signature	Date
(day/month/year)		
Name, Witness (Print)	Signature	Date
(day/month/year)	C	
If you have any questions now or	later, you can contact	
Lisa De Panfilis RN, BScN		
Master of Science in Nursing stud	lent	
School of Nursing, McMaster Un		
905-525-9140 Ext. 21222	j,	
Email: depanl@mcmaster.ca		

# **Appendix S: Subthemes by Ecological Level and Access Dimension**

Theme: "It was all in my head"

Ecological level	Access dimension	Subtheme
Individual	ndividual Factors beyond access framework Awareness	Uncertainty of mental illness symptoms and the need to access help Fear of stigmatization Fear of hospitalization
		Not knowing about primary care mental health services

Theme: "I needed help"

Ecological level	Access dimension	Subtheme
Interpersonal	Factors beyond access framework	Parent role in enabling accessEncouragement from friendsFamily perceptions of mental health concerns
	Awareness	Researching online about mental illnesses and others' experiences

# Appendix S (continued)

Theme: "I wanted to be seen as a person"

Subtheme	Ecological level	Access dimension	Characteristics of the subtheme
The relationship	Interpersonal	Acceptability	Patient-centred care considerations
among primary care practitioners, adolescents			Supporting development during adolescents' emerging adulthood
and parents			Primary care practitioner relationship with parents
Primary care processes and structures	Organizational	Accommodation	Clinic organization: staffing, scheduling, and layout
		Awareness	Marketing of primary care mental health services to adolescents
		Accessibility	Location of practice
Influences extending beyond primary care	Community	Awareness	The need for improved collaboration to meet adolescents' multiple individual needs
	Policy	Acceptability	The need for updated mental health knowledge for primary care practitioners to understand illness during emerging adulthood
		Affordability	Cost of accessing mental health care