Exploring the Knowledge Gap in ADHD Literacy:

A Mixed-Methods Investigation of Parental Information Needs

by

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Abstract

Although treatments for childhood attention-deficit/hyperactivity disorder (ADHD) are available, treatment uptake is low and parental misconceptions are common, indicating gaps in the knowledge translation of ADHD research to parents. Knowledge translation conceptual models may address these gaps. These encourage study of contexts and barriers where information is sought, to enhance effective dissemination to users. Objectives of this project are to improve understanding of parents' informational needs and preferences pertaining to childhood ADHD, to identify barriers for parents' ADHD literacy, and to better understand how ADHD literacy is related to parents' comfort making treatment decisions. A concurrent mixed-methods design was used to study these objectives. For the quantitative strand, a purposive sample of 55 Manitoban parents of children with ADHD completed an online survey addressing their information needs, information sources, ADHD literacy, and comfort with treatment decisions. Descriptive data explored information needs and sources. Multiple regression analysis examined factors associated with ADHD literacy and decisional conflict. For the qualitative strand, semi-structured interviews were conducted with a sub-sample of 13 survey respondents allowing parents to reflect broadly on their information and treatment needs. Interviews were analysed inductively using thematic analysis (TA). Data were merged by comparing points of convergence and divergence across datasets in relation to project objectives. Results indicated that parents experience widespread challenges accessing ADHD information due to poor readability, relatability, and distribution of informational materials. Social location and personal stress are additional barriers to ADHD literacy. Parents value both community networks and health-care providers as information sources, for unique reasons. As parents gain ADHD literacy, they report less treatment decisional conflict, yet still describe unsatisfactory treatment

experiences. Results demonstrate the utility of knowledge translation frameworks within the study of mental health literacy. Recommendations include development of community-research partnerships for ongoing study of parent needs, use of community-based ADHD resource hubs, and greater collaboration across and between ADHD supports and treatment providers. Limitations include a small and homogenous sample, and generalizability concerns due to the COVID-19 pandemic. Future research identifying the determinants of parental mental health literacy is encouraged.

Keywords: Childhood ADHD, information needs and preferences, mental health literacy, knowledge translation, decisional conflict

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achieve this work without your commitment to me, and without your unconditional love and support. I am forever grateful.

Dedication

I dedicate this thesis to my daughters, Brianna and Madeline. You have shaped my life in the most beautiful and profound way, and words will never capture the love and meaning you bring to my life, and to our family. You are my biggest gifts, and a constant source of personal inspiration.

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Chapter 1: General Introduction

The current emphasis on a client-centered and collaborative approach to health care has led to novel challenges in health-care provision. Specifically, as patients are increasingly encouraged and expected to take an active role in the medical decision-making process, it is increasingly important that they can access evidence-based information to inform their decision-making. Additionally, patients must be able to access information that is relevant for their needs and concerns, and that it can be delivered to them in a usable format. Accordingly, patient-directed knowledge translation initiatives are receiving increased attention within our health-care environments.

Attention-Deficit/Hyperactivity Disorder (ADHD) is one of the most diagnosed childhood neurodevelopmental disorders, occurring in 5 to 8% of children worldwide (Belanger et al., 2018; Polanczyk et al., 2014). The functional consequences of untreated ADHD are numerous, including reduced school performance and achievement in childhood, and in adults, poorer occupational attainment, higher unemployment rates, higher rates of motor vehicle accidents, addictions, and psychiatric co-morbidities (APA, 2013). Although many empirically validated treatments for ADHD are available, rates of ADHD treatment uptake and treatment adherence are low, and parental misconceptions about ADHD are common (Bussing et al., 2012; Climie & Henley, 2018; Moldovsky & Sayal, 2013). This discrepancy suggests that there are significant shortcomings in the knowledge translation of research findings to parents and families.

The objectives of this research project are to improve our understanding of the informational needs and preferences of parents whose children are recently diagnosed with ADHD, to identify the personal and structural barriers that hinder parents being able to access

information that is relevant for their needs, and to better understand how information acquisition is related to parents' comfort with treatment decision-making.

The current work will first outline recent developments in models of health-care treatment decision-making, with emphasis on how the shift to a shared decision-making approach necessitates greater levels of health literacy and mental health literacy on the part of patients, and how this is relevant for the treatment of childhood ADHD. Next, I review the literature specific to the understanding and treatment of childhood ADHD, including common misconceptions about ADHD, and ADHD-related information needs and treatment preferences of parents. Finally, I discuss how using conceptual models for knowledge translation research can be used to improve the way we deliver information to parents, and thus address some of the current information gaps and misunderstandings about childhood ADHD. After reviewing these literatures, I outline my research objectives and methodology, and philosophical assumptions that underlie this investigation. I will then present the quantitative strand of my study, followed by the qualitative strand of my study. An integrated discussion of these two datasets will follow. I will then provide an overall conclusion, limitations of the current investigation, and directions for future research.

Chapter 2: Literature Review

Health Care Decision-Making and Mental Health Literacy

Traditionally, models of treatment decision-making have operated from a paternalistic (i.e., a doctor as expert) framework. Doctors were assumed to have expert knowledge, and they could ostensibly know what treatment would be in the patient's best interest, with little to no input from the patient themselves. The patient role was simply to comply with doctor's orders, and to be a passive recipient of care. The primary moral principle was one of physician beneficence, with the doctor acting as a guardian for the patient's best interests (Brody, 1980; Deber, 1994).

Over the course of the last several decades, there has been growing emphasis on patient autonomy in health care. Changing societal attitudes about equal rights and individual freedoms for all people has been accompanied by shifts in thinking about the principles of ethical physician conduct, including the need to consider patient rights, the need to consider diverse patient values and perspectives about treatment options, standards of informed consent, and communication of risks (Brody, 1980; Veatch, 1972). As well, increased patient participation in health care has been thought to improve health-care delivery outcomes due to patients having more realistic understandings about their medical care and improved rates of treatment adherence, while also having the potential to reduce unwarranted practice variation across physicians (Brody, 1980; Stiggelbout et al., 2015). Accordingly, models of treatment decision-making have shifted towards more contractual, egalitarian models of doctor-patient relationships, that emphasize patient engagement and agency in the decision-making process (Brody, 1980; Deber, 1994; Stiggelbout et al., 2015).

Numerous models of treatment decision-making have been discussed within the health care literature, each with various gradations of the respective roles of physicians and patients. For instance, Veatch (1972) outlined differences between an "engineering model" whereby the physician shares treatment options with the patient but the patient is responsible for making a treatment choice, a "priestly model" whereby the physician makes the treatment choice in the best interest of the patient, a "collegial model" whereby the physician and patient share decision-making responsibility on the basis of mutually shared goals, and a "contractual model" whereby the physician and patient share decision-making responsibility on the basis of their differing social obligations to each other. Emanuel and Emanuel (1992) outline a similar spectrum of differences for treatment decision-making, including a paternalist model where the physician makes treatment choices on behalf of patients, an informative model where the patient makes treatment choices based on information provided by the physician, an interpretive model whereby the physician acts as a mentor to help the patient understand their values of what would constitute the best treatment choice, and a deliberative model where the physician gives moral guidance about the "most admirable" values that ought to underlie a patients treatment choice.

Currently, models of treatment decision making are broadly conceptualized as paternalistic (solely physician decided), informed (solely patient decided), or shared between physician and patient. Of these models, shared decision-making (SDM) is accepted as the ideal standard of patient-centered care, and this model is considered to be fundamental to responsible health care practice when legitimate and/or value-sensitive treatment options are available (Charles et al., 1997; Coulter & Collins, 2011; Deber, 1994; Stiggelbout et al., 2015). Numerous elements and definitions for SDM have been identified within the literature (see Makoul & Clayman, 2006; Moumjid et al., 2007, for two systematic reviews on this topic); however, the

essential components of the SDM process include (a) that patients know treatment choices exist; (b) exchange of information between physician and patient to discuss various treatment choices as they relate to patient preferences; and (c) a mutually agreed upon treatment decision, including follow-up (Charles et al., 1999; Elwyn et al., 2012; Stiggelbout et al., 2015). SDM has also been recognized as an essential element in pediatric care and it is recommended by pediatric regulatory associations (Fiks & Jiminez, 2010; Harrison, 2004; Wyatt et al., 2015). Accordingly, numerous interventions have been developed to support a shared decision-making approach to care, including decision aids, educational coaching, and question prompt lists (Coulter & Ellins, 2006). These interventions have also been used in the context of pediatric care, with parents acting as surrogate decision-makers on behalf of their children (Liverpool et al., 2021; Wyatt et al., 2015).

Mental Health Literacy in Treatment Decision-Making

The increasing expectation for patient involvement and agency in treatment decision-making has obvious implications in terms of patient engagement with health-related information, and the expectation that patients will have the skills to meaningfully participate in their medical care. Beginning in the 1970s, public health researchers introduced the concept of health literacy, initially conceived as the ability to read and understand medical information and instructions (Simonds, 1974). Today, health literacy is broadly understood as multi-dimensional construct that encompasses the motivation, knowledge, and sets of competencies that are needed to manage one's health and make effective health-related decisions (Nutbeam, 2000; Sorensen et al., 2012). It is understood to be fundamental to all aspects of patient engagement in health care (Coulter & Ellins, 2007; IOM, 2004).

An extensive field of research has examined health literacy as it pertains to physical illness. Within Canada, an estimated 55% of individuals between the ages of 16 to 65 are considered to have low health literacy (Rootman & Gordon El-Bihbety, 2008). The associations between low health literacy and adverse health outcomes are numerous and profound, including higher rates of chronic disease, higher rates of hospitalization, lower use of preventative health care, poorer treatment decision-making, poorer treatment adherence, poorer self-perceived health status, and increased mortality (Berkman et al., 2011; Edwards et al., 2009; Osborne et al., 2013; Rootman & Gordon El-Bihbety, 2008). In their review of evidence, the American Medical Association found that health literacy was a stronger predictor of health status than age, income, employment status, education status, or race (Ad Hoc Committee on Health Literacy, 1999). Health literacy is thus understood to be a key determinant of health (Altin et al., 2011; Chinn, 2011), underscoring the need for individual-level as well as structural/environmental interventions that have capacity to improve patients' abilities to acquire information about, and subsequently manage, their health needs (Chinn, 2011; Coulter & Ellins, 2007).

The US Institute of Medicine has identified three broad factors that impact the development of health literacy, including cultural conceptualizations of health, the educational system and consequent development of general literacy and numeracy skills, and health-related messaging and recommendations from the health-care system (IOM, 2004). Accordingly, there is a significant research base devoted to interventions to address these factors and impart actionable health-related knowledge at a broad population level. Specific health literacy strategies have included general literacy initiatives, the development of written materials to supplement medical consultations (e.g., leaflets), digital and/or interactive resources that provide personalized health information, and mass-media campaigns (Coulter & Ellis, 2006, 2007). In their synthesis of

outcome research on health-literacy interventions across a range of medical conditions, Coulter and Ellis (2006, 2007) found that patients generally want more information than is supplied by their doctors, and relatedly, that patients often report concerns regarding the quality, accessibility, readability, and usefulness of information available to them. These findings indicate an ongoing need to study the most effective ways of delivering usable health-related information to the public, particularly in the case of low literacy and/or other hard to reach groups.

The concept of health literacy has since been applied to the field of mental health. First introduced by Jorm and colleagues (Jorm et al., 1997; 2012), mental health literacy (MHL) refers to the knowledge and beliefs about mental disorders that aid in their recognition, management, and treatment. It involves knowing how to prevent mental disorders, being able to recognize them when they develop, knowing appropriate help-seeking options and treatments, and knowing how to support others affected by mental health problems. The construct of MHL has had a powerful impact on mental health research and policy, most notably on providing an impetus to develop broad psycho-educational initiatives to promote public awareness and knowledge of mental health (Jorm, 2015).

As one might expect, providing mental health information to the general public has consistently been found to improve knowledge and attitudes about mental illness (Hadlacszky et al., 2014; Lo et al; 2018). This enhanced understanding is thought to be highly influential on numerous aspects of help-seeking behaviour, including attitudes towards treatment initiation and treatment compliance (Hadlaczky et al., 2014; Lo et al., 2018; Furnham & Swami, 2018). However, more research is needed to understand whether and how improved mental health literacy is related to functional mental health outcomes and actual help-seeking behaviour. For

instance, a recent systematic review of MHL interventions in adolescents and young adults (Tay et al., 2018) found that while MHL interventions were associated with improved symptom recognition and reduced stigma about seeking help, this improved mental health knowledge was not associated with any increase in help-seeking behaviour. Accordingly, we need to better understand the relationship between mental health knowledge and the various competencies needed for individuals to put knowledge into practice. We also need better understanding of potential structural or contextual difficulties associated with mental health care delivery that prevent people from getting the support they need, even if they know they need it.

As the study of MHL has evolved, researchers in the field are developing a more nuanced appreciation of the personal and contextual factors that influence its development. A recent review of the MHL construct (Furnham & Swami, 2018) concluded that acquisition of MHL varies as a function of cultural understandings of mental illness, experience with mental illness, and socio-demographic characteristics such as age, gender, educational attainment, and religiosity. Additionally, targeted educational interventions for specific mental health disorders may be differentially effective for some domains of mental health literacy relative to others, with negative stigma reduction and intention to seek treatment being less likely to change despite improved mental health knowledge (Furnham & Swami, 2018; Lo et al., 2018; Jorm, 2015). Thus, while provision of mental health information is undeniably important, we also need greater understanding the specific contexts and sociodemographic factors that might influence whether people are able to successfully use this information. Moreover, we also need to identify underdeveloped content areas that pertain to mental health.

Theoretical Formulations of MHL

Interestingly, and in contrast to the extensive body of research around health literacy, the current literature does not offer any theoretical models outlining the factors and processes thought to impact the development of mental health literacy. However, various theoretical models of mental health service use may offer some perspective in this regard. Specifically, as these models examine factors and processes that impact how an individual comes to seek mental health treatment, they necessarily imply the development of mental health literacy skills (i.e., the decision to access to mental health services requires awareness of symptoms, and the understanding of how to seek appropriate supports).

Parsons (1951) is credited with developing the first model explaining how people come to recognize the need for treatment. In his model, an individual's illness career begins with the onset of symptoms. The individual then evaluates their circumstances rationally and scientifically, and then decides to seek help (i.e., assume a sick role), and could enter treatment upon the decision of a health-care professional (i.e., assume a patient role). Once recovered, individuals return to their normal roles.

In this early model, help-seeking and mental health literacy are viewed in a sequential and relatively simplistic way, resting on an individual's rational decision making, a practitioner's recognition and legitimation of symptoms, and then recovery. Since this initial model, many additional and more complex models of mental health service use have been developed. For instance, Goldberg and Huxley's (1980) filter model posits that individual characteristics and symptom severity mediate the pathway to mental health treatment, and that health-care system factors (i.e., physician gatekeepers) play an influential role in determining service use. The Health Belief Model (Henshaw & Freedman-Doan, 2009) asserts that the decision to seek

treatment for mental health is determined by one's perceptions of their symptoms, expectations and beliefs about treatments, social cues about mental illness, and socio-demographic characteristics. Andersen's behavioural model of health service use (1995, 2008) notes the interplay of individual predisposing characteristics (e.g., socio-demographics, health-care beliefs), personal resources that enable service use (e.g., financial), and community factors that enable service use (e.g., availability, logistics, cost). Andersen's model also recognizes the dynamic and recursive nature of health care service use, such that outcomes from initial service use affect subsequent predisposing factors and later health outcomes.

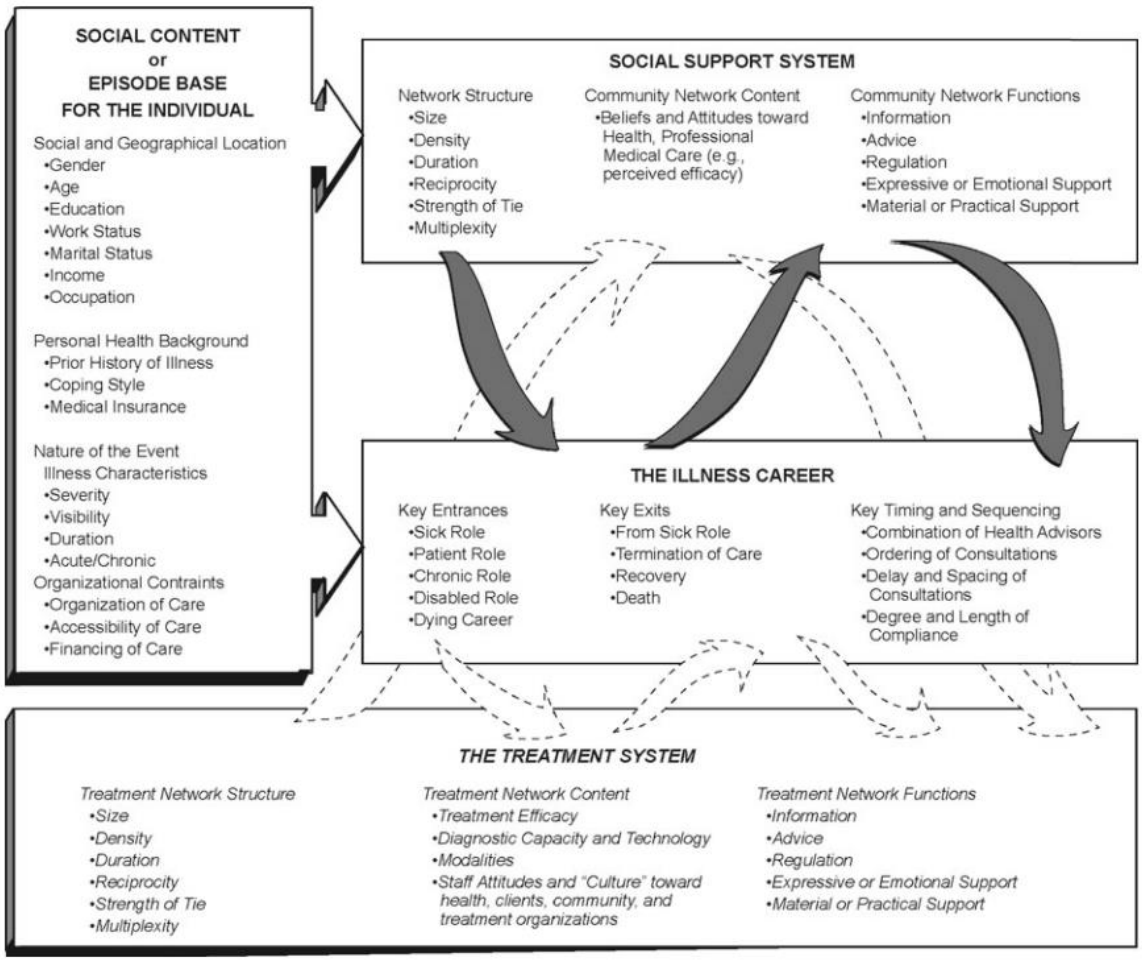
The Network Episode Model-II

The Network Episode Model-II (NEM-II; Pescosolido et al., 2013) is a sociological model depicting the pathways and trajectories of mental health service users on the basis of individual characteristics, treatment system possibilities, and social networks. This model is particularly well-suited as a potential framework for understanding how individuals acquire mental health literacy skills. First, the NEM-II is unique in that it includes social networks as a fundamental component of how individuals understand and manage their mental health, and the way they access supports. Understanding of mental health symptoms and the decision to seek treatment is thus considered to be a social process and to be understood within a social context. Additionally, the NEM-II specifically acknowledges that our understanding of mental health needs, and mental health service use, must not end at the point of diagnosis. Rather, the NEM-II model considers how individual factors, treatment-system factors, and social network factors interact to shape the way that individuals understand and manage their mental health on an ongoing basis. A depiction of the NEM-II model is provided in Figure 1.

Notably, many factors currently associated with greater ADHD service utilization also reflect the various NEM-II domains, including higher socio-economic status (e.g., Bax et al., 2019), the presence of parental social networks and supports (e.g., Bussing et al., 2015), symptom severity (Sayal et al., 2015), and availability of treatment services (e.g., Koerting et al., 2013). Corkum et al. (2015) provide a comprehensive review on this topic.

Figure 1

The Network Episode Model-II



Shared Decision-Making and (Mental) Health Literacy in Childhood ADHD

A shared decision-making approach, with the consequent need for parental mental health literacy, is inherent in the current diagnostic and treatment guidelines for childhood ADHD. Although ADHD is one of the most common childhood neurodevelopmental disorders, timely diagnosis of ADHD is often challenging due to the lack of biomedical markers for the condition, high rates of comorbid conditions, heterogeneity in symptom presentation, and the fact that the core symptoms of ADHD are not typically present within a clinical office setting. Accordingly, the Canadian Paediatric Society clinical practice guidelines for diagnosing ADHD include obtaining a comprehensive physical and clinical history from parents or caregivers, and they stress the importance of obtaining information about a child's behaviour and attention across environments (Belanger et al., 2018). Parental mental health literacy in the form of awareness and understanding of attentional and related behaviour difficulties, and the ability for effective exchanges of information between parents and their physicians, thus plays a critical role in the formulation of an ADHD diagnosis.

In terms of treatment, ADHD is understood to be a lifelong condition requiring ongoing and evolving therapeutic management over the course of a child's development (Belanger et al., 2018; CADDRA, 2018). The many empirically validated treatments for ADHD rely heavily on parental involvement and education, including parent behaviour training (Charach et al., 2013; Daley et al., 2014) and psychoeducation (Bai et al. 2015; Feldman et al., 2018; Ferrin et al., 2014, Ferrin et al. 2016). Parent education and engagement, and the ability for parents to interact effectively within health care systems, thus plays a critical role in the development and ongoing implementation of ADHD treatment plans. Specifically, Canadian clinical practice guidelines recommend a multi-modal approach to ADHD treatment, and stress that a shared-care

approach must be initiated first and foremost, such that health-care practitioners and parents/clients have a shared understanding of treatment goals and preferences, and accurate information about the condition (Feldman et al., 2018). The first ADHD treatment recommendation of the Canadian Paediatric Society states:

> Treatment approaches for children and youth with ADHD and comorbidities must be multimodal and part of an individualized, comprehensive care plan. A psychoeducational plan of interventions should be initiated first, combined with other nonpharmacological interventions and medication when indicated, always keeping specific functional or behavioural goals in mind (p.464).

Parent Understanding of ADHD and Treatment Preferences

As described above, parental mental health literacy, with informed and engaged parents, plays a foundational role in the successful diagnosis and treatment of childhood ADHD. As such, it is imperative that parents can access evidence-based information that is relevant to their needs, and that can facilitate treatment decisions which best reflect the needs of their children and families. Unfortunately, misconceptions about ADHD and its treatments are quite common. A survey investigation by Bussing et al. (2012) reported that among a sample of 374 parents whose adolescents were at-risk for ADHD, a large majority (78%) generally considered themselves to be knowledgeable about ADHD, yet one-quarter of the sample believed that ADHD was caused by sugar (25%), and most felt that ADHD was treated with too many medications (85%). More recently, Climie & Henley (2018) surveyed parents of children with an ADHD diagnosis and found that parents were generally very proficient in recognizing the symptoms of ADHD, but less proficient in answering questions about ADHD treatments, and even less proficient in their general understanding of the condition. These types of findings are commonly reported within

the ADHD literature. A systematic review of parental MHL as pertaining to childhood ADHD concluded that members of the general public tend to misunderstand many aspects of ADHD, such that large portions of parents and teachers (40-60%) struggle to correctly recognize ADHD symptoms from case vignettes, and they fail to recognize when ADHD symptoms require treatment. Large portions of the general population also possess suspicious or negative attitudes about medication treatments for ADHD, and many prefer the idea of diet or vitamin therapies to treat ADHD (Swami, 2013). In their review on knowledge and attitudes about ADHD from the perspectives of parents, teachers, health care professionals, and children, Moldavky and Sayal (2013) similarly noted gaps in parent general knowledge about ADHD, particularly with respect to etiology, developmental course, and understanding of ADHD treatments. Negative and stigmatizing views about ADHD were also common, including negative views about medication, and beliefs that ADHD diagnoses reflected poor parenting skills.

The Influence of (Mis)Information on ADHD Treatment

Limited information, and misinformation about ADHD, has obvious and significant implications for ADHD management and treatment. As one might expect, numerous studies have found that parents with lower levels of ADHD related knowledge, and/or who have negative beliefs and perceptions about treatments, are less likely to initiate treatment, or adhere to a treatment course (Corkum et al., 2016; Dahl et al., 2019; Leslie et al., 2007; Sciutto, 2015), and several literature and systematic reviews have pointed to gaps in parent knowledge about ADHD as a significant barrier to utilization of evidence-based treatments (e.g., Brinkman & Epstein, 2011; Corkum et al., 2015; Koerting et al., 2013; Wright et al., 2015).

Several investigations have found that providing parents with targeted and specific information in areas of concern improves treatment adherence and reduces the severity of ADHD

symptoms. Monastra (2014) used a 2-step approach to develop an educational program for parents who were resistant to treatment. Parents who had discontinued their child's ADHD medication treatment were surveyed about their barriers to treatment adherence. Survey results were used to design an educational intervention that specifically addressed their concerns. A separate sample of parents who had previously discontinued their children's ADHD treatment then received the parent-informed educational program. Impressively, 95% of these parents remained in treatment at a 2-year follow up. Similarly, Bai et al. (2015) developed a psychoeducational program for parents to improve their ADHD knowledge, with content of the program based on parent-reported information needs. Relative to a general counseling control group, parents who received the psychoeducational program reported significantly greater ADHD knowledge, higher rates of treatment compliance, and lower rates of ADHD symptoms in their children. A positive impact of parent-driven educational content was also found in a study by Kolko and colleagues (2014), who found greater levels of treatment compliance, ADHD symptom reduction, and positive functional changes in the children of parents who received individualized collaborative psychoeducational programs, relative to children whose parents had received a standardized psychoeducational program.

Information and Parental Treatment Preferences in ADHD

In light of the growing understanding that parent knowledge and perspectives are powerful influencers on initiation and maintenance of ADHD treatment, a growing body of research is examining factors that govern parental treatment preferences, and response to the initiation of treatment. Research examining parental treatment preferences for childhood ADHD indicates that parents consider a range of factors in making their treatment decisions. Schatz et al. (2015) synthesized the literature on stated preference studies (i.e., discrete choice

experiments, best-worst scaling, and other utility-value methods), and found that parents prefer ADHD treatments that maximize positive outcomes (e.g., symptom reduction, improved behaviour or academic functioning) while minimizing negative outcomes (e.g., side-effects). Additionally, parents are more likely to initiate a medication course of treatment when their children's ADHD symptoms are more severe, even if medication is not a preferred treatment choice.

While these broad trends make intuitive sense, findings from quantitative paradigms such as these do not fully capture to the complexity and nuance involved with the decision-making process. Indeed, qualitative investigations have found that parental decision-making for ADHD is often an exceptionally difficult process, with parents experiencing high levels of doubt and personal turmoil around their treatment decisions. For instance, Taylor et al. (2006) interviewed parents about their decisions to pursue medications for their children's ADHD symptoms and found that parents go through a grieving process upon their child's diagnosis, moving through distinct stages of grief, and then cynicism and doubt, before they were able to come to terms with their child's diagnosis and initiate ADHD treatment from a proactive perspective. Movement through the process from grief to action was highly influenced by support from their family and social networks, and from their experiential and acquired knowledge about ADHD. Using focus group methodology, Brinkman et al. (2009) similarly found that parental decision-making for ADHD occurs in a highly emotional context, with parents experiencing high levels of doubt, family conflict, stressful family conditions and daily struggles resulting from ADHD symptoms, and the emotional burdens of caring for a struggling child. Parental decisions to initiate ADHD treatment (usually medication) were influenced by the presence of supportive networks, the support of a physician, and sufficient information to understand the implications of an ADHD

diagnosis. In their qualitative examination of parental perspectives on ADHD treatment decision making, Davis et al. (2012) found that parents considered areas of impairment that extended beyond the core ADHD symptoms, including concerns with family functioning, parental stress, and impacts on their child's social-functioning and self-esteem. Accordingly, many parents expressed interest in a broader, more holistic approach to understanding and treating ADHD, rather than simply learning about medication options. Coletti et al. (2012) similarly found that parents felt more comfortable initiating medication treatment for their children's ADHD symptoms when physicians worked collaboratively with parents, actively listened to their concerns, and were able to strike a balance between comprehensive and comprehensible information on a range of topics. These qualitative findings reinforce the importance of understanding parental perspectives and concerns about ADHD treatment decision-making, and further suggest that many parents feel they do not receive adequate and relevant information to meet with their concerns and which allow them to feel comfortable with their treatment decisions.

Parent Information Needs and Preferences in ADHD

To date, very few studies have directly queried parents about their information needs and preferences around ADHD treatment decision-making. Sciberras et al. (2010) administered a cross-sectional survey with parents who were largely drawn from a pediatric ADHD treatment clinic to better understand their treatment needs. Results indicated that parents relied on a variety of sources to get information about ADHD, with pediatricians, books, general practitioners, and schools being the most frequently used information sources. Parents rated the quality of information that they received from pediatricians as most helpful and trustworthy, relative to other sources. Consistent with previous research on treatment decision-making, parents felt that a

wide variety of ADHD content areas were considered important, including information about social skills, education strategies, co-occurring problems, behaviour management, and updates on the latest research findings. This study did not, however, examine how well parents were able to access the information they deemed important. Moreover, because most parents in this study were already under the regular care of ADHD specialists, their experiences might not be representative of the general experience of parents.

More recently, Ahmed et al. (2014) used focus groups to examine whether a more diverse, community-based sample of parents felt they had received sufficient information about ADHD pre- and post- diagnosis. Results indicated that while parents felt their knowledge of ADHD improved after their children were diagnosed, they remained largely dissatisfied with the information they were able to access. Similar to Davis et al. (2012), this sample of parents felt that information from health-care providers was highly technical and overly medication-focused, and that information obtained from the internet was too broad and excessive, and not tailored to their specific concerns. Parents desired a way to obtain information that was concise, tailored to their needs, addressed their specific parenting concerns, and that reflected the real-life experiences of other parents.

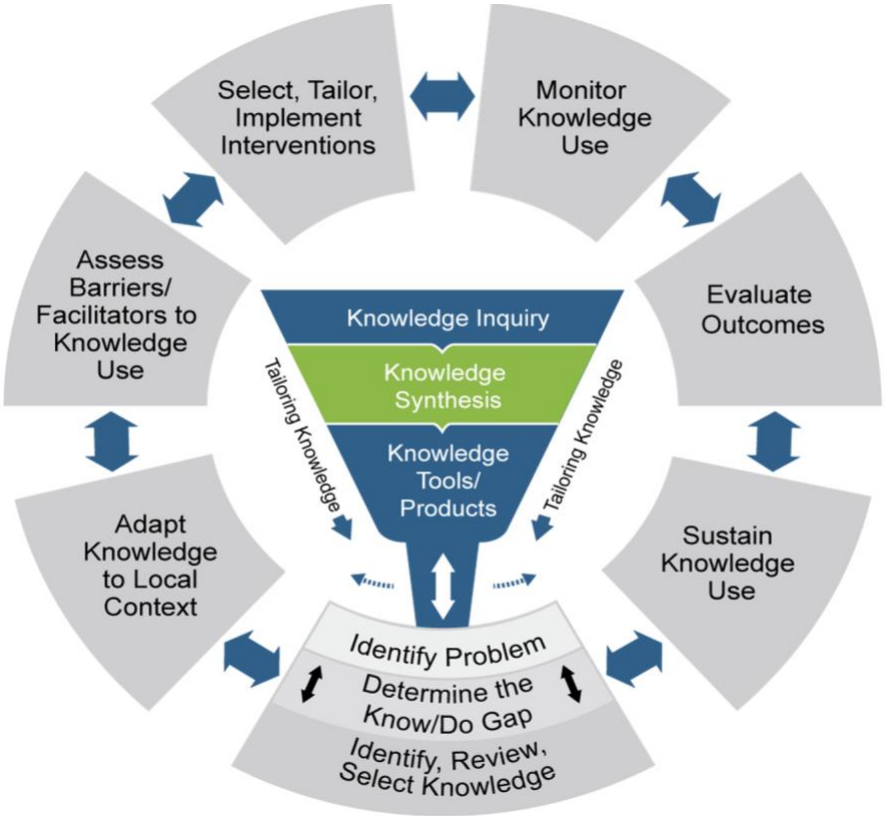
These findings shed some important perspective on the information needs of parents seeking to make treatment decisions for their children. However, there are many aspects of parental information acquisition that remain unexplored, including how well parents can access the specific types of information that they deem important, where parents are most likely to obtain their information about ADHD, and the barriers experienced by parents as they seek to learn about ADHD.

The Knowledge-to-Action (KTA) Model

The growing awareness that research findings often do not make their way into practice in a timely fashion has generated increased interest in using knowledge translation (KT) frameworks for closing the knowledge-to-action gap (Straus et al., 2013). Graham and colleagues (2006) conceptual model of knowledge translation, the Knowledge to Action (KTA) cycle, has been adopted by the Canadian Institute of Health Research (CIHR) as the accepted model for promoting the application of knowledge translation research in Canada (http://wwww.cihr-irsc.gc.ca/e/39033.html; see Figure 2). Their model is iterative and dynamic, including processes of knowledge creation and knowledge application.

Figure 2

The Knowledge to Action (KTA) Cycle



Knowledge creation, or the production of knowledge, includes the progressive phases of knowledge inquiry (i.e., primary studies with information of variable quality), knowledge synthesis (i.e., aggregation of primary research in meta-analyses, systematic reviews, etc.), and the development of knowledge tools (i.e., action tools and products such as practice guidelines and decision aids). As knowledge moves through each of these phases, it becomes more distilled and refined, and presumably more valid and useful to stakeholders.

Knowledge application includes seven action phases that are needed to implement knowledge in health care: (1) naming the problem (i.e., becoming aware of knowledge to action gap); (2) adapting knowledge to local context (i.e., customizing knowledge so it is appropriate for the particular situation); (3) identifying facilitators and barriers to knowledge use (i.e., assessing for factors that support and/or impede knowledge use); (4) selecting and tailoring interventions (i.e., selecting, tailoring, and executing interventions to implement knowledge, with considerations to local context and barriers); (5) monitoring knowledge use (i.e., defining what constitutes a use of knowledge, and measuring it to determine whether the intervention has been successful); (6) evaluating knowledge outcomes (i.e., assessing the impact of knowledge use); and (7) sustaining knowledge use (i.e., ensuring that the use of knowledge in practice is sustained over time). Each action phase may be influenced by the preceding phases, and feedback between the phases may occur.

Graham and colleagues (2006) further note the importance of integrating action phases with both local and external research. For instance, local research is needed to determine the magnitude of specific knowledge to action gaps, to understand the contextual barriers to knowledge use, and to monitor outcomes. External research from the larger literature may be

used to guide questions around barriers to knowledge use and to identify implementation interventions that have been demonstrated to be effective.

Application of the KTA Model for Childhood ADHD

The KTA framework may be used to guide the question of how to address the knowledge translation gap for parents making treatment decisions for their children's ADHD symptoms, as follows. Existing research sheds some preliminary understanding into the nature of the knowledge gap experienced by parents when they seek to make treatment decisions about their children's ADHD symptoms, in that we understand that parents seek information about a broad variety of topics about ADHD to inform their treatment decision-making, including options for treatment that do not include medication, information about familial, emotional, social, and developmental aspects of ADHD, and how to access ongoing community-based experiential supports. However, we now need systematic study of how to best convey knowledge about ADHD to parents in a way that meaningfully addresses their questions and concerns, and that can also effectively reach parents within their local health care system and/or communities. (i.e., we need to study knowledge application). In terms of the KTA model, we have extensive ADHD knowledge creation, but little research on how to apply this knowledge to parents in meaningful and targeted ways.

A discussion paper by Levesque and colleagues (2007) further articulates these underdeveloped areas in knowledge translation research on ADHD. Noting the high levels of confusion and misinformation surrounding ADHD and its treatments, they discuss the need to develop resources and infrastructure that can deliver concise, evidence-based, audience-specific information about ADHD to the multiple audiences that need it, including parents and caregivers, practitioners, researchers, administrators, and policy makers. In order to do this

effectively, Levesque et al. (2007) stress the importance of understanding the situational contexts (i.e., KTA action phase 2) surrounding knowledge acquisition, including the need to identify physical and conceptual barriers faced by individuals who seek to access knowledge, and organizational barriers that impact whether resources are being used to their best capacity such that acquired knowledge is being effectively shared (i.e., KTA action phase 3). Equally important, they stress that knowledge translation initiatives need to be delivered in accordance with audience preferences, including the format, source, and timing of information delivery. Surprisingly, none of these topics have been explored within the existing literature on parent knowledge and treatment decision-making about ADHD.

Local Considerations

Given the importance of understanding situational contexts for developing effective knowledge translation initiatives, it makes sense to consider the contextual features of our local mental health landscape as they pertain to childhood ADHD. Consistent with broader epidemiological studies, a recent provincial report found the diagnostic prevalence of ADHD in Manitoba youth is 6.8%, with a higher prevalence in children 6- through 12-years old, versus 13- through 19-years old (prevalence rates of 8.7% and 4.8%, respectively). These findings are felt to underestimate the true diagnostic prevalence of ADHD in Manitoba, however, as this report only captured physician diagnoses. Not surprisingly, relative to youth without any diagnosed mental health disorders, youth diagnosed with externalizing disorders such as ADHD had more frequent contact with a wide array of health and social service agencies, experienced poorer educational outcomes, and had more frequent involvement with the justice system (Chartier et al., 2016). These findings reinforce the importance of developing local mental health promotion

initiatives, and to continue working towards timely identification and treatment engagement for local youth with ADHD, and their families.

Provision of mental health services within Manitoba has received recent systematic attention in the form of a commissioned program review and resulting provincial strategic plan intended to improve access and coordination of services for individuals with mental health and addiction problems. Several findings from this report, developed by Virgo Planning and Evaluation Consultants (Virgo, 2018) provide important contextual information about local child and adolescent mental health treatment service delivery.

Through their review, the Virgo consultation group noted several key gaps in the access and coordination of mental health care including lengthy waits for service, limited capacity of treatment agencies to meet service demands, and poor coordination of services across systems and with schools. Additionally, their review found that mental health services were often not client-informed, thus posing an additional barrier for effective service delivery. Examples of this included services being provided in hours or locations that were inaccessible to clients, intake processes that were overwhelming, use of interventions that were not perceived as meaningful by youth, and conditions for participation that were not realistic. Based on these types of concerns, the Virgo report noted that accessible and appropriate service based on client needs were aspirational components of a high-performing mental health care system. Other more specific recommendations to improve client-informed service delivery included use of a multi-sectoral approach to mental health care, with ongoing research and development activities to improve the design and delivery of treatment and support services for youth, as well as more flexibility and coordination in the way that mental health care is delivered.

While care for ADHD was not discussed specifically within the report from the Virgo group, several aspects of local ADHD treatment provision mirror the above-mentioned systemic concerns. Issues pertaining to accessible care are evident. There is a significant shortage of child psychologists within Manitoba, both within the health-care system and in private-practice, resulting in lengthy delays of service (Unger & Dyck, 2021). Additionally, while many types of care providers can treat ADHD within Manitoba, including pediatricians, family doctors, clinical psychologists, psychiatrists, and occupational therapists, there is no coordinated approach to ADHD care between practitioners in the provincial health care system and practitioners who work in private practice, or between private or public care providers and school systems. Perhaps most notably, however, there is a dearth of local research initiatives that have examined how local situational contexts influence the experiences of parents navigating information and treatment about childhood ADHD, and similarly, how well our existing models of care are meeting the informational and treatment needs of parents. As features of our mental health care system shift and evolve, it is vital that we identify the informational and treatment needs of parents, so that our systems can ultimately provide accessible, appropriate, and effective care to children with ADHD and their families.

COVID-19 Considerations

These questions have added significance in light of the current COVID-19 pandemic. Preliminary research conducted in Europe and Asia suggests that children with ADHD may suffer exacerbated behavioural symptoms during this pandemic because of changes to their daily routines and school closures (Jefsen et al. 2020; Zhang et al., 2020), thus impacting the information needs and types of supports that would likely be important to parents. Moreover, emerging data suggests that the COVID-19 pandemic has resulted in significant changes in the

locus of service delivery for children with ADHD, such that parents and children are increasingly relying on tele-health and virtual care options for ADHD management in place of face-to-face consultations and group supports (CADDRA, 2020; Knopf, 2020; McGrath, 2020). As parental access to ADHD support is changing, it is quite possible that the way parents use various information sources to learn about ADHD is changing too. Understanding the informational needs and preferences of parents in the context of the COVID-19 pandemic, and as we emerge from it, will allow for the development of knowledge translation initiatives that are appropriate and accessible for this novel era.

Chapter 3: Research Objectives and Methodology

Objectives of the Current Investigation

The overarching objective of the proposed investigation was to improve understanding of the pathways and processes through which parents acquire information about ADHD, and to explore the functional impacts of information acquisition on treatment decision-making. A mixed-methods research design was used to explore the following broad research questions:

(1) Are parents receiving adequate information about ADHD and its treatments?

(2) What information sources do parents use to understand ADHD and its treatments?

(3) What types of barriers make it difficult for parents to access the information they need to understand ADHD and its treatments?

(4) What is the relationship between access to information and comfort with ADHD treatments?

The findings from this investigation will be used to improve the quality and delivery of educational outreach initiatives about ADHD so that needed information about ADHD can be more effectively disseminated to parents within our local health care system and mental health community. Additionally, findings of this investigation will be used to improve the delivery of client-focused ADHD care.

Overview of Research Design

Rationale for a Mixed Method Design

As noted within the KTA model, Graham and colleagues (2006) posit that studies promoting knowledge application require integration of general literature findings with understanding of how those findings apply within local contexts. However, there is a scarcity of research in general on the information needs of parents as they impact on treatment decision-

making for ADHD, and no existing research has explored the situational contexts and barriers faced by parents when they seek information to make ADHD-related treatment decisions. Additionally, these questions have not been explored within the context of our local community. As such, I felt that multiple layers of understanding were needed to explore my research questions, and that a mixed-methods approach would thus be particularly well-suited for my topic.

For this investigation, I made the decision to use a convergent parallel mixed methods design (Creswell & Clark, 2018), a type of design in which a quantitative data strand and a qualitative data strand are collected concurrently, analysed separately, and then merged with equal priority given to each set of results. In the quantitative strand, I obtained a purposive sample of parents whose school-aged children were recently diagnosed with ADHD, and I collected survey data to identify the general types of content areas and information sources that are important to parents when making treatment decisions. Survey data was also used to examine whether factors associated with mental health service use, as articulated within the NEM-II model, are also associated with parents' ability to access information about ADHD, and to examine the relationship between information acquisition and comfort making treatment decisions.

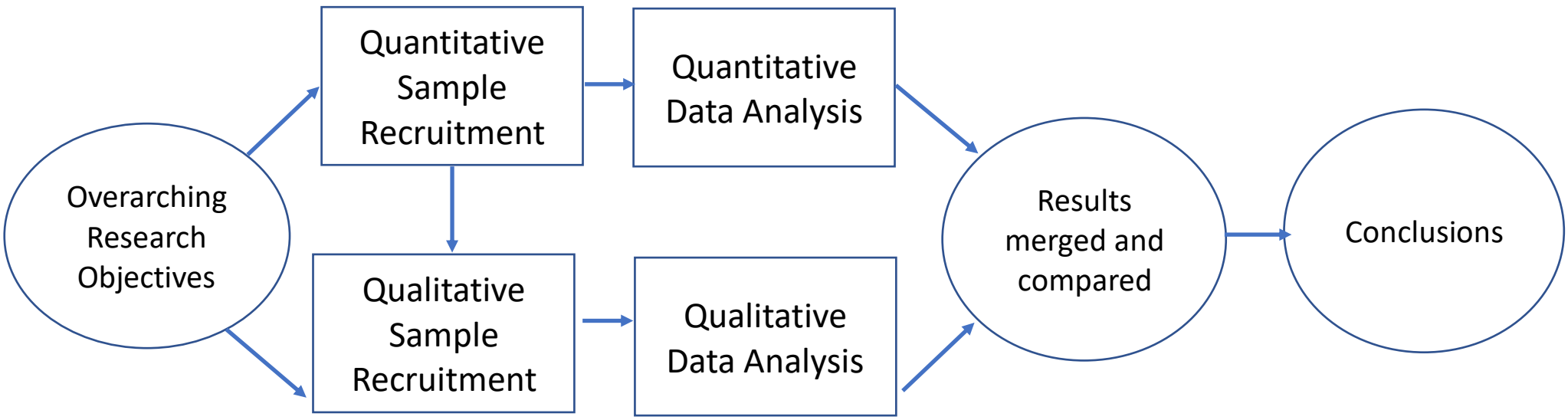
In the qualitative strand, I obtained a sub-sample of survey participants and conducted semi-structured interviews with them to gain understanding about how parental ADHD-related information needs and preferences from an atheoretical perspective, exploring the lived experiences of parents as they sought ADHD-related information and made treatment decisions for their children. With additional and concurrent examination of the experiences of parents in their own words, I felt that I would gain greater understanding into the situations and experiences

that were salient for them when navigating information about childhood ADHD and its treatments, particularly as they operate within our local health-care system. Interview data was thus intended to lend an additional and nuanced perspective to the questions of *how* parents gain knowledge about ADHD, *why* specific types and sources are meaningful for parents, and to generate understanding about *what kinds* of experiences promote confident decision making for parents.

Results from these different yet complementary perspectives were merged and integrated following processes outlined by Creswell and Clark (2018). First, I considered the intent of integration in the context of my research questions, namely, to obtain an expanded understanding about parental information needs and treatment decisions in childhood ADHD. Based on this, I chose to integrate my data by comparing how results in my quantitative and qualitative datasets each informed my overarching research objectives. In my comparisons, I looked for points of convergence and common concepts across both sets of data, and I also looked for points where findings differed. If findings differed across datasets, I considered explanations to understand why I obtained different results. My integrated findings are represented through joint displays, in the form of tables that present quantitative and qualitative results side-by-side, thus facilitating a direct and nuanced discussion of my findings. I then developed the final conclusions and implications of my investigation based on my integrated findings. A procedural diagram summarizing my research design is provided in Figure 3.

Figure 3

Procedural Summary of Research Design



Philosophical Considerations

By nature, mixed method designs reflect opposing ideologies, each with their respective ontological and epistemological perspectives. Quantitative methods are typically rooted within positivist frameworks, assuming a singular objective reality that is knowable when appropriate methods are applied. By contrast, qualitative methods draw on interpretive paradigms. Here, the experience of reality is considered subjective and socially constructed, and the meaning of reality does not exist outside of its social context. Knowledge is not objective and waiting to be uncovered, but rather, is something to be understood through understanding the subjective meanings that individuals ascribe to their social worlds (Hesse-Biber, 2017). Therefore, converging these vastly different worldviews in a mixed-methods study requires consideration about how to coherently reconcile their differing underlying philosophies.

In resolving these differences, it makes sense to consider the ontological and epistemological assumptions of the current investigation. There are notable positivist elements in my proposed research questions. Specifically, by examining the determinants of parental knowledge about ADHD and the impact of knowledge on ADHD treatment, I am treating the condition of ADHD as an objective ontological truth (i.e., I am not questioning the nature of its existence), and I am also treating specific types of knowledge as necessary to parents being able to make treatment decisions (i.e., knowledge about ADHD is not socially constructed, but is based on whether a parent has acquired certain objective facts about the condition). With that said, I also recognize that the experience of knowledge acquisition is variable and that parents will have different perceptions about the value of various types of information. Thus, while ADHD and knowledge about ADHD are seen as objective realities, I also recognized that individuals may have different meanings and experiences as they operate within these realities.

Accordingly, the philosophical stance of the current study must allow for convergence of these two different worldviews.

In light of the pluralistic worldview of the proposed investigation, I viewed my datasets using a pragmatic lens. As outlined by Creswell and Clark (2018), pragmatism is ideally suited for mixed methods designs as it abandons the dichotomy between positivist and interpretive approaches in favour of a problem-centered approach. As such, pragmatists consider the research question to be of primary importance, rather than focusing on use of a specific method. They often combine multiple paradigms and philosophical perspectives, and their associated methodologies, so that they can best understand the problem they are studying. As such, pragmatist perspectives are oriented to a "what works" and practical approach to answer their research questions. This focus lends itself well to the applied nature of the current work, allowing for recognition of objective realities about ADHD and its treatments, while also allowing for appreciation of parents' unique experiences.

Chapter 3: Quantitative Strand

The quantitative data strand of this mixed-methods study consisted of an anonymized online survey where parents provided basic demographic information, information about their child's ADHD treatment history, reported on the types and sources of ADHD information that were important and accessible to them, and reported on their comfort making ADHD-related treatment decisions. Specific research objectives from this strand of the study included (1) identifying ADHD topics that parents deemed important but found hard to access; (2) identifying which sources of information parents used most often to understand ADHD and guide treatment decisions; (3) identifying factors associated with acquisition of ADHD information; and (4) examining the relationship between parents' information acquisition and their comfort making treatment decisions. Given previous research, I hypothesized that parents would find a wide range of ADHD topics to be important, and that information about medications would be more accessible than information about psychosocial components of ADHD (e.g., behaviour/emotional difficulties, parenting strategies, school supports). I also hypothesized that parents would use a variety of sources to learn about ADHD, but they would most often use information from health care providers to guide their treatment decisions. I hypothesized that factors associated with mental health service use (e.g., severity of illness, education level, social support networks, access to health care providers) would facilitate acquisition of ADHD-related information. Lastly, I hypothesized that increased information acquisition about ADHD would be associated with greater confidence in making ADHD treatment decisions.

Methods

Recruitment

My participant recruitment took place during the COVID-19 pandemic, between April 2021 through April 2022. After obtaining ethics approval, I used electronic and social media to recruit a purposive community-based sample of Manitoba parents with a school-aged child (age range 6-12 years) who had been diagnosed with ADHD by a medical doctor, clinical psychologist, or school psychologist since the onset of public health restrictions related to COVID-19 (March 2020, or later). My rationale for this narrow time frame since ADHD diagnosis was two-fold. First, I wanted to ensure that parents' experiences learning about ADHD and treatment options was relatively novel, and that they would have a high level of interest and need for ADHD-related information. Additionally, given the significant social and environmental changes that resulted from COVID-19 public health restrictions, I wanted to ensure that all parents were learning about ADHD within a similar environmental context. I selected the age range of 6 through 12 years of age to capture the peak window for identification and diagnosis of ADHD in children (American Psychiatric Association, 2013). An additional inclusion criterion was for all participants to be able to understand and complete the online survey written in English.

To help ensure that participants represented a broad range of experiences, I reached out to a range of local medical, psychological, and community organizations with electronic and/or paper advertisements. Recruitment sites included local pediatric and mental health clinics, psychological and mental health community associations, learning disorder associations, online ADHD support groups, tutoring centres, and parenting magazines. I also advertised on social

media (e.g., Twitter, Reddit, Facebook, and Instagram). Advertisements were reposted at three- to four-month intervals over the year-long recruitment period.

Procedures

Due to COVID-19 public health restrictions in effect during this investigation, study advertisements were distributed to participating health care clinics and organizations electronically. Advertisements included a number for telephone contact, as well as a web-address and QR code for a study-specific website (www.adhdinfostudy.com). The website outlined the purpose of the study, inclusion criteria, and a link to access the survey online. To reduce technological barriers for participation, an option to receive a paper-and-pencil copy of the survey was also provided on the website; however, I did not receive any requests to participate via this format.

The online link transferred potential participants to the Qualtrics platform, which hosted the survey and associated materials. Upon accessing the on-line survey, all individuals were first given a set of screening questions to ensure they met the inclusion criteria outlined above. Individuals who did not meet inclusion criteria were directed to an exit screen which thanked them for their interest, and which included a resource list of evidence-based websites and support organizations for ADHD (Appendix A). Interested individuals who met eligibility criteria were directed to an on-line informed consent form (Appendix B). After providing informed consent, participants received survey instructions and access to the survey. Once a survey was started, each participant's survey form remained active for one week, thus allowing participants the option to complete their survey in multiple sittings. Upon completion of the survey, participants were directed to an exit screen thanking them for their participation, and they were offered the choice to provide their contact information if they wished to be mailed a $15.00 gift card to a

local grocery store as compensation for their time, and/or a copy of study findings. Participants were told that their contact information would be stored separately from their survey responses. Participants who did not wish to provide their contact information were able to exit the survey anonymously.

After completing all materials related to the survey, participants were given the option of providing additional contact information if they wished to learn about the qualitative (semi-structured interview) portion of the study, as outlined further in the next chapter. Before leaving the Qualtrics platform, all participants were directed to an exit screen that included additional evidence-based resources and support for childhood ADHD.

Measures

Measures from the questionnaire battery that were used in this study included:

Demographic Information. Participants provided information on their age, gender, and education level, marital status, their child's gender and age, annual household income, household size, and cultural/racial background.

ADHD Treatment History. Participants provided information on how long they had been concerned about their child's ADHD symptoms prior to diagnosis, when (month/year) their child was diagnosed with ADHD, the types of health care professionals that provided a diagnosis and/or treatment for their child, their number of appointments with various health care professionals, the types of ADHD treatment that their child had received, whether their child was currently or had ever taken medication for ADHD, and whether their child had any co-occurring disorders.

Information Needs and Preferences. Data on parents' information needs and preferences was obtained using a format that has been used in previous investigations of parental

information needs for childhood anxiety (Mak et al., 2017), information needs of young adults with stress, anxiety, and depression (Stewart et al., 2014), and information needs of patients with inflammatory bowel disease (Wong et al., 2012). On this measure, participants rated the degree of importance of ADHD-related topics using a 0- to 8-point rating scale, with anchors 0-2 (not important), 3 to 5 (moderately important), and 6 to 8 (very important). Seven ADHD-related topics were selected based on content areas included in standard psychoeducational interventions (Dahl et al., 2019), and included ADHD symptom recognition, causes of ADHD, co-occurring emotional and/or behavioural difficulties, medication treatments, parenting/behaviour management strategies, educational strategies, and developmental concerns. Based on concerns identified through review of the literature, I added three additional questions including information about alternative ADHD treatments, local ADHD resources, and information about talking to children about ADHD. I also included two open-ended questions at the end of the survey, probing for any additional ADHD-related topics that were important to parents.

Novel to the current study, I supplemented this measure with accessibility ratings, such that participants were also asked how easily they had been able to access information on each ADHD-related topic. Accessibility ratings used the same Likert-style format as importance ratings, using a 0- to 8-point rating scale, with anchors 0-2 (not easily accessed), 3 to 5 (moderately easy to access), and 6 to 8 (very easy to access). To minimize potential order effects and the potential of response fatigue, the importance and accessibility ratings for each of the ADHD-topics were randomized across surveys.

Following administration of these items, participants were asked to rate their overall level of satisfaction with the ADHD-related information they had accessed, using the same 0- to 8-point rating scale.

ADHD Literacy. Participants completed a brief measure of their perceptions of their ADHD-related mental health literacy by using an adapted version of the Mental Health Literacy questionnaire (Reynolds et al., in preparation). On the original version of this measure, respondents rate their level of mental health knowledge on each of the 4-domains of mental health literacy outlined by Jorm and colleagues (1997; 2012), including knowledge of signs and symptoms of common mental health problems, knowledge of causes for common mental health problems, knowledge of help-seeking options for common mental health problems, and knowing how to seek help for common mental health problems. Each scale ranges from 1 (not at all knowledgeable) to 5 (extremely knowledgeable). Preliminary data indicates this brief measure has a high level of internal consistency (Cronbach α = .91), is positively correlated with measures of mental-health service use, and negatively correlated with self-stigma (Reynolds et al., in preparation). The current investigation used an adaptation of this measure such that participants responded to each of the 4 domains as they pertained to their knowledge about ADHD.

Participants also completed a 27-item checklist where they marked off the various information sources they had ever used in their learning about ADHD. From the items they endorsed, they were asked to rank the top three sources that had been most helpful for them when making treatment decisions for their child.

Current ADHD Symptom Severity. Participants completed the Vanderbilt ADHD Diagnostic Rating Scale (VADRS) as a measure of their child's current ADHD symptom severity (NICHQ, 2002). On the VADRS, respondents rate how frequently their child exhibits diagnostic symptoms of ADHD on a 0-to-3-point scale (0 = never; 1 = occasionally; 2 = often; 3 = very often). The VADRS has established psychometric properties for use with community and

clinical samples of parents, including test-retest reliability coefficients > .80, Cronbach $\alpha > .90$, and moderate to high correlations with structured diagnostic interviews for ADHD (NICHQ, 2002; Collett et al., 2003; Bard et al., 2013; Wolraich et al., 2003).

Treatment Making Preferences. Parent preferences for treatment decision-making were assessed using a modified version of the Control Preferences Scale for Pediatrics (CPS-P; Pyke-Grimm et al., 1999). The original version of the CPS-P consists of a card-sort procedure, with five cards consisting of written statements and illustrative drawings describing various degrees of control a parent may wish to assume when decisions are being made about their child's medical treatment. For this investigation, participants were asked to select one statement from a list of five statements corresponding with their preferred role in treatment decision-making. Previous investigations (e.g., Gagnon & Recklitis, 2003; Mak et al., 2017) have used this modified format of the CPS-P as a nominal measure of parent treatment preferences.

Decisional Conflict. Participants completed the Decisional Conflict Scale (DCS; O'Connor, 1994) as a measure of their conflict and uncertainty related to treatment decision-making for their child's ADHD. The DCS is a 16-item scale composed of five sub-scales capturing different dimensions of treatment decisions including uncertainty, feeling uninformed, feeling unclear about values, feeling unsupported, and effective choices. For each item, respondents rate how strongly they agree with each statement on a 0- to 4-point scale (0 = strongly agree; 1 = agree; 2 = neither agree nor disagree; 3 = disagree; 4 = strongly disagree). The DCS is scored by summing all items, dividing by 16 and multiplying by 5. Scores thus range from 0 (no decisional conflict) to 100 (extremely high decisional conflict). The DCS manual notes that scores lower than 25 are usually associated with implementing treatment decisions, and scores exceeding 37.5 are associated with decision delay or feelings of insecurity about

decision implementation. The DCS is designed so that researchers may substitute any health care choice or decision into the statements of the scale. It has been widely used as a measure of parent decision-making certainty with a variety of pediatric populations (e.g., Knapp et al., 2014; Knapp et al., 2009; McKenna et al., 2010; Stremler et al., 2017). It has well established psychometric properties, with test-retest reliability coefficients of 0.81, Cronbach α of 0.78–0.92, and demonstrated ability to discriminate between those with strong intentions to accept or decline health care interventions and those whose intentions were uncertain (O'Connor, 1994).

The survey questionnaire battery underwent pilot testing with three parents of children with ADHD, recruited within the general community through word of mouth. Parents reviewed and completed the questionnaire for readability, length, and content. Parents indicated that they completed the survey in 15 to 20 minutes, and they found the survey questions clear and understandable. Other than the small text revisions to clarify the confidentiality of their information, they did not recommend any substantive or content-related changes or additions to the survey. A copy of the survey battery is provided in Appendix C.

Quantitative Results

Results from the survey battery were analyzed using IPM SPSS Statistics version 28.0.1.1. A total of 95 individuals accessed the survey during the 1-year recruitment period. Of these, 35 individuals either did not meet inclusion criteria and were screened out of the study, or they did not complete the informed consent form. Another five individuals were found to not meet inclusion criteria based on their survey responses (e.g., their child had been diagnosed with ADHD for several years, and several years before COVID-19 public health restrictions). This left a sample size of 55 participants.

Although this sample size was considerably smaller than anticipated and resulted in some of my analyses being underpowered (as will be outlined below), my research team and I felt that continuing to collect data and/or broadening my inclusion criteria to increase my sample size could be problematic for several reasons. First, the easing of COVID-19 pandemic restrictions created concern that any newly recruited participants would be experiencing their child's ADHD symptoms and learning about ADHD under much changed social and environmental conditions, thus creating a strong likelihood of significant and artifactual heterogeneity within any additional collected data. Second, with this study's focus on obtaining local level contextual data to ultimately inform the development of improved local knowledge translation and application strategies (e.g., Graham et al., 2006), it would not have been appropriate to expand inclusion criteria beyond our local community (i.e., outside Manitoba). I also considered that any underpowered analyses in the quantitative strand of this study could also be examined from a qualitative perspective, thus allowing a supplemental lens to explore my research questions. Based on these factors, together with the novel and exploratory nature of the data being collected, it was felt that the drawbacks of having a smaller sample would be offset by the benefits of obtaining multi-modal, interpretable, and highly actionable local level data.

A missing values analysis indicated 97.5% complete values in my data, and the absence of a clear pattern of missing data (Little's MCAR chi-square = 1482.0, $p = .999$). Because any missing data was random, I imputed their values using a single imputation of expectation maximization. This resulted in imputed values for ADHD information needs and preferences, mental health literacy, decisional conflict, and ADHD symptoms. All other variables were not imputed due to no or too few missing values.

Sample Composition

Table 1 depicts the demographics of the 55 parent participants who completed the survey. As noted in the table, most participants identified as White and were married. Participants were relatively well-educated and financially stable, such that almost all had finished high school and over half had attained at least one university degree. Half of the participants fell into an income bracket of $85,000 or higher of annual income. Survey respondents were overwhelmingly female caregivers. The target children of the participant parents were mostly boys, with an average age of approximately 8 years old.

Table 1

Participant Sample Characteristics

	Total Sample (n = 55)
Parent Gender n (%)	
Female	53 (96.4)
Male	1 (1.8)
Prefer not to say	1 (1.8)
Parent Age M (SD, range)	38.7 years (5.2; 30 – 59)
Marital Status n (%)	
Married or Common Law	42 (76.4)
Single	5 (9.1)
Separated or Divorced	5 (9.1)
Living with a partner	2 (3.6)
Widowed	1 (1.8)
Racial/Cultural Background n (%)	
White	40 (72.7)
Indigenous (First Nations, Metis, Inuit)	5 (9.1)
White and Indigenous	5 (9.1)
Other	4 (7.2)
Prefer not to say	1 (1.8)
Annual Household Income n (%)	
$40,000 or Lower	7 (12.7)
$40,000 - $60,000	8 (14.5)
$60,000 - $85,000	11 (20.0)
$85,000 - $125,000	17 (30.9)
$125,000 or higher	11 (20.0)
Prefer not to say	1 (1.8)
Highest Level of Education n (%)	
Some High School	1 (1.8)
High School Diploma or GED	6 (10.9)
College or Technical Degree	19 (34.5)
Bachelor's Degree	21 (38.2)
Master's Degree	6 (10.9)
Professional or Doctoral Degree	2 (3.6)
Household size M (SD; range)	3.93 (1.1; 2 – 7)
Child's Age M (SD; range)	8.42 (1.9; 6 – 12)
Child's Gender n (%)	
Male	35 (63.6)
Female	16 (29.1)
Non-binary/Other	2 (3.6)

ADHD Treatment History

Information on children and their ADHD treatment histories is depicted in Table 2. Parent ratings on the VADRS suggest that their children were continuing to experience significant ADHD symptoms during their participation in this study. Almost half of the children had at least one additional diagnosis besides ADHD which encompassed a range of conditions commonly seen among youth with ADHD, including anxiety disorders (n = 14), oppositional defiant disorder and emotional regulation problems (n = 6), sensory processing disorder (n = 3), learning disorders (n = 3), intellectual disability (n = 3), Tourette's disorder (n = 1), Tic disorder (n = 1), and genetic disorders (n = 2).

Parents in this sample had accessed a wide range of clinical supports and treatments specifically for their children's ADHD symptoms. On average, parents had accessed more than two different health care providers for ADHD treatment, including family doctors and pediatricians, psychiatrists, clinical and school psychologists, and therapists. On average, parents had also used more than three types of treatments for their children's ADHD, including medication, parent behaviour support, school supports, counselling, and occupational therapy support. At the time of this study, more than two-thirds of the children were taking medication for their ADHD symptoms. Notably, most participants reported a lengthy wait for their children to receive an ADHD diagnosis. Close to three-quarters of the parent participants were concerned about their children's ADHD symptoms for more than a year before their diagnosis, and almost half were concerned for over two years before their diagnosis.

Table 2

Children's ADHD Treatment Histories

	Total Sample (n = 55)
VADRS total symptom score M (SD; range)	37 (8.7; 21 – 54)
Concurrent diagnoses n (%)	
None	28 (50.1)
One	16 (29.1)
Two or More	11 (20.0)
Current ADHD medications n (%)	
Yes	39 (70.9)
No	16 (29.1)
Types of treatment providers[A] n (%)	
Pediatricians	35 (36.3)
Occupational therapists	22 (40.0)
Family physicians	19 (34.5)
Clinical psychologists	16 (29.1)
School psychologists	12 (21.8)
Therapists/Counsellors	11 (20.0)
Child psychiatrists	10 (18.2)
Other	16 (29.1)
Total number of treatment providers accessed M (SD; range)	2.5 (1.3; 1 – 6)
Treatments ever used[A] n (%)	
Medication	42 (76.3)
Parenting support	34 (61.8)
School support	33 (60.0)
Occupational therapy	25 (45.5)
General counselling	18 (32.7)
Diet changes	13 (23.6)
Exercise	11 (20.0)
Neurofeedback	5 (9.1)
Other	9 (16.4)
Total number of ADHD treatments used M (SD; range)	3.6 (1.4; 1 – 7)
Time from concerns to diagnosis n (%)	
Greater than 2 years	27 (49.1)
Between 1 and 2 years	14 (25.5)
6 months to 1 year	3 (5.5)
3 to 6 months	3 (5.5)
Less than a month	2 (3.6)
Didn’t notice ADHD symptoms pre-diagnosis	3 (5.5)

Note: VADRS – Vanderbilt ADHD Diagnostic Rating Scale. [A] Percentages exceed 100% as participants were able to endorse more than response

Objective 1: Identifying ADHD Topics that Parents Deem Important but Find Hard to Access

I addressed this research objective in two ways. First, I examined participant ratings of the importance of the 10 ADHD-related topic areas, and their respective accessibility ratings. I used confidence intervals to examine mean differences across the various ratings of importance and accessibility. Within survey research, this method has been increasingly recommended in comparison to pairwise significance tests, particularly for exploratory and descriptive research questions (Cumming, 2014; Cumming & Finch, 2005; Cummings & Koepsell, 2010; Finch & Cumming, 2009). The benefits of using confidence intervals for mean comparisons in this context include decreased reliance on the unstable measurement of *p* as employed in traditional null hypothesis significance testing, decreased possibility of type 1 error with multiple pairwise comparisons, and appropriateness in their application to exploratory and descriptive research questions (Cummings & Finch, 2005).

Results indicated that ADHD-related topic importance and access items had adequate internal consistency (Cronbach's $\alpha = .827$). Examination of score distributions found that the distribution on importance items skewed left, extending towards higher importance levels, while the score distribution on access items were normally distributed. Table 3 and Figure 4 illustrate the mean ratings and 95% confidence intervals for each of the 10 ADHD-related topics and their accessibility. Topics and their respective accessibilities are presented in order from those rated most important to those rated least important.

Notably, there were significant differences between each ADHD information topic and its respective accessibility rating, based on non-overlapping confidence intervals. Specifically, while all ADHD information topics were rated at or near the "extremely important" anchor of the

rating scale, accessibility ratings for each ADHD information topic were rated significantly lower, at or below the "moderately accessible" anchor of the rating scale. This finding suggests that parents consistently experience challenges accessing the numerous types of ADHD-related information they consider important. While I hypothesized this finding for psychosocial topics pertaining to ADHD, I did not anticipate this pattern to be so widespread. This discrepancy has significant implications for future dissemination of ADHD-related materials to parents.

There were also some significant differences between the importance of various ADHD-topics, based on non-overlapping confidence intervals. Specifically, parents rated information about co-occurring behaviour/emotional problems as most important, followed closely by educational supports. Information on these two topics was rated as significantly more important than information about medications for ADHD, understanding the causes of ADHD, and alternative interventions for ADHD, which were the three topics rated of least importance, respectively. Parents also rated information about behaviour management/parenting strategies and local supports as more important than information about the causes of ADHD and alternative interventions for ADHD, and information about symptom recognition was rated as more important than information about alternative interventions for ADHD.

More than half of the participants (n = 32; 58.2%) used the open-ended questions to list at least one additional ADHD-related topic that they considered important, or to expand on topics already listed. Responses covered a wide range of areas. Information on how to access additional or specific types of clinical support was listed most frequently (n = 17), followed by information pertaining to parenting and managing family dynamics (n = 8), information about identifying and managing comorbidities (n = 7), information about accessing school supports (n = 5), and information about medications and their side effects (n = 4). Other listed topics included

information about diet (n = 3), neurodiversity (n = 3), social skills (n = 2), ADHD without hyperactivity (n = 2), sleep (n = 1), ADHD in girls (n = 1), executive function (n = 1), goal setting (n = 1), environment (n = 1), and gender dysphoria (n = 1).

Table 3

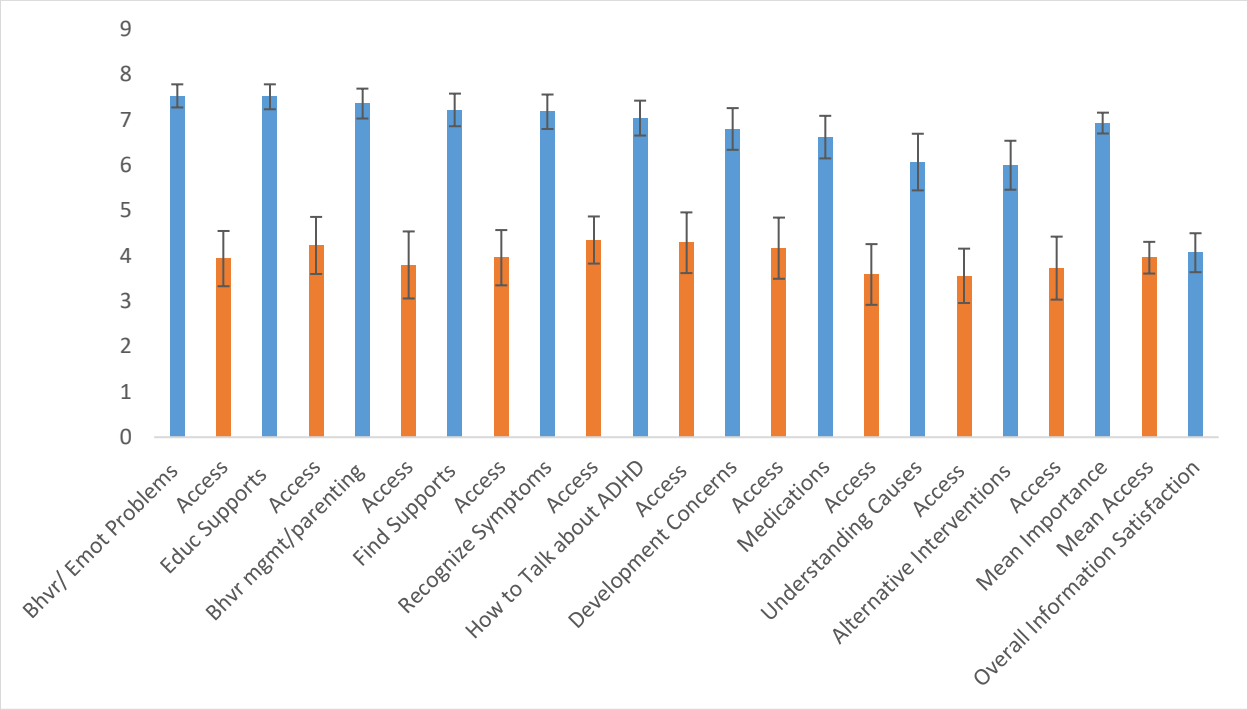
Parents' Ratings of Importance and Accessibility for ADHD Topics

	Mean	SE	95% Confidence Interval
Behaviour and/or emotional problems	7.53	.13	7.27 – 7.78
Accessibility	3.94	.30	3.33 – 4.55
Educational supports and strategies	7.51	.13	7.23 – 7.78
Accessibility	4.23	.31	3.60 – 4.86
Behaviour management/parenting strategies	7.36	.16	7.03 – 7.69
Accessibility	3.80	.36	3.06 – 4.54
Where I can find supports for my child and family	7.22	.18	6.86 – 7.58
Accessibility	3.96	.30	3.35 – 4.57
Recognizing symptoms	7.18	.19	6.80 – 7.56[C]
Accessibility	4.35	.25	3.83 – 4.87
How to talk with my child about ADHD	7.04	.19	6.65 – 7.42
Accessibility	4.29	.33	3.62 – 4.96
Developmental concerns/symptoms change over time	6.80	.23	6.34 – 7.26
Accessibility	4.17	.34	3.50 – 4.85
Medication treatments	6.62	.24	6.15 – 7.09
Accessibility	3.59	.34	2.92 – 4.26
Understanding what causes ADHD	6.07	.31	5.45 – 6.70
Accessibility	3.56	.30	2.96 – 4.16
Alternative interventions (e.g., neurofeedback, diet, supplements, exercise)	6.00	.28	5.46 – 6.54
Accessibility	3.73	.34	3.04 – 4.43
Mean importance rating	6.93	.11	6.70-7.16
Mean accessibility rating	3.96	.17	3.61-4.31
Overall level of information satisfaction	4.07	.21	3.61-4.47

Note: SE = standard error. Importance and ease of access ratings from 0 (not at all important/not at all easily) to 8 (very important/very easily).

Figure 4

Parents' Ratings of Importance and Accessibility for ADHD Topics



Note: Importance and ease of access ratings range from 0 (not at all important/not at all easily) to 8 (very important/very easily).

I additionally addressed my objective of identifying ADHD-related topics that parents deemed important but found hard to access by examining parent ratings of their ADHD mental health literacy. As depicted in Table 4 and Figure 5, participants largely rated their ADHD literacy to be within a moderate range. However, based on non-overlapping confidence intervals, participants rated themselves to be significantly more knowledgeable about ADHD signs and symptoms relative to their knowledge of causes of ADHD, types of professional help for ADHD, and how to access professional help for ADHD.

Table 4

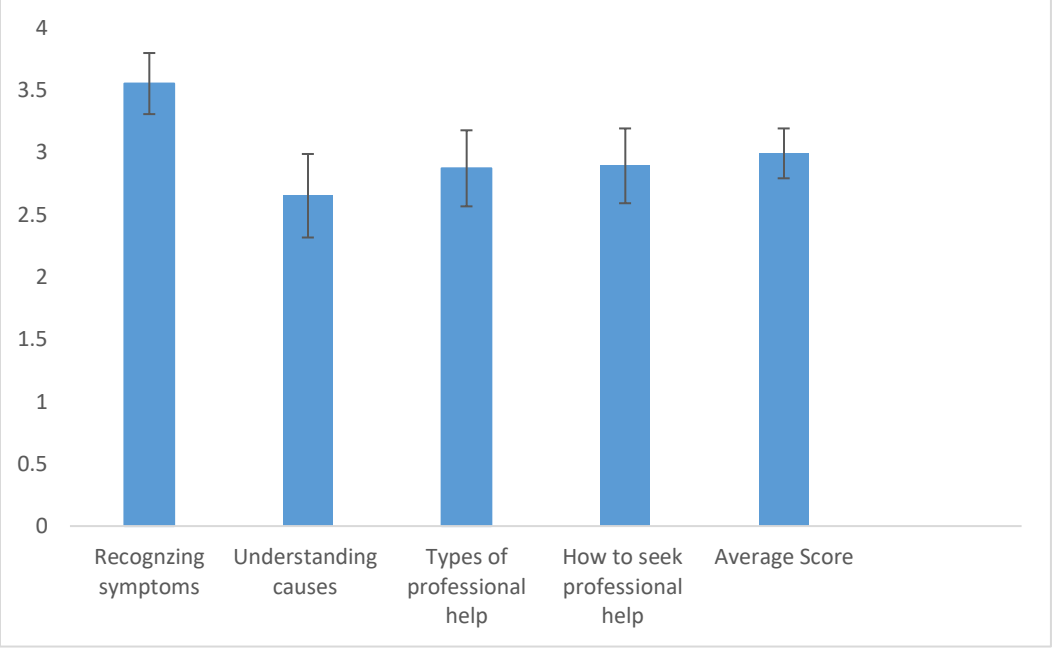
Parents' Ratings of ADHD Literacy

Item	Mean	SE	95% Confidence Interval
Recognizing the signs and symptoms of ADHD	3.55	0.124	3.30 - 3.79
Understanding the possible causes of ADHD	2.65	0.168	2.31 - 2.98
The types of professional help available for ADHD	2.87	0.151	2.57 - 3.18
How to go about seeking professional help for ADHD	2.89	0.148	2.59 - 3.19
ADHD literacy average Score	2.99	0.101	2.79 - 3.19
ADHD literacy total Score	11.96	0.406	11.14 - 12.77

Note: SE = standard error. Mental health literacy ratings range from 1 (not at all knowledgeable)

Figure 5

Parents' Ratings of ADHD Literacy



Note: ADHD literacy ratings range from 1 (not at all knowledgeable) to 5 (extremely knowledgeable).

Objective 2: Identifying the Sources of Information that Parents Use to Understand ADHD and Guide their Treatment Decisions

To address this objective, I analyzed responses from the 27-item checklist indicating the number of information sources that parents had ever used to learn about ADHD, and their rank orderings of the information sources that they found most helpful in making ADHD-related treatment decisions. Responses were categorized into mutually exclusive categories representing clinical information sources requiring a medical appointment or specialized referral (pediatricians, family doctors, clinical and school psychologists, occupational therapists, general therapists, school social workers, other clinical-based ADHD care providers), community-based information sources where parents interacted with community members or peers to learn about ADHD (in-person or online ADHD support groups, friends, family, cultural beliefs and practices, religious beliefs and practices), school-based information sources (classroom teachers, guidance counsellors, resource teachers, other school supports), and independently-accessed information sources whereby parents accessed ADHD information without interacting with others (ADHD specific websites, general internet information, books or magazines, TV news coverage, informational pamphlets, podcasts). Categories were created in collaboration with a graduate research assistant, and they were reviewed for consensus with a member of my research team.

Consistent with my hypotheses, participants frequently accessed information sources across all categories to learn about ADHD. Across the 55 participants, clinical sources of information were accessed most often, followed closely by independent sources, community sources, and school sources. The total number of times each category was accessed, and the average number of sources accessed within each category, is presented in Table 5.

Table 5

Frequency of Parents' Access to Information Sources by Category

	Total Times Accessed	Average Number Accessed M (SD)	Range
Clinical sources	150	2.55 (1.26)	0 – 6
Independent sources	145	2.67 (1.41)	0 – 6
Community sources	62	1.25 (1.10)	0 – 4
School sources	59	1.09 (0.88)	0 – 3
Total sources	416	7.56 (3.15)	0 – 19

Figures 6 and 7 depict parents' rankings of their top three information sources that helped to guide their treatment decisions. Figure 6 depicts the number of times each category of information source (e.g., clinical sources, independent sources, school sources, community sources) was ranked, and Figure 7 depicts the frequency of rankings for specific information sources within each category. As shown, despite accessing many different types of sources to learn about ADHD, participants reported a very clear preference for information coming from clinical sources to help with their ADHD treatment decisions, a finding consistent with my hypotheses. Pediatricians were most frequently ranked as the top information source for making treatment decisions by a wide margin, followed by other clinical sources including clinical psychologists, occupational therapists, and family doctors. Notably, ADHD websites and general internet websites were also ranked relatively frequently as a top information source for making treatment decisions. Overall, clinical information sources were ranked most frequently as helping with treatment decisions, followed by information obtained independently from the Internet (ADHD-specific websites and general internet information), followed by information from school sources, and then community sources (ADHD support groups, family members, and friends). Of the 27 possible information sources, three received no endorsements. These included TV news coverage, religious beliefs, and magazines.

Figure 6

Frequency of Parents' Rankings of ADHD Information Source by Category

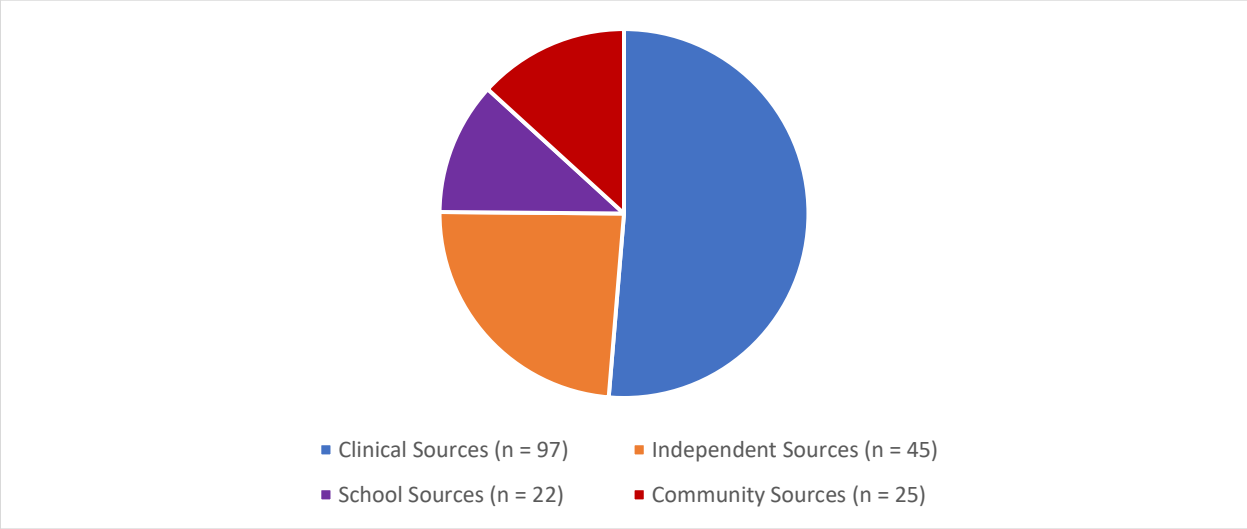
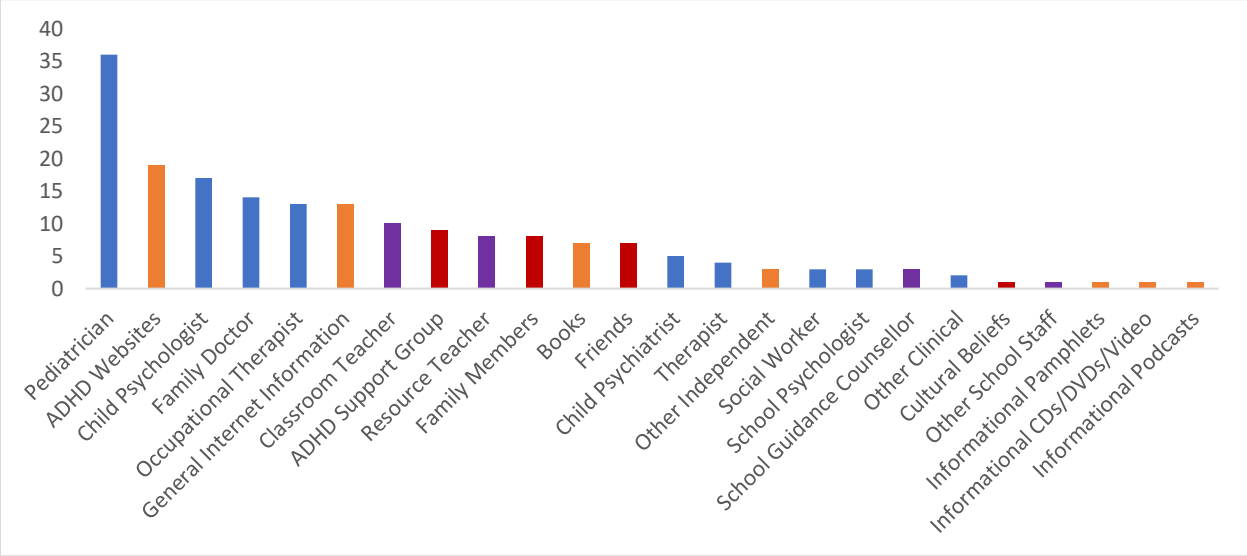


Figure 7

Frequency of Parents' Rankings of ADHD Information Source by Type



Objective 3: Identifying Factors Associated with Acquisition of ADHD Information

To address this objective, I used the NEM-II model of mental health service use as a conceptual framework to explore the associations between ADHD severity, socio-demographic factors, community networks, and health-care system access with levels of information satisfaction about ADHD and with ADHD literacy. I chose to use the NEM-II model to frame this question because of its recognition of social networks as a component of coming to understand one's mental health needs, which is important given the inherently social nature of information acquisition. I also felt this model was well-suited to my question because it acknowledges that understanding about mental health does not end at the point of diagnosis, and that acquiring understanding of mental health conditions is the result of ongoing and recursive relationships between the various NEM-II domains.

I operationalized the NEM-II model using VADRS Total Symptom Score as an indicator of ADHD severity, education level as an indicator of social location, number of community and number of school-based information sources (combined) as an indicator of community networks, and number of clinical information sources as an indicator of health-care system access. Given the high frequency with which participants also accessed independent information sources to learn about ADHD, I also included this variable in my analysis. I used participants ratings of their overall information satisfaction about ADHD and their ratings of ADHD literacy as measures of their information acquisition.

My first step in exploring the patterns of relationships between these variables was to look at their intercorrelations. I hypothesized that higher levels of education and use of each of the information sources would be associated with greater levels of information acquisition. I also

hypothesized that parents whose children had more severe ADHD symptoms (i.e., higher scores on the VADRS) would be less satisfied with the information they had accessed.

Bivariate correlations are presented in Table 6. As presented, parental education was negatively associated with severity of children's ADHD symptoms, but ADHD symptom severity was not associated with parental use of any type of information source, or with any of the measures of information acquisition. Higher parental education levels were also positively associated with use of independent sources of information, and they were negatively associated with information satisfaction. There was some inter-relationship between information sources, in that use of independent sources was positively associated with use of clinical sources as well as use of community network sources. There was a trending relationship between parental ADHD-literacy and their overall information satisfaction. Parental ADHD literacy was positively associated with the use of independent sources of information. There were small positive effects between parental ADHD-literacy and education level, use of clinical sources, and use of community sources, but these associations fell short of statistical significance.

Table 6.

Bivariate Correlations between NEM-II Variables and Information Acquisition

	1	2	3	4	5	6	7
1. VADRS	--						
2. Education	-.36**	--					
3. Clinical sources	0.146	0.006	--				
4. Community network information sources	-0.103	0.001	0.139	--			
5. Independent sources	-0.040	.266*	.381**	.494**	--		
6. Information satisfaction	-0.002	-.291*	-0.013	0.100	-0.178	--	
7. ADHD Literacy	0.124	0.097	0.211†	0.201	.374**	0.236T	--

Note: * p < .05. ** p < .01. T p < .10 † p < .15

My next step in this analysis was using multiple regression to examine the unique contributions of the various components of the NEM-II model on ADHD information acquisition. Variables for my regression were selected based on the conceptual framework of the NEM-II model (i.e., socio-demographic factors operating in concert with social and treatment system networks to influence mental health knowledge acquisition), and in collaboration with my primary research advisor. In selecting my predictor variables, I examined the pattern of inter-correlations between potential variables, while also keeping my small sample size and applied focus of this project in mind. I selected parent education level to represent parents' socio-demographic position, use of community information sources to reflect parents' social networks, and use of clinical information sources to reflect treatment system access. Although not part of the NEM-II model, I additionally selected use of independent information sources as a predictor

variable due to its strong correlations with other variables of interest. My outcome measure was ADHD literacy. Prior to running my analysis, I examined scatterplots of all my variables, and I also tested to ensure that my set of variables met the required assumptions for multiple regression analysis (i.e., linearity, normality, heteroscedasticity, multicollinearity).

The omnibus effect of this linear regression was marginally significant F (4,50) = 2.14, p = .089, such that the combined effects of parent education and use of all three types of information sources accounted for 14.6% of the variance in ADHD literacy. Table 7 depicts standardized and unstandardized regression coefficients and the t-test statistic for the significance of each variable in the multiple regression model. As shown, examination of the individual predictors found that the use of independent information sources had a unique marginally significant effect on ADHD literacy.

Table 7

Regression of Education and Access to Information Sources on ADHD Literacy

	B	SE	β	T
Parent education	.03	.41	.01	.07
Use of clinical information sources	.19	.33	.08	.58
Use of community network information sources	.09	.51	.03	.18
Use of independent information sources	.71	.37	.33	**1.92**^{T}

Note: B = unstandardized regression coefficient, SE = standard error; β = standardized regression coefficient, T = T-test statistic. ^{T} p = .06

Objective 4: Examining the Relationship between Information Acquisition and Comfort Making ADHD Treatment Decisions.

I addressed this research objective in two ways. First, I examined whether information acquisition was related to parental preferences for decisional control when making ADHD treatment decisions. I operationalized decisional control by using responses on the Treatment Control Preferences measure (TPS). As depicted in Table 8, a large majority of parents (89.1%)

endorsed a style of collaboration with their health-care provider when making ADHD treatment decisions. The most common preference was for parents to assume final control over treatment decisions after considering the opinion of their health-care provider (56.4% of parents), followed by the preference that parents and health-care providers share control over treatment decisions (32.7%). Preferences for parents to make final treatment decisions without health-care provider input were rare, and notably, none of the parents wanted to leave all treatment decisions solely in the hands of health-care providers without offering their opinion.

Table 8

Parents' Self-Reported Treatment Control Preferences

	n (%)
I prefer to leave all decisions regarding treatment with my child's health-care provider	0 (0)
I prefer that my child's health-care provider makes the final decision about which treatment will be used, but seriously considers my opinion	1 (1.8)
I prefer that my child's health-care provider and I share responsibility for deciding which treatment is best for my child	18 (32.7)
I prefer to make the final decision of my child's treatment after seriously considering my child's health-care provider's opinion	31 (56.4)
I prefer to make the final decision about which treatment my child will receive	4 (7.3)
Missing	1 (1.8)

Based on this distribution of parental decisional control styles, I dichotomized parental control styles into two groups reflecting parents who preferred equal or less control with their health care provider over treatment decision making (n = 19) and parents who preferred to assume greater control than their health care provider over treatment decision making (n = 35). An independent samples *t*-test found that these two groups did not differ in their level of ADHD literacy, $t(53) = 0.114$, $p = .910$. As such, contrary to my hypothesis, parents who had acquired greater levels of ADHD information did not prefer to have greater levels of control over ADHD treatment decisions for their children.

I also examined the relationships between socio-demographic factors, parental ADHD information acquisition, and parents' confidence about their treatment decisions. I operationalized confidence in making treatment decisions by using total scores on the Decisional Conflict Scale (M = 36.87, SD = 15.17; Chronbach's α = .912). In keeping with the NEM-II framework of this study, sociodemographic predictor variables included parent education levels and children's ADHD symptom severity (i.e., VADRS score). ADHD information acquisition was operationalized as parental ADHD literacy. I used hierarchical multiple regression for this analysis, entering the two socio-demographic predictor variables in step one, and entering ADHD literacy in step two. Prior to running my analysis, I examined scatterplots of all my variables, and I also tested to ensure that my set of variables met the required assumptions for multiple regression analysis (i.e., linearity, normality, heteroscedasticity, multicollinearity).

In step one of this analysis, sociodemographic variables accounted for 8% of the variance in decisional conflict, F (2, 52), p = .113. Although this omnibus test fell short of statistical significance, parent education was found to have a significant positive association with decisional conflict. Adding ADHD literacy to the model in step two accounted for an additional 23.5% of the variance in decisional conflict, F (3,51) = 7.8, p < .001. Examination of individual predictors found that parental education remained positively associated with decisional conflict, a finding which was contrary to my hypotheses. Consistent with my hypotheses, however, there was a significant negative association between ADHD literacy and decisional conflict, with parents who reported greater levels of ADHD literacy experiencing less decisional conflict about their choice of ADHD treatment. Results of this analysis are provided in Table 9.

Table 9

Regression of Sociodemographic Characteristics and ADHD Literacy on Decisional Conflict

		B	SE	β	T
Step 1					
VADRS score		.19	.25	.10	.75
Parent education		4.55	2.13	.30	2.13*
R^2	.08				
Step 2					
VADRS Score		.35	.22	.19	1.56
Parent Education		5.76	1.88	.38	**3.06****
ADHD Literacy		-2.49	.60	-.49	**-4.18*****
ΔR^2	.235				
R^2	**.315****				

Note: B = unstandardized regression coefficient, SE = standard error; β = standardized regression coefficient, T = T-test statistic, R^2 = proportion of variance explained. *p < .05, **p < .01, ***p < .001

Quantitative Discussion

The objectives of my quantitative research were to identify the ADHD topics that parents deemed important but found hard to access, to identify the sources of information parents used to understand ADHD and guide treatment decisions, to identify predictors of information acquisition about ADHD, and to examine the relationship between parents' information acquisition and their comfort making treatment decisions. I obtained several noteworthy results in examining these questions.

On the topic of ADHD content areas, while parents considered all ADHD topics to be considerably important, their top information needs were understanding the emotional and behavioural difficulties that co-occur with ADHD, educational strategies for ADHD, and behaviour management/parenting strategies. These findings are consistent with the types of ADHD information that have been expressed as important by parents in previous quantitative and qualitative research (Ahmed et al., 2014; Sciberras et al., 2010), and reinforce the importance of providing parents with information that has high practical and functional value, and which they can use to make a meaningful difference in the day-to-day lives of their children.

Notably, parents consistently reported significant differences between the importance and accessibility of information for all queried ADHD-content areas. Thus, while all content areas pertaining to ADHD were important to them, parents experienced at least moderate levels of difficulty in accessing information about each of them. Difficulties with parents' access to relevant ADHD information is further indicated from their responses about their ADHD literacy. Specifically, while parents rated information about educational and behavioural interventions to be of top importance to them, they reported lower ADHD literacy in these areas (i.e., in knowing about ADHD treatments). Consistent with previous research by Climie and Henley (2018),

parents felt most well-versed in recognizing the symptoms of ADHD; however, this information topic was not one of their top needs. This is the first known investigation that has queried the accessibility of ADHD information that is deemed important by parents. Current findings illustrate a clear need for further exploration of this topic. As articulated within the Knowledge-to-Action conceptual model (Graham et al., 2006), we need better understanding of the contextual factors that may underlie poor access to information before we can improve the content and methods of information delivery.

Although parents reported only moderate levels of satisfaction with ADHD information and ADHD literacy, they nonetheless sought and accessed information from a wide range of sources including primary care providers, clinical specialists such as psychiatrists, psychologists and occupational therapists, counsellors, school staff, family members, and friends. They also used independent sources of information to learn about ADHD, mostly from internet-based information, and to a lesser extent via podcasts and various text materials. When considering the large number of different ADHD information sources used by parents vis-à-vis their only moderate ratings of information accessibility, there is a likely gap between the availability and the usability of information that parents can obtain. One potential reason for this gap might be a "quantity over quality" scenario, whereby parents are overloaded with an abundance of information that is difficult to sift through. Alternatively, or additionally, there might be a mismatch between available ADHD information and how it aligns with parents' information needs.

Further on the topic of information sources, parents reported an overwhelming preference to access information about ADHD from clinical sources when making treatment decisions, a finding that is consistent with previous investigations (Ahmed et al., 2014; Sciberras et al.,

2010). However, when looking at their actual use of the various types of information sources, parents relied quite significantly on independent information sources, specifically internet-based information, both for learning about ADHD and for making treatment decisions.

Parents' frequent use of independent information sources is an unexpected and interesting finding. This finding may be partially related to the COVID-19 pandemic, in that participants completed this survey during a period of pandemic restrictions and this may have reduced their access to other types of information sources. This finding may similarly reflect that parents are encountering barriers to accessing their most preferred clinical sources of information, thus contributing to their feeling that ADHD information is not sufficiently accessible. Given the rising use of the Internet as a primary information source, better understanding of how parents use independent sources to learn about ADHD will be important. For instance, this raises the question of whether parents have sufficient skills and/or guidance to help them identify sources of information that are evidence-supported, and similarly, whether evidence-supported information is easily discernable from less reliable information sources.

In terms of identifying factors associated with parents' acquisition of ADHD literacy using the NEM-II model, the current investigation yielded mixed results. Consistent with the interactional framework of the NEM-II (Pescosolido et al, 2013), variables reflecting parents' use of independent, community, and clinical information sources are positively inter-correlated, thus suggesting that use of any one of these three types of information networks to learn about ADHD is also associated with using the other two types of information networks. This suggests that parents access information about ADHD through a dynamic and ongoing process. With respect to the acquisition of ADHD literacy, however, the majority of my hypothesized NEM-II predictor variables, including parent education, use of community networks, and use of clinical

sources, were not directly associated with parents ADHD literacy. The lack of association between use of clinical information sources and ADHD literacy is particularly surprising considering the high value and overwhelming preference of parents to access clinical sources relative to others.

Parent education levels were significantly positively associated with their use of independent information sources to learn about ADHD, and the use of independent information sources had a modest positive association with ADHD literacy. This finding suggests a potential mediational relationship between parents' education and ADHD literacy, such that parents with higher levels of education are more likely to seek out information about ADHD via independent reading and research, which in turn contributes to the feeling that they understand ADHD and report higher levels of ADHD-literacy. Although this mediational hypothesis is not fully supported by the pattern of statistical associations found in the current study (i.e., parent education levels were not associated with ADHD literacy; Baron & Kenny, 1986), it bears noting that the positive relationship between education level and mental health literacy, and education level and health literacy, has been well-documented in numerous other studies (Furnham & Swami, 2018; Institute of Medicine, 2004). It is possible that the small size and high levels of education within the current sample make it difficult to discern these relationships.

It is interesting that parents with higher education levels, who tended to access more independent information sources, also reported lower levels of satisfaction with the information they had acquired. This finding suggests that simply accessing information was not sufficient for parents to feel they understand ADHD, and furthermore, that accessing too much information in the absence of clinical guidance may have resulted in parents feeling dissatisfied and confused. Thus, although an abundance of ADHD content is available for parents who wish to seek it out,

there is room to improve the formulation and delivery of informational materials so that it better aligns with parents' needs. This finding reinforces the importance of using a Knowledge to Action approach in developing knowledge translation tools, such that informational materials are developed, such they meet the characteristics and needs of their target audiences.

In terms of comfort making treatment decisions, parents in this investigation clearly articulated their preference to collaborate with their health care providers when making treatment choices, regardless of their level of ADHD literacy. This finding is consistent with the predominant expectation of shared decision making as a fundamental component of current health care delivery (Elwyn et al., 2012). ADHD literacy figured more prominently in parents' feelings of decisional conflict, however, such that parents who felt more literate about ADHD experienced less decisional conflict about their choice of ADHD treatment. This finding is consistent a host of studies showing that parents who feel informed about ADHD are more likely to have a positive attitude about and adherence to ADHD treatments (Bai et al., 2015; Monastra, 2014; Kolko et al., 2014), and provides further support to the broader finding that mental health literacy is highly influential for individuals' engagement with mental health care in general (Hadlaczky et al., 2014).

Notably, parental education level had an independent positive association with decisional conflict, even after controlling for level of mental health literacy as well as the severity of their children's ADHD symptoms. This is an interesting finding, and not altogether surprising since parents with higher education levels also reported lower levels of satisfaction with the ADHD information they had accessed. One potential explanation for these negative associations might be that parents who have higher levels of education also have tendencies to be highly discerning and critical of the information they read, and similarly be inclined to overthink their treatment

decisions. Alternatively, or additionally, it is possible that the truncated educational range of this sample prevented a full exploration of the relationship between education and decisional conflict, as well as between education and information satisfaction. For instance, education might have a curvilinear relationship with these latter variables, such that parents with a middle range of education report the most confidence with the information they acquire and with their treatment decisions, while parents with very low or very high education levels are less satisfied in these areas, albeit for different reasons. Additional research with a more diverse sample will be helpful in greater understanding of this topic.

Overall, results of the current quantitative strand of this study indicate numerous areas ripe for further investigation. Parents clearly wish to learn about practical strategies for managing the behavioural and emotional sequalae of childhood ADHD in daily life, and they clearly wish to access ADHD information from clinical sources. It is also clear that parents who feel that they understand ADHD feel less conflicted about their treatment decisions. Less clear, however, are the reasons why parents find it difficult to access the information they deem important, and why parents often feel dissatisfied with the information they can access. Understanding of these latter topics is critical for the development of more effective parent-focused knowledge translation tools.

Chapter 4: Qualitative Data Strand

The qualitative strand of this mixed-methods study consisted of semi-structured individual research interviews where parents shared their experiences learning about ADHD and making treatment decisions for their children. The objective of this strand of the study was to better understand the information needs and preferences of parents without any preconceptions or pre-existing hypotheses. I was interested in learning about parents' opinions and perceptions based on their experiences within our local health-care context (see Chapter 3 for previous discussion of this point). I was particularly interested in understanding *why* specific types and sources of information are important and meaningful for parents, and *how* parents gain access to and interact with various sources of information to learn about ADHD. I was also interested in *what* kinds of experiences promote parents feeling comfortable with their treatment decisions. As this investigation occurred during the COVID-19 pandemic, I additionally asked parents about the impact of the COVID-19 pandemic on their experiences living with and learning about childhood ADHD.

Recruitment

Participants in the qualitative strand were comprised of a sub-sample of 13 participants who had completed the quantitative survey. Given the exploratory nature of this project, I was interested in capturing a range of parent experiences in learning about childhood ADHD. I thus chose to interview a random sub-sample of survey respondents, rather than purposefully interviewing parents who had a specific type of experience or information need. Participants who had completed their survey and who had expressed interest in an interview were contacted at random (i.e., without my reviewing their survey responses). To ensure that participants' information needs and/or treatment experiences remained relatively similar between the time of

their survey and their interview, and to minimize participant attrition, I contacted each potential participant within two to three days of receiving their completed survey and arranged to interview them shortly thereafter. The interview process was described to potential participants over the phone using a recruitment script (Appendix D), and those who wished to participate were scheduled for an interview at a time of their convenience. All interviews took place between June of 2021 and February of 2022, concurrent with my quantitative data collection.

Procedures

Interview participants were emailed an informed consent document (Appendix E) and an interview guide (Appendix F.) prior to their interview date. These materials were provided in advance to give participants the opportunity to review the nature of their participation, and to reflect on their ADHD experiences.

Due to ongoing COVID-19 public health restrictions, all interviews took place on the Zoom platform, in a password-protected and private virtual meeting room. All interviews were audio-recorded for later transcription. Before each interview began, I verbally reviewed the informed consent document with each participant, and I obtained relevant contact information for those participants who wished to receive compensation for their time (a $45.00 gift card to a local grocery store) and/or study findings. Each participant was verbally reminded that they could discontinue the interview at any time without penalty. After ensuring all questions were answered, I started the interview recordings.

I designed my interview protocol such that participants had an opportunity to reflect broadly on their experiences learning about ADHD. All interviews began with a central question: "What has been your experience in learning about ADHD?", with follow-up questions based on the comprehensiveness of participants' responses to this broad question.

Research Strategy

I chose to analyze my qualitative data were using reflexive thematic analysis. Originally outlined by Braun and Clarke (2006), thematic analysis (TA) is a method for searching across data sets for repeated patterns of meaning (themes) in a manner that minimally organizes data. Several types of TA have evolved since it was first introduced, including coding reliability, codebook, and reflexive TA (Braun et al., 2019; Braun and Clark, 2020). The former two of these TA types are considered to take a structured approach to coding, with themes often determined in advance of a full analysis and guided by a coding frame based on specific descriptions and data examples. In reflexive TA, codes are not fixed at the start of the analytic process and do not aim to summarize content. Instead, themes evolve through an organic and iterative coding process across an entire qualitative data, resulting in themes that are grounded in data and interpreted through the lens of the researcher (Braun et al., 2019).

Depending on how themes are coded, reflexive TA can operate across a range of theoretical frameworks, including "contextualist" approaches which address how individuals make meaning of their experiences as well as more descriptive and applied approaches, thus making it well suited for mixed-methods research (Braun and Clark, 2020). Decision points for coding in reflexive TA include the choice of analysing an entire dataset or a detailed account of one aspect of the dataset, the decision to code inductively (i.e., without using research or theory to guide code development) or theoretically (i.e., coding is driven by a specific analytic interest), and the decision to code for semantic themes (i.e., based on surface meanings of the content) or latent themes (i.e., based on the underlying ideas and assumptions of the content). As one might expect, these decision points tend to cluster together based on the epistemological assumptions of one's research questions. Questions from constructionist perspectives lend themselves to coding

strategies that focus on specific aspects of a dataset and latent themes, whereas questions that come from realist perspectives tend to utilize coding strategies that consider meanings across entire data sets and use semantic themes. Braun and Clarke (2006, 2014) note that there are no "hard-and-fast" rules in relation to the selection of coding variants. Rather, what is most important is that the choice of methods and theoretical orientations match one's research questions.

As noted above, the rationale for the current mixed method study was to examine the determinants and impacts of parental knowledge acquisition about ADHD from two complementary perspectives: a broad quantitative perspective examining the associations of various factors to ADHD literacy based on the existing literature, and a qualitative atheoretical perspective that explores how parents acquire understanding about ADHD based on their lived experiences. Given my interest in capturing parents' experiences from these two different perspectives, and to ensure a thorough analysis of each of my datasets, I felt that reflexive TA would be best suited for analysis of my interview data due to its inductive and open-ended approach to coding. Accordingly, I used line-by-line semantic coding for my qualitative data across my entire qualitative dataset, without consideration of pre-existing themes.

Interviews were audio-recorded and transcribed verbatim by me or by a research assistant with previous experience with transcription. Interview transcripts were analyzed in accordance with the 6-stage TA process outlined by Braun and Clarke (2006). These steps included: (1) familiarization with my data, including reading and re-reading transcribed data, and noting initial ideas; (2) generating initial codes across the entire data set; (3) searching for themes, whereby codes were collated into potential themes; (4) reviewing potential themes to see if they work in relationship to coded extracts across the entire data set and revising as necessary; (5) defining

and naming themes, including identifying the essential elements within each theme and analysing the content within them (i.e., explaining what is of interest within the theme, and why); and (6) producing a final write-up of content.

I made decisions regarding sample size based on recommendations from Braun and Clarke (2019). In their recent paper, they discuss philosophical and pragmatic difficulties with the traditional concept of data saturation, as it implies a complete and objective "end-point" understanding of data which is often at odds with the epistemological framework of TA, particularly when a researcher is not coding data based on pre-existing themes. Instead, they explain that sample size ought to reflect a variety of factors, including the breadth and focus of the research question, the scope of the research project, the social diversity of participants, the experiential diversity of participants, the methods of data collection and demand placed on participants, the depth of data provided by each participant, and pragmatic factors related to time and resource availability. I considered each of these factors as I interviewed my participants, ultimately deciding to end my qualitative data collection based on a combination of factors that included in depth data from my existing sample, limited new data that I was gaining from interviews. I also considered pragmatic factors relating to the lifting of COVID-19 pandemic restrictions and the resulting changes in the way parents were experiencing their children's ADHD symptoms.

Trustworthiness

I used a combination of strategies to establish reliability and validity in my data analysis process, as outlined by Creswell and Clark (2018) and Hesse-Biber (2017). To help ensure reflexivity and that I was considering alternative interpretations to my participant's experiences, I developed my themes in collaboration with a research assistant who had previous experience in

qualitative data analysis. We coded a random subset of 5 transcripts using line-by-line descriptive codes that were intentionally close to text, and these codes were combined into conceptual themes through mutual discussion, and through regular meetings with a member of my research team who has expertise in qualitative data analysis. I then coded across my entire data set using these themes, revising and refining themes when appropriate, before finalizing and naming my final themes. I kept a research diary where I detailed and explained my analytic decisions. I also took field notes immediately after each interview that outlined my initial impressions, and I reviewed my field notes for points of convergence and/or divergence as I developed my themes. I have also included verbatim participant quotes to exemplify and provide context for my themes.

I additionally chose to use the strategy of "member-checking" after I finished analyzing my qualitative data, whereby I invited participants to share their thoughts on my analytic ideas and conclusions. Although member-checking is not required within reflexive thematic analysis, and I did not change any of my conclusions because of participant feedback, I felt that given the overall pragmatic framework and applied objectives of this project, that it was important to know if I was capturing the meaning of participants' experiences in a way that made sense to them.

Consenting participants received a brief anonymous questionnaire via email (Appendix G), where they were asked to rate the understandability, reasonability, and level of agreement with my conclusions using a ten-point rating scale. Feedback from seven of the 13 participants indicated the conclusions were highly understandable (M = 8.8; SD = 2.6) and highly reasonable (M = 9.5; SD = .78). Participants also indicated a high level of agreement with study conclusions (M = 9.5; SD = .78)

I practiced reflexivity throughout the research process, recognizing how my own social location, attitudes, and previous experiences impacted the knowledge and the mutual understanding that was created through my interviews with each participant. I recognized how these have the potential to shape my interpretations of what I hear.

In my previous employment as a school psychologist, and current employment as a psychological associate providing care to children and adolescents experiencing a range of mental health difficulties, I have often worked with parents whose children have diagnoses of ADHD. I currently work in a setting that operates within a traditional medical model, where medications are typically seen as a standard part of providing ADHD care. I have witnessed a wide range of responses in the way that parents manage their children's needs, some of which are more successful than others. I was careful to stay aware of my personal opinions and biases as they pertain to ADHD and its treatments, and I was careful to ensure that these did not find their way into my interactions with parents. I did not want my experiences or personal beliefs to impact the course of our conversations, or my interpretation of conversations.

I was cautious in my disclosures to parents about my previous experiences working with children who have ADHD diagnoses. Some parents asked me why I was conducting this study or if I had personal experience with ADHD. I was candid and forthright with participants if they asked these questions, sharing how my previous experiences have sensitized me to the many challenges facing parents after an ADHD diagnosis, and that I would like to find ways to make navigating an ADHD diagnosis easier for parents. I was careful to minimize any perceived power differentials, as I did not want parents to feel that I was looking for certain types of responses during their interviews. I would clearly explain to parents that all their perceptions and opinions were important.

I shared some commonality with my participants in that I too am a parent, and I could identify with their care and concerns for their children's well-being. However, I was cognizant of the fact that I am privileged in many aspects of my life, including the fact that I am not a visible minority, that I have had access to higher education, and that I have financial security. I am also cognizant that my grown children do not have ADHD diagnoses and that my family has not faced extensive psycho-social hardships. Thus, while I have very deep respect for parents and feel strongly about helping parents become more empowered when seeking mental health care for their children, I recognized that my personal experiences in raising children and in responding to their needs was very different than theirs. I was careful to remain encouraging and empathic in my conversations with parents, so that parents could feel at ease sharing their stories with me.

To help practice reflexivity, I documented my personal reactions to interviews in reflexive memos and consulted with members of my research team throughout my qualitative data collection, thus giving me an opportunity to reflect on how my personal attitudes shape my understanding of my data. I cannot remove my personal history and attitudes from my identity as a researcher; however, by staying aware and reflective of my personal history, I can help to minimize the influence of my history on my interpretation and analysis of parents' experiences.

Qualitative Results

Participant Characteristics

All the interview participants identified as Caucasian, and one additionally identified as Jewish/Caucasian. All interview participants were female, and one participant had her husband contribute information during part of her interview. Participants ranged in age from 29- to 59-years of age (average age 40.1 years). Ten of the 13 participants were raising their children in 2-

parent households. Education levels included three participants with high school diplomas or GEDs, four participants with college or technical degrees, four participants with bachelor's degrees, and two participants with master's degrees. Annual household income levels included two participants within the $40,000 - $60,000 bracket, three participants within the $60,000 - $85,000 bracket, six participants within the $85,000 - $125,000 bracket, and one participant reporting annual income of $125,000 or higher. One participant chose not to disclose their income. Participants' children ranged from 6- through 11-years of age (average age: 8.2). Nine of the children were identified by their parent as boys, and four were identified by their parent as girls.

Thematic Findings

My thematic analysis identified three common themes that were prominent for this sample of parents as they learned about childhood ADHD and made treatment decisions: (1) abundant information needs (2) learning through multiple pathways; and (3) responsive systems build treatment confidence. Although not part of my primary research objectives, my analysis also recognized important contextual elements of (4) stressors and burdens; and (5) the impacts of COVID-19 and ADHD.

Theme 1: Abundant Information Needs

In general, parents shared their need to access a broad range of information about ADHD, expressed by statements such as: "what I needed to learn about ADHD was everything" and "as a parent, it's just helpful to have all the information". Within this general need for information, parents conveyed several aspects of ADHD information that mattered for them. These included subthemes of (a) improved content about ADHD; (b) improved relatability in

information about ADHD, and (c) improved distribution of ADHD information. Representative quotations for each of these areas are provided in Table 10.

Improved Content. Parents shared how specific types of ADHD-related content could be helpful for them, including information to help them recognize ADHD symptoms, information about how to respond to various ADHD-related behaviours, and information to help them navigate treatment systems.

Recognizing ADHD Symptoms. Parents explained how they wanted information about how to recognize the many kinds of symptoms that are typical of ADHD. Parents whose children exhibited seemingly obvious ADHD symptoms such as impulsivity, inability to focus or concentrate, and hyperactivity struggled to differentiate between "normal" levels of behaviour versus a need for clinical intervention. Parents also wanted more information about inattentive symptoms of ADHD, noting how ADHD could be overlooked and misunderstood when it wasn't "in your face", or when it was "subtle". Parents similarly shared that they sought information that promoted recognition of the executive skill challenges that commonly occur in ADHD, including difficulties with motivation, organization, and time management. Parents also wanted better information about how ADHD presents in girls, noting a lack of information on this topic.

Consistent with broad diagnostic trends and the high rates of psychiatric comorbidities and complex family histories that often occur with ADHD, many parents felt they needed better information about potential co-occurring conditions and their interplay with ADHD symptoms. Participants referenced a range of additional suspected or confirmed diagnoses for their children, including autism spectrum disorder, anxiety, intellectual disability, and prenatal substance exposure, and the symptoms of these additional conditions made it hard for them to understand what their child needed. Parents also expressed a need to better understand how psychosocial

factors contributed to their child's ADHD symptoms, particularly when their children had experienced adverse events that might be "playing into" their behaviour.

Responding to ADHD Symptoms. In addition to wanting information about recognizing ADHD symptoms, parents also shared their need for more information about how to respond to their children's ADHD symptoms, and how they could help their children. Statements such as "the most important thing for me was really to understand what my daughter was going through and how to help her", "how I can help my child" and "I was trying to find information on ways to help him" were frequent. This desire to find information on how to respond to ADHD was multi-faceted, with parents expressing the need for information about a variety of ADHD treatment approaches and types of service providers.

More information about psychosocial interventions for ADHD was a common discussion point for parents, and parents listed a wide range of behaviours where they thought strategies would be helpful. Examples of this included managing tantrums, sibling conflict, inability to sit still, and creating routines. Even when parents were using ADHD medications, they frequently expressed a need for hands-on and functional approaches to handling these types of daily household challenges. Parents also shared how they wanted information on how they could help their children learn better, and they specifically wanted information about the types of educational strategies that could be most helpful for their children.

Parents also wanted more information about ADHD medications, including a range of topics that included better information about how medications work, how medications can be explained to children, how to understand different medication options, outlining of the trial-and-error process of finding the right medication, and managing side effects. Parents expressed that better understanding about medications could provide a more realistic understanding about what

to expect when medications are introduced, and it could also help to debunk some of the worrisome and stigmatizing misbeliefs about ADHD medications in general.

Navigating Systems. Parents wanted information on how to access treatment providers so they could obtain effective ADHD treatment for their children. Parents shared experiences of new and unfamiliar systems, and unfamiliar processes through systems, and they wanted information that could help them navigate their search for appropriate ADHD supports. This need for content on systems navigation occurred throughout the course of parents' diagnostic and treatment journeys. At the outset, parents recounted their need for better information about where and how to ask for an ADHD diagnostic referral, and what the referral process would look like. After receiving an ADHD diagnosis, parents expressed a need for better information about specific types of ADHD treatment providers, so that they knew "who could do what" to help their children with various types of problems.

Importantly, while parents articulated how they wanted information about specific ADHD topics, they also expressed how it was hard to know what they needed to know. This made it difficult for them to navigate information altogether and contributed to a sense of worry and unease that they might be missing important information that could potentially help their child. This sentiment was well-captured by the parent of a 7-year-old child (participant 7), who expressed this concern is follows: "It's hard to navigate when you aren't really sure which route to go. I think that's probably the biggest thing. I know I'm looking for help. I know I need it somehow, but I don't know what I need".

Improved Relatability. While parents' experiences clearly conveyed a need for specific content about ADHD, their experiences also suggested that qualities of existing information hinder their ability to understand and make sense of the material they do receive. Within this

subtheme, parents described how alternative formats for ADHD information, development of audience-specific information, and more relevant ADHD information could make ADHD informational materials more relatable and helpful.

Alternative Formats. Parents shared how they were confused by overly technical and scientific language when reading about ADHD, and how they wished information could be presented in "layman's terms" or in "dumbed down language". Parents expressed a need for information that wasn't lengthy or voluminous, and which made use of alternative and creative formats to explain ideas and concepts in simple terms. Parents felt that the use of videos or graphic novels could convey information about ADHD in a matter that held more emotional resonance and salience for viewers, relative to material that is highly text focused. Parents additionally mentioned how visuals, infographics, and charts could be helpful adjuncts and/or replacements for traditional written materials. Parents also suggested that video-based social media platforms, such as Instagram and TikTok, could convey information about ADHD in a brief yet highly engaging format, noting that the proliferation of the Internet as an information source in general made this a natural place to look for ADHD information.

Audience-Specific Materials. In addition to being less technical, parents also shared how they wanted information crafted for and meaningful to specific target audiences. For instance, parents who themselves had ADHD found it difficult to engage with conventional ADHD informational materials due to their own shortened attention spans. They suggested that ADHD content be presented in a way that would be easier for them to digest, included the creation of ADHD informational materials that were short, that presented information in "nuggets", and which used colour and graphics to make the material more visually interesting. Parents also expressed that they wanted informational materials that were specifically geared to the

perspectives of different family members, such as dads and siblings. Finally, many parents shared that they wanted child-focused ADHD information so that they could help their children understand what it meant to have ADHD. Although some parents mentioned that they were not successful in finding child-friendly materials, parents who found such material described positive results including their children's improved medication compliance and self-understanding.

Relevancy. In addition to language-based concerns and monolithic perspectives on ADHD that hampered relatability, parents also shared that they struggled to find ADHD information that felt relevant for their needs. One aspect of this entailed the heterogeneous nature of ADHD, with parents sharing that ADHD had many different "personalities" and that informational materials they had accessed often didn't capture their experiences or didn't feel relevant for what they were going through. They also shared that recommendations often didn't match the qualities or developmental needs of their child.

Many parents offered suggestions for how information about ADHD could be made more relevant to their experiences. A desire for anecdotal and personal information that captured a range of experiences and perspectives was consistently voiced by parents, with parents expressing that they would like to hear from people who were in similar situations as them. They expressed a desire for first-person accounts about parenting children with ADHD, such as through stories and videos, as well as learning about ADHD directly with other parents. They expressed a wish to access trusted ADHD informational material that was less "clinical", which went beyond basic facts and offered an experiential and deeper understanding of what it meant to live with ADHD. The following statement from the parent of an 11-year-old child (participant 2) stated the following, which captures this sentiment:

> I think that to me, the facts are out there. Like, I could get the facts. These are the medications. This is what's recommended. These are signs. These are symptoms. To me that was all out there. So I felt I got all of that. So how the personal makes it better... I guess just because each child I know is different. I know my child isn't going to specifically fit the general of what happens. So just, to get a variety of different experiences I think gives me a better picture.

Improved Distribution. As they recounted their experiences learning about ADHD, parents shared how they desired improved distribution of ADHD materials so that they could find trustworthy information more easily. Numerous parents explained that it was easy to access information about ADHD via the Internet, and they made many references to "just googling it", "going down rabbit holes" and "doing internet research". However, despite its abundance, parents shared how internet-based information had limited utility in meeting their information needs. Many parents described being "overwhelmed" by the amount of information available and having to piece together multiple articles and websites, and of having to make sense of conflicting data. They shared difficulties navigating dense medical websites. They shared concerns about misinformation and not knowing what to believe from online sources such as blogs. The parent of a 10-year-old child (participant 13) summarized these concerns as follows: "It's great I can Google whatever I want and I could find, you know, misguided information all over the Internet. And hell, if you look up ADHD hard enough, you probably link it back to aliens". Parents conveyed ways in which trustable ADHD information could be more effectively distributed within community settings, as well as within health care systems.

Community Distribution. Parents shared how that they wanted better community-based distribution of ADHD information, similar to how information pertaining to childcare and

physical health is distributed within the community (e.g., breastfeeding, smoking cessation). They felt greater community distribution of information about ADHD might bring increased awareness and normalization of the topic. Parents discussed how they wished they could find ADHD information at trusted community locations, such as at pharmacies and schools. Parents expressed that schools could be particularly useful for providing information about ADHD, noting how they were natural touchpoints for parents and could also thus provide more equitable access to ADHD information. Parents also felt that community access to trusted information would be helpful because it would reduce the sense of passively waiting for an appointment, and it could be a constructive and helpful use of time.

Health-Care System Distribution. In addition to providing trusted information within community locations to improve general awareness about ADHD, parents also shared how ADHD information could be better disseminated within the health care system. Parents cited the point of diagnosis, and/or within diagnostic assessment reports, as natural timepoints where it made sense to provide informational materials and psychoeducation about ADHD. Parents also reported how they wanted their care providers to give them trusted recommendations for where they could go to learn more, including books or websites. Unfortunately, however, parents consistently reported limited information distribution within the health care system, leaving them feeling as though they needed to fend for themselves to learn about ADHD. This sentiment was keenly expressed by the parent of an 8-year-old child (participant 4) who had received a diagnosis of ADHD through his primary care provider, and who was awaiting additional psychiatric consultation:

> I feel like there should be somewhere from the health care system where we can access information that we need, because right now I'm reading random mom blogs. I shouldn't

be able to get my best information from Tik-Tok. I have more trust, I'm not sure why, but I have more trust in our health care system than I do random strangers on the Internet, even though I get better information from random strangers on the Internet than my health care system right now.

Table 10

Representative Quotations for Theme One: Abundant Information Needs

Subtheme	Quotation
Content, Recognizing Symptoms	My kid is like, doing circles and donuts from like five am to bed. So yeah, it was like, I don't know if this is normal or not (P1)
Content, Recognizing Symptoms	Understanding that ADHD has to do with organization and motivation and timekeeping and just sort of every area in that executive functioning piece, I think it's just helpful to know that that's kind of all part and parcel (P2)
Content, Recognizing Symptoms	I found a huge lack of resources for girls and in learning about how there are some gender differences in how ADHD can present in kids. So that was really frustrating (P3)
Content, Recognizing symptoms	I'm trying to figure out whether or not it was a bunch of comorbid things or whether or not it was multiple different forms of symptoms coming from the same thing (P4)
Content, Recognizing Symptoms	My daughter's also been through a lot in her life too, it's kind of been hard on her. I don't know if maybe that's part of the reason why she acts the way she does sometimes (P5)
Content, Responding to symptoms	Trying to find information on ways to help him, but don't involve medication. It's basically, it was just like the life hacks, the little things that help make the day-to-day frustration less frustrating (P6)
Content, Responding to Symptoms	I had always been seeking out ways to help my child that didn't involve medication, because regardless I would have done both if I had chosen medication (P3)
Content, Responding to symptoms	So I'm not really sure what I was looking for other than give me some new idea on how to calm the tantrum down. Give me something you know, on how to help her know right from wrong, but it's hard (P7)
Content, Responding to Symptoms	What kinds of things would be helpful. It doesn't matter what this is labeled. If this is what's happening, here is some things we can do to support this (P2)
Content, Responding to Symptoms	I guess it's more or less strategies to help them just to be able to concentrate and to do the work that he has to do (P8)
Content, Responding to Symptoms	He may be in school at some point and I need to know what to ask the teacher for when he goes to school, or if he goes to school (P9)

Content, Responding to Symptoms	I didn't know a lot about medication. There are so many options out there. I was really overwhelmed when I tried to look into it. (P7)
Content, Responding to Symptoms	There needs to be more vocalization from people who are on pharmaceuticals, about how it's actually changed things for them. There's very little out there about how it changed it for them taking it. (P4)
Content, Responding to Symptoms	I don't think there's enough information about the medication that is out there for parents to make informed choices (P10)
Content, Responding to Symptoms	I think it's good to know that it's not altering the brain somehow kind of thing. It's kind of taking your natural stuff that's there and just helping it to work better. It can reduce some of that stigma.(P2)
Content, Navigating Systems	How long could it potentially take? Who should you start with? What is the referral, how to ask for a referral? Some basic, basic information. Because most people don't go to the doctor unless it's like a cold or an infection. Most people don't ever have an experience with what these processes look like (P4)
Content, Navigating Systems	Am I seeing a psychologist for that? Do I see an occupational therapist for that? Like, I don't know what I need. I don't know which is the right avenue (P7).
Content, Navigating Systems	In the beginning, I didn't even know that the pediatrician could give the medication. I didn't know where to look, where to go, who can help me. I felt lost (P11)
Content, Navigating Systems	The barrier is just knowing how to access the information and access to professionals (P3)
Relatability, Format	It's scientific like stuff, it didn't really, it didn't really explain that that's, that's what he needed. Or at least not in a way that I understood it (P6)
Relatability, Format	Not having to read through a lengthy thing or take a whole course or whatever to learn stuff, but being able to kind of have infographics or cheat sheets and those kinds of things that give the basics that make it easier for people to be able to pick up on that stuff (P2)
Relatability, Format	Tik Tok or Instagram or Facebook…if people are going to be on them, then roll out the information that way and like fun, little cute, bright graphics with like bubbles or whatever to break it down (P1)
Relatability, Format	There are few descriptive words you can show somebody visually. And you can get them to actually have an emotional response by seeing something, whereas words are only words. You can't get someone to have an emotional response and emotional attachment to it. (P6)
Relatability, Audiences	Like myself having ADHD, I like little nuggets. Like I can't read a novel. I could read a magazine where it's like bite sized pieces of info, and especially if they're really bright and colourful.(P1)
Relatability, Audiences	If I could find the right podcast for my husband, maybe that. Maybe he would hear something in there that might spark something for him that might be like oh, I can try that, or hey that sounds like her. (P7)

Relatability, Audiences	We actually found a children's book at the library that was really great for explaining it to him. So that him taking his meds everyday made sense (P6)
Relatability, Audiences	He was so pumped up to read it because it was in a cartoon format and it was like, my brain has ADHD. And he loved it. And he's like, this is what my brain does? And I was like, yeah, buddy. And it was really engaging for him and it was a really cool book (P1)
Relatability, Relevancy	There are so many different attributes that go along with ADHD. So many different personalities of ADHD that you can find. It's so hard to find the right part that you're needing help with or that you're looking for guidance on (P7)
Relatability, Relevancy	It's very frustrating to try and get the correct information pertaining to your situation. I've always thought that when you've met one ADHD child, you've met one ADHD child. So with them being different, it's not a one size fits all (P10)
Relatability, Relevancy	The way that I would learn it would be attending some sort of class with people who are in the exact same position that I am in trying to figure out paths (P8)
Relatability, Relevancy	Personal experiences, either written stories or videos of just what parents' experiences were for their kids or kids directly saying what their experiences were. Just that part I kind of would have liked (9)
Distribution, Community	I think it should be just as commonplace as giving out information for breast feeding. Or how to eat nutritious when you're pregnant. Like there's tons of stuff like that. Why is there no prevention to the issues that could happen along the way in diagnosis for ADHD or ADD or behavioral disorders or mental health issues (P7)
Distribution, Community	Have an ADHD event, you know what I mean? There's the Bell Let's Talk and it's a designated day to talk about it. I don't even know if there's a date of let's just talk about ADHD. Let's get some experts in, make it virtual. Something like that would be amazing (P1)
Distribution, Community	I would say school would be the first place. The school is constantly sending home educational material on how to pack healthy lunches and mental health in general and things like that. But I haven't seen a lot around ADHD (P2)
Distribution, Community	So access and having the same information available for every school. For every school psychologist (P3)
Distribution, Community	Knowing the options beforehand of all these appointments, just to be able to do my own research on them instead of waiting weeks for someone to tell me what options there are (P8)
Distribution, Community	It gives somebody something to do rather than just sit around and stew about it and feel like they're being ignored and dismissed (P4)
Distribution, Systems	There was no introduction to even just a pamphlet that says you're not alone. You might be walking a new road, but it's a road that that we've walked many times and we're going to support you through it and it's going to be OK. There was nothing. I would have some documentation, something that's nonclinical, that talks in regular language that's like given

	to you at diagnosis that basically says it's going to be OK. These are the things you should know (P12)
Distribution, Systems	I think if information was just given from more sources, like if her family physician maybe had information on that, if it was included in some of the material that even came with the report, some dedicated sites or book suggestions (P3)
Distribution, Systems	Like a pamphlet or something they hand you, like they do when you get your vaccines. They hand you a pamphlet of information on it. I would have something like that handed to me by a doctor saying these are trusted resources that you can go and learn and read up on it (P8)

Note: Each of the 13 parent participants are identified in parentheses, P1 through P13.

Theme 2: Learning Through Multiple Pathways

Parents' experiences learning about ADHD were broad, including multiple and often interactive pathways of information that each contributed to their overall understanding about ADHD. These included subthemes of (a) personal pathways; (b) community pathways, and (d) health care pathways. Representative quotations for each of these areas are provided in Table 11.

Personal Pathways. Parents shared several ways in which personal factors and characteristics helped them learn about ADHD, including intra-individual characteristics and aspects of their social location.

Intra-individual Characteristics. Parents recounted a variety of internal, individual characteristics that they felt helped them learn about childhood ADHD. Even before their children were diagnosed, parents referenced their personal intuition and "gut feelings", and that they could sense that their child was not developing in a neurotypical fashion. Parents' internal senses of something "off" were powerful catalysts, triggering them to search for additional information so they could better understand and support their child.

As well, parents shared how certain of their personal attributes helped them further learn about ADHD. Parents who described themselves as independent learners and readers felt they were able to seek out information to assist their learning. Characteristics such as being vocal and

unintimidated to ask questions made it easier for parents to learn about ADHD from their care providers. Parents also expressed that they made a conscious decision to take control of their information needs, in a manner resembling self-efficacy or having an internal locus of control. An illustrative example of this sentiment is shown in the following statement from the parent of a 9-year-old child (participant 3): “And then I just thought, no, you’re not powerless, you’re the mom, you’re her mom, so you’re going to find information. And I did it, yeah. But it was really tough”.

Social Location. The role of personal factors in learning about ADHD was also evident through aspects of parents’ social locations. Even within this relatively well-educated and financially secure sample, parents noted the high monetary costs associated with learning about and then treating ADHD, including costs for assessment, private therapies, reading materials, and medications. Parents shared a sense of luck and gratitude when they could pay for services, and they expressed appreciation for the hardships that might befall parents who had to wait to access ADHD supports through the public health care system.

Parents’ personal and social histories also served as a pathway for learning about ADHD. Parents who had pre-existing familiarity with research, with medical systems, and/or other child-focused systems (e.g., child welfare, education) felt that this facilitated their ability to seek out information and gain access to resources. Similarly, parents who had previously sought mental health treatment, either for themselves or for other family members, also felt that they knew what to do when they wanted information or support for their children. The parent of a 7-year-old child (P7) provided a comment that illustrates how social history influenced the way she and her partner have each been able to learn about ADHD:

> I mean, like I was an EA. I get the education lingo. I now work in a hospital. I get the medication lingo. And to break it down, he's so not. Like we own a mechanical business. Like, he's all about putting parts together and stuff. And it's a hard delivery if you're not in that field or you have no connection of any sort to education or medical.

Community Pathways. Parents learned about ADHD through interactions within their community, including connections with peers as well through connections with their children's schools.

Peer Connections. Interactions with peers provided information to parents in several meaningful ways throughout their ADHD journeys. Parents shared how informal conversations with friends and family members provided them with meaningful frames of reference for their children's behaviour, helping them recognize when their children were experiencing developmental challenges and clinical intervention. Peer connections continued to play an important role for parents after an ADHD diagnosis as well, with parents often describing that they purposefully sought out relationships with other parents whose children also had ADHD via social media and internet support groups. One parent of a 6-year-old child (participant 12) described social media as a "conduit" to finding other parents, stating: "I've started lots of conversations with other moms saying hey, I noticed you are a member of this group. Maybe we could connect some time to talk a little bit about what we're going through and stuff".

Parents found relationships with other parents experiencing childhood ADHD to be meaningful on a variety of levels. Many parents explained that it was helpful to talk with parents going through a similar experience because they could share opinions about ADHD resources, such as specific reading materials and clinician names. Other parents accessed peers when they wanted to hear other parents' perspectives and experiences on specific topics, such as how to

parent multiple children with different needs, manage sibling relationships, or whether to pursue private or public treatment providers. Many parents specifically turned to peers to gain information about ADHD medications, or to supplement information given to them by health care providers. Parents expressed that they found parent-to-parent conversations about their children to be powerful learning experiences, and that they were able to relate to the information and experiences shared by other parents in ways that couldn't be captured via other information sources. Parents appreciated the interactional nature of social conversations relative to the "one-sided" information presented in reading materials. They also appreciated how information from other parents felt more relatable and practical than information offered by health care professionals.

In addition to providing a personal and highly relatable lens on ADHD, information shared between parents also provided a sense of connection and shared experience. Parents shared how they felt less alone when they heard the stories of other parents going through the similar struggles, and they described a sense of acknowledgement and relief to know that other parents also found it difficult to parent a child with ADHD. An illustrative example of this sentiment is conveyed by the following statement from the parent of a 6-year-old (participant 12):

> Occasionally, there's a post from a desperate parent and I'm like, yup. I read it and at least it's some kind of acknowledgment that having a child with ADHD is challenging from a parental perspective and that so many of these parents are just like me trying to do the best they can.

School Connections. In addition to learning through peers, parents also shared how their connections with schools helped them learn about ADHD. Parents explained that school

difficulties were often their first signal of ADHD-related symptoms, and that conversations with school staff prompted them to seek consultation from a health care professional. School personnel additionally facilitated children's ADHD diagnoses through giving collateral information to health care providers and giving parents feedback on how their child was responding to ADHD medications. For some parents, school personnel became valued sources of ADHD information as well, providing psychoeducation and/or helping parents access ADHD-related resources.

Health Care Pathways. Parents shared how their connections with health care providers and health care systems were a vital component of their ADHD learning. Even within this largely community-recruited sample, every parent shared that they chose to seek advice from health care providers once they became concerned about their children. Interactions within the health care system helped shape parents' understanding of ADHD in several ways, including through their relationships with primary care providers, the expected provision of expert knowledge, and provision of diagnostic clarity.

Primary Care Providers. Primary care providers, such as family doctors and/or pediatricians, were a crucial information pathway for parents. They served as an entry point into the health care system and access to clinical specialists. Parents described their pediatricians as their "first line" or "that first phone call" when they started to have concern about their child's development, and how they relied on their primary care providers as guides through the health care system. An illustrative example of this is provided in the following statement from the parent of a 10-year-old child (participant 13): "So it all starts with health care professionals, like the doctor being able to actually point you in the right direction".

Parents recounted a range of experiences with their child's primary care doctors which shaped the trajectory of their learning. Some parents were fortunate to have doctors who recognized their concerns, either by providing a diagnosis of ADHD or referring them to specialists who could help them better understand what was happening for their child. Alternatively, other parents shared how their experiences with primary care doctors became barriers to understanding because they were seen by parents as unwilling or unable to understand the nature of their concerns, or dismissive of their concerns altogether. An illustrative comment of the key role of primary care providers is seen in the following statement from the parent of a a 10-year-old child (participant 13):

> This first level of care, the family physician. It almost like stonewalls people into getting the proper care, because if that family physician at any time messes up cause people are fallible, then you lose an entire section of care in the health system because you didn't make it past that first step.

Expert Knowledge. In addition to turning to primary care providers as an access point for additional interventions, parents also shared how they valued the expert knowledge of all types of clinical care providers. Parents shared how they utilized specific sources of information based on recommendations from clinical specialists, including purchasing books, accessing specific ADHD websites, and trialing specific types of behaviour and parenting strategies. Parents also shared their deference and trust for information provided to them by clinical sources. An illustrative example of this sentiment is conveyed in the following statement from the parent of a 7-year-old child (participant 7) who had been searching for information about ADHD: "I was really overwhelmed when I tried to look into it. So I just stopped because I don't want any of this to skew my conversation with the pediatrician."

The high value of information from clinical care providers was further underscored within the experiences of parents who felt their care providers did not give them enough information about ADHD. Their experiences conveyed a sense of expectation for health care providers to provide them with high-level knowledge and clinical guidance, and parents expressed disappointment and frustration when this did not occur. This sentiment was captured within the following statement from the parent of a 10-year-old child (participant 13):

> That's the most frustrating part. The medical professionals have the true information. They have all the tests. They have all the research. Why do I have to go and pretty much sign up online to join a doctor forum to get the same information that should be available to us with our free health care system?

Diagnostic Clarity. Of the information provided to parents through health care providers, parents shared how diagnostic clarification became a pivotal moment in their ADHD journeys. Diagnosis mattered to parents because it provided an explanation for their children's difficulties, thusly allowing to them to start accessing resources that could help meet their children's needs. Parents also recounted how diagnosis mattered for them at a more personal level in that it helped to confirm and normalize their concerns, providing them with a sense of validation.

Diagnosis also mattered for parents because it served as a springboard into deeper understanding and reflection about ADHD altogether. Parents shared how they thought they might have understood ADHD prior to their child's diagnosis. However, with diagnosis came a renewed sense of purpose to understand the condition. As such, parents commonly reported going back to revisit information they had previously accessed, and/or re-accessing other sources of information, such as the Internet and ADHD support groups, because ADHD information now felt more relevant for them.

Table 11

Representative Quotations for Theme Two: Learning Through Multiple Pathways

Subtheme	
Individual, Intrapersonal	My momma gut is telling me there's something more here. This is not just a cranky child that had too much sugar. This is a reoccurring issue that is indicative of something bigger and I want it investigated. And whatever it is, I want to tackle it and I want to work on it and I want to move forward (P12)
Individual, Intrapersonal	I just knew that there was something wrong. So I asked to talk to a pediatrician, a pediatric psychologist, like…something (P13)
Individual, Intrapersonal	I'm the type of person who asks a bazillion questions. So I get some information, go to the doctor and ask him to explain to me. Explain it to me like I'm a child. Why does it work? How does it work? Why do you think this? And a lot of people I know who have been through the same situation weren't confident or direct enough to do that. But I asked a lot of questions (P4).
Individual, Intrapersonal	I think partly it's my personality that I just want to learn things and totally know what I'm getting into. So, yeah, so that was good for me (P2)
Individual, Intrapersonal	We're pretty purposeful, and really love to read both of us just recreationally, so, yeah, we've bought all the books and we tried to do the work to prepare ourselves to parent a child that needs extra help (P12)
Individual, Social Location	Finances is certainly a barrier. If you're going through the public system or something, it's free. But if we're trying to supplement with therapy or doing a psych-ed assessment or something and not take years to do it, then financially, to do that, for sure (P3)
Individual, Social Location	We paid for her to get tested on our own. And I feel like we're really lucky because there's so many out there that are waiting for their referrals and that crushes me because I can't imagine the stress load on that household (P7)
Individual, Social Location	I grew up in a medical family with a parent who is a physician and one who was a nurse and just sort of understanding the kinds of professionals that are available (P3)
Individual, Social Location	I've had a pretty good experience learning about ADHD because I have ADHD and my daughter has ADHD, so it's been something I've been able to learn about, like pretty much all my life (P5)
Individual, Social Location	My husband has tics and as a child had very intense tics as well. And so I think we have a wide awareness around some of these neurotypical and non-neurotypical types of things from family experience (P12)
Community, Peers	Being a new mom, you go, well this is my normal. But then talking with other parents going, no my kid doesn't do that. No, my kids sit still, my kid can do a craft or read or focus, and I'm like, uh not mine (P1)
Community, Peers	The talking to friends. I guess it probably is the most important thing for me. So if you don't have a friend whose child also has ADHD that's gone through some of the things, you wouldn't know where to go next, right? To me, if I'm only relying on a doctor or only relying on information online...That's not enough to make the decisions (P9)

Community, Peers	I needed some validation. So I discussed the matter with coworkers and my sister and people around me. Looking for validation (P11)
Community, Peers	I've also reached out to other parents on social media, on different parent groups that have kids that have ADHD that can give you advice and stuff like that. I kind of get their input, their opinions on stuff (P5)
Community, Peers	When you're learning it from other parents and hearing their current stories and what's working for them, it stands out better than just reading it from a book that's just a one-sided perspective (P8)
Community, Peers	It's very relatable. Tips or advice and things that help kids respond better, learn better, focus better, has all been through groups via the Internet, as opposed to any medical professional suggesting anything (P13)
Community, Peers	I just felt relief knowing that we weren't the only parents out there that were thinking we were shitty parents or that we missed something. Finding other people in our circle made me feel like I wasn't raising a shitty kid (P7)
Community, School	When he started school, things started to pop up and he couldn't follow. And then I started to take him to several health practicers (sic; P11)
Community School	I don't know if they're able to say, I suspect she has ADHD or I suspect she might be autistic. But [the teacher] called me and she really pushed to say, like, I'm making some adjustments…So that's what first kind of triggered in my mind (P2)
Community, School	That's kind of where I kind of was like, OK, you know, I need to go talk to her doctor and figure this out because, you know, that's not OK behavior for her to be doing at school (P5)
Community, School	It was the school that explained it the best way. They had explained it, that his brain is like an internet browser with 50 tabs open and he can't stay on the same tab for more than a minute or two. Which is the best way to be able to explain it for me, to understand how he sees everything and why he can't do some of the things that he should be doing (P8)
Community, School	The school provided me with the resources I could look for. Like you can go to the audiologist, you can go back to the pediatrician, you can try a psychologist, you can try an OT. I guess that was the main theme from school, which actually was very important (P11)
Health Care, Primary care	I really like him a lot. He essentially said he doesn't provide a diagnosis. He can refer me. I take her to see the doctor, which I would have anyways, and then I can get her a diagnosis and then the school system can help and then she can get a referral to a psychologist (P3)
Health Care, Primary Care	The professionals that are out there not listening. Not hearing what I as a parent have to offer and have to say about our particular situation, if that makes sense (P10)
Health Care, Primary Care	He made the initial referral, wasn't terribly supportive, actually. I had to kind of go back and tell him what he needs to put in the referral so that I could actually get the referral that I wanted because he wasn't really clear on what we were looking for or, or what was needed (P2)
Health Care, Primary Care	My daughter's family doctor, for over a year I tried asking her to get a referral to see a psychologist about ADHD and stuff like that. He made me fill out the same questionnaire twice, two different times, didn't talk to me at

	all about ADHD. And then after the year I really pushed for it and I was getting mad. He finally sent me to a pediatrician that specializes in ADHD and that's where she was properly diagnosed (P13)
Health Care, Expertise	His behavior, in explaining to me, where does it come from and how we can deal with it our routine. It felt very good and again, even if I don't understand the deep thing inside, I could relate why she was telling me to do this when he does that. The connection was clear (P11)
Health Care, Expertise	I defer to him because he does this all the time. I need some professionals to tell me, help tell me what we need because I only, we only know so much (P12)
Health Care, Expertise	It's the hardest person to get to, the hardest source to get information from. But it was the best information I found (P3)
Health Care, Expertise	I kind of feel left in the dark by all these professionals that are supposed to have these answers and have the time to answer, but they don't because they've got the next patient to deal with (P8).
Health Care, Diagnosis	I was actually very happy that like something was finally like properly diagnosed, that we weren't guessing that what's different about him (P1)
Health Care, Diagnosis	We were able to take something to the school that was like an official diagnosis so that he could get the support that he needed there (P6)
Health Care, Diagnosis	Having that [diagnosis] just gives a lot more compassion and a lot more ability to respond in a calmer and a more needs meeting way, for myself. Yeah, so for me that was helpful (P2)
Health Care, Diagnosis	The big moment is finally having the diagnosis. The suspicion was finally confirmed (P8)
Health Care, Diagnosis	I thought I already knew about ADHD, because I thought about it years before. But until I actually had a diagnosis for one of my kids, I didn't realize how little I actually knew. Before it was like oh maybe oh it's no big deal. Now it's like, oh this is a big deal, I need to remember this and learn this and be able to use it (P9).
Health Care, Diagnosis	Once you get that diagnosis, then you can dive back into the Internet and start looking again (P13)

Note: Each of the 13 parent participants are identified in parentheses, P1 through P13.

Theme 3: Responsive Systems Build Treatment Confidence

When recounting their ADHD journeys, parents spoke extensively about their treatment experiences, and they shared specific aspects of their experiences that created a sense of confidence in their treatment choices. These included subthemes of: (a) collaborative professionals; (b) comprehensive treatment; and (c) effective systems. Representative quotations for each of these subthemes are provided in Table 12.

Collaborative Professionals. As they reflected on their decisions about ADHD treatment, parents described how collaboration with their health care providers was essential in helping them feel confident about their choices. The need for collaboration was expressed in several ways, including medication decisions and rapport.

Medication Decisions. One important area for parent-professional collaboration was in the decision of whether to initiate medications to treat childhood ADHD. Parents consistently expressed how the decision of whether to use medications was difficult and fraught with worry, and they frequently described the medication decision as "overwhelming" and "scary", and of being "nervous" or "afraid of making a mistake". Parents expressed how they needed physicians to collaborate with them by hearing their perspective and providing them with latitude and autonomy to make choices that met their comfort level, whether they ultimately chose to use ADHD medications or not. This link between collaborative professionals and treatment confidence is exemplified in the following statement from the parent of a 6-year-old child (participant 10):

> As a parent that you feel more empowered to make better choices for what's going on with your child because you feel supported. When you don't feel supported by your own pediatrician, it can really turn into a negative experience.

Rapport. Another aspect of professional collaboration helping build treatment confidence was shown through the experiences of parents whose children were continuing to struggle despite receiving treatment for their ADHD symptoms. Parents often recounted how ADHD treatments did not proceed smoothly for their child. They shared a range of ongoing challenges including poor school performance, ongoing behaviour difficulties, and/or poor responses to medications. However, rapport with care providers shown in the form of open and respectful

communication, making time to hear from parents when they were having concerns, and empathy helped parents persist in their chosen treatment course. Parents described a feeling of partnership and trust when they were able to work with their care providers in this way.

Comprehensive Treatment. Regardless of whether parents chose medication treatment for their children's ADHD symptoms, and even when children were responding well to medication, many parents described how they wanted ADHD treatments to be more comprehensive. They shared perceptions of over-reliance on medication as a primary treatment modality, and they also shared a wish to access emotional supports.

Over-Reliance on Medication. Parents described how treatments that were offered for their children's ADHD were primarily focused on medication, with doctors offering medication treatment seemingly very quickly. Disappointment about the over-reliance on medications was expressed by parents regardless of whether they had chosen to use medications for their child. Parents who did not choose medication expressed that it was difficult to find "holistic" approaches to managing ADHD. Parents who did choose to use medications expressed a sense of relief about reduction of their children's ADHD symptoms; however, their experiences also conveyed a sentiment that the quick offering of ADHD medications to the exclusion of other psychosocial or behavioural treatments resulted in a simplistic and incomplete understanding of their child's needs. Parents also expressed concern the easy availability of medication resulted in over-reliance on medications to curb challenging behaviours, and this might inadvertently result in the overdiagnosis or misdiagnosis of ADHD in general. Parents shared a variety of ways in which they wished that medications and other ADHD treatments could be more integrated, including clinical discussion of other non-medication treatments, and offering non-pharmacological treatments as a first line approach.

Emotional Support. In addition to a perceived over-reliance on medications relative to psychosocial treatments, parents shared how ADHD treatments were specifically lacking in the provision of emotional support for their children. Parents shared how the experience of childhood ADHD left their children feeling isolated and "broken". They described areas of secondary difficulty stemming from ADHD, including social difficulties, academic difficulties, and feelings of anxiety and depression. Parents explained how they needed counselling supports for their children so they could learn how to manage these challenges. They also shared how they wanted their children to understand that other children faced similar difficulties, so that their experiences could become more normalized and validated.

Effective Systems. As they sought support for their children, parents consistently described poor treatment experiences within the health care system, often leaving them unhappy and not confident about the care being provided. Perceptions of an unresponsive system occurred along several common lines, including a lengthy waiting process, disjointed care within the health care system, and a need for community connections.

Lengthy Waiting. Parents consistently recounted a lengthy process for obtaining an ADHD-related interventions, often extending for a period of years. Parents described that waiting began even before clinical referrals and potential diagnoses were in play, because they often recognized difficulties when their child was "too young for a diagnosis" and they were told to "watch and wait" to see how their children developed. Parents whose children were already diagnosed with ADHD and were seeking treatment also described lengthy waits for service, including significant wait times between each different referred professional as well as referrals that ultimately fell through on account of the duration of wait times. Parents shared that lengthy wait times within the public health care system often led them to seek care from private

practitioners. However, they shared similarly lengthy waits for service in the private sector, leaving them feeling alone and helpless in their ability to find care.

Disjointed Care. In addition to lengthy wait times, parents shared how ADHD specialty care within the public health care system did not meet their needs, with experiences ranging from inaccessible care to highly fragmented and chaotic care experiences. Parents shared experiences of not being able to access ADHD specialist care within the health care system, citing instances of referrals being refused, lost paperwork, and doctors who were not reachable to discuss their concerns or to follow-up on referrals. Parents who received support within the health care system described similar unsatisfactory experiences, including numerous visits across specialists without receiving answers, doctors who retired in between visits, and specialists who could not be reached following an appointment. Perceptions of disjointed and discontinuous care were also common among parents who had successfully obtained treatment within the health care system. An illustrative example of this sentiment is conveyed from the parent of a 9-year-old child (participant 3): “It’s interesting, each of the professionals who I saw didn’t necessarily highlight the importance of having like a well-rounded approach. They sort of offered their part of the solution”. This parent went on to express: “I was able to find a link for everything, but making the link more evident maybe is, is the best way of putting it”.

Community Connections. In addition to better continuity within health care systems, parents also shared how effective treatment required strong linkages between the health care system and their broader community. Schools were frequently mentioned by parents as a requisite partner in providing ADHD interventions for their children. Parents shared a range of accommodations and interventions that schools provided for their children. These included academic supports such as educational aides, extra time on tests, quiet work locations, and

assistive devices. Parent also appreciated when schools "worked with" their children rather than being punitive in response to their behaviour and/or emotional struggles.

Unfortunately, not all parents experienced support from their children's schools. Several parents expressed how they needed better connections between schools and doctors and a need to "bridge the gap". Parents expressed a need for partnership and collaboration after receiving an ADHD diagnosis, and they expressed sentiments that conveyed a sense of profound disappointment and frustration when an ADHD diagnosis did not result in appropriate academic programming for their child. A particularly poignant example of this sentiment is conveyed in the following statement from the parent of an 11-year-old child (participant 2):

> I would say it kind of feels like a lonely place to be. I feel like I've got this and I know this is the right way of going, but I need the support of the other people working with my kids to make this work. Unfortunately, it's made me more aware of the deficits that there are, and in some cases, with what the teacher's knowledge is or even if the teachers are willing, and the inability of the system to be able to actually flex and respond appropriately.

In addition to schools, parents shared other ways in which they felt health care systems could be more closely tied to communities. Parents expressed how they wanted health care providers to be connected to community-based supports such as ADHD education and support groups, parenting programs, and in-home supports. They additionally expressed how they wished information about community supports could be provided to them in written form, or within the body of diagnostic reports.

Access to coordinated and responsive ADHD treatment systems, as outlined above, was of paramount importance for parents. As they recounted their experiences navigating childhood

ADHD, parents often expressed that their biggest concern was less about finding information, but rather, their need for timely access to responsive and comprehensive treatment systems that could meaningfully support their children. As stated by the parent of a 10-year-old child (participant 13): “We’ve been talking a lot about information, but the thing that I think that was missing the most was the actual treatment, like why we were seeking help in the first place”.

Table 12.

Representative Quotations for Theme Three: Responsive Systems Build Treatment Confidence

Subtheme	
Collaborative Professionals, Medication Decisions	She was so quick to suggest it [medication]. It’s thrown me off a little bit. I really question whether I want to keep her as a doctor or find one who’s more like OK, well, let’s figure this out together to help you (P8)
Collaborative Professionals, Medication Decisions	He gave me a trial start, like for a week to just try it out and see how it was with her and then kind of make the decision after that. So that’s what I did. I did a week trial on it to see how it was with her and if there were any side effects that I had to talk to the doctor about (P5)
Collaborative Professionals, Medication Decisions	It was positive. He just kind of helped to guide and said, whatever you decide to do, come see me and we can, I can help you (P2)
Collaborative Professionals, Rapport	She says trust the process. She says as soon as he loses weight, we’re pulling him off, OK? She said just trust me and I was OK, we’re going to trust the process. And that was the only encouraging thing was her phone calls and just saying, let’s just work with it. (P1)
Collaborative Professionals, Rapport	He’s our partner in this. He is reliable. He shows up for us and he empathizes with us. He said, I’m sorry you guys are going through this. This sounds really tough. And usually I say, yeah, it’s pretty tough, so I’m relying on you to help us through this. And so he tells us what options we have and he always tells us what we have if they don’t work. And that’s really important (P12)
Collaborative Professionals, Rapport	He was very open and he said you can call if you have any concerns. And even on the beginning of the medication, I did call because my son wasn’t doing well in the first week (P11)
Collaborative Professionals, Rapport	The behavior is kind of still an ongoing issue. So I am going to be talking to her doctor this year about that (P5)

Comprehensive Treatment, Medication Reliance	We ended up trying meds, which have been beneficial, but it didn't give us the end result that we are looking for, which is the help (P6)
Comprehensive Treatment, Medication Reliance	The famous saying skills not pills in terms of working on stuff, right? Acknowledging that sometimes we need the pills to get us stable enough, to work on those skills (P2)
Comprehensive Treatment, Medication Reliance	We've seen great benefits from the medication with her focus and attention. So I'm not going to say the medication is bad, but we were given zero other options other than to medicate our daughter (P13).
Comprehensive Treatment, Medication Reliance	I think medication is quite often used not as a last resort, but as a first resort and without trying behavior modification or trying other things. And just jumping into medication right away can really be detrimental. You have to try everything first and use medications as a last resort, but in combination with other things that are out there (P10)
Comprehensive Treatment, Medication Reliance	It was a relief because it I could see the change instantly. So it worked very well for my son. On the other side it, it made me reflect like this is probably why we have so many misdiagnosed cases, because I felt that a very complex matter is dealt in a very simple way (P11)
Comprehensive Treatment, Emotional Support	That's the breakdown that I see. They have a have a treatment for it in their mind, like a chemical treatment. But there, there's no emotional or mental treatment after the fact, even though it is a mental illness, there's no support for that whatsoever (P13)
Comprehensive Treatment, Emotional Support	I do want to take him to a counselor for the anxiety part, to learn more about managing (P9)
Comprehensive Treatment, Emotional Support	It would be nice to be able to get them together in some sort of a therapy type group to talk, just to get them together and just make them feel like they are normal people. Stuff like that to make them feel like, no, there isn't something wrong with you. It's just you have a different way of thinking and a different way of learning (P13)
Comprehensive Treatment, Emotional Support	I need something hands on. I need something that my child can go to realize that she's not broken (P7)
Comprehensive Treatment, Emotional Support	It was good for her to speak to kids in her age group, who have ADHD, to see what worked for them, what didn't work for them(P3)
Effective Systems, Lengthy Waiting	He said for a long time, we watch and wait. We watch and wait. He's too young for a diagnosis. We watch and wait. At the end of the day, we had to seek a private assessment and pay out of pocket because to wait for it wasn't something that we were comfortable doing (P12)
Effective Systems, Lengthy Waiting	It's like, see one person, get referred to the next, a little bit of a wait list, and then get to another one and then a little bit of a wait list (P13)
Coordinated Systems, Lengthy Waiting	He's like, I can't get you into a psychiatrist because the waitlists are astronomically long (P6)

Effective Systems, Lengthy Waiting	Have you ever tried to get in? You need a referral. And if you can get in in six months, you're doing something amazing. We were on their list with our older one for just counseling in general. And that was never happening (P2)
Effective Systems, Lengthy Waiting	We got her final report card and I can't let her start the next school year in this situation. And we went for a private route because I couldn't stand the thought of having to wait a whole new school year (P7)
Effective Systems, Lengthy Waiting	Nobody had any availability. And I was like, is there nothing you can do? Like I'll pay you extra to do on the weekend? Like, is there nothing we can do? (P12)
Effective Systems, Lengthy Waiting	Access, access to professionals, access to folks of all different situations, to the same level of services. Taking away some of those barriers. Some of the barriers to access being removed would be hugely helpful (P3)
Effective Systems, Disjointed Care	He said, I don't understand why you were referred. Usually the doctor only sends to us if they are not sure about the diagnosis or if he doesn't find the right medication. So that's when the pediatrician usually sends the children. And I don't understand why you were sent. He basically sent me back to the pediatrician (P11).
Effective Systems, Disjointed Care	We submitted paperwork to our doctor who is supposed to pass it all on, but he's unreachable right now, so I don't even know what happened (P6)
Effective Systems, Disjointed Care	We have to literally get another referral to talk to that guy that initially diagnosed her. We'll never speak to him again. There's no communication, even though he technically is now her ADHD doctor…why is it that the specialist is so unreachable? (P13)
Effective Systems, Disjointed Care	Bring the different parts together. And whether that's professionals being aware of areas that they aren't experts in but that they think could help, or having all the information, the pediatrician or family doctor having like lots of information, or even private practitioners having more information. All of that I think would be helpful (P3).
Effective Systems, Community Connections	What now that it's been identified at school to go from identification to assessment to diagnosis? What are the options? Things like that. It would be nicer if there was a closer connection from school to doctor. And it would bridge that gap (P4)
Effective Systems, Community Connections	The school has the report, and it stays with her until she graduates from high school so that a plan can be made at different levels of her education for her to succeed (P3)
Effective Systems, Community Connections	We wanted a partner in the school, a culture of collaboration. Adaptations aren't happening. Once we had the diagnosis, we really thought it would make all the difference. We thought once we had it, we would provide it to the school and the school would get on board and the school would provide us support. The school psychologist, or the division psychologist never even reached out to us. It's been very disappointing, frankly, because we finally have this document that

	says our son actually really does have considerations that need to be taken into account and his learning needs to be accommodated. We just keep hearing push back (P12).
Effective Systems, Community Connections	I can't answer your question, I can't give you a diagnosis, I can't give you an assessment, but here are some support groups. Until then, here is a community center in your area that does parent and kid classes on how to deal with oppositional like behavior or explosive or violent behavior. I think, there needs to be more connection to community. And helping you deal (P4).
Effective Systems, Community Connections	Having the information readily available from different professionals and presented with the overall information that comes from the report that your family physician or pediatrician can give to you (P3)
Effective Systems, Community Connections	In home support allows you a chance to go and meet up with people who may be walking a similar path and allows you the chance to go out to a support group that allows you the chance to go out and get yourself some counseling. It allows you to go out and maybe go to a parenting group to learn more. Yeah, I can't say enough about in home support (P10)
Effective Systems, Community Connections	What I really need is not a website. What I need is the proper supports in place for my child and that is the uphill battle that we keep hitting a wall (P7).
Effective Systems, Community Connections	He has no external supports because we haven't been able to get that wrap around approach for him.We are sitting and waiting on referrals blah blah blah. So, you know, when I think about what difference the diagnosis has made, I'm not really sure (P12).

Note: Each of the 13 parent participants are identified in parentheses, P1 through P13.

Stressors and Burdens.

Throughout their interviews, parents spontaneously shared high levels of stress surrounding their experiences, and almost every parent became tearful at one point or another as they shared their stories. Even when parents could acknowledge improvement in their children, they described the initial period surrounding their child's ADHD diagnosis using words such as "hard", "challenging", "frustrating", "awful", and "survival mode". Although the emotional experiences of parents while navigating ADHD was not within the scope of the current project, their consistent outpouring of emotion strongly suggests that acute emotional stress and burden is an important contextual component that underpins the experiences of parents seeking

information about ADHD and its treatments. Accordingly, recognition of parental stress, and the areas where it is most keenly felt, plays an important role in truly understanding parental needs and it merits attention. Areas of stress for commonly reported by parents included ongoing advocacy, family stress, and personal well-being. Representative quotations depicting each of these areas are presented in Table 13.

Advocacy. Parents entailed their ongoing and constant advocacy for their children. They described middle of the night internet searches and numerous phone calls to potential care providers as they sought information about how they could help their child. They shared stories of numerous physician appointments, instances when they "begged and pleaded" for additional referrals from their primary care doctors, and of coping with answers that didn't make sense to them. Parents also shared ongoing advocacy efforts with their children's schools. They shared how they would initiate meetings with school staff to explain their children's needs and made ongoing efforts to ensure that their children received necessary interventions and adaptations, only to repeat the process the next school year or anytime their child had a new teacher. Parents described walking a balance between working with schools and holding them accountable. They talked about having "difficult conversations" with other adults to encourage them to support their child. An illustrative example depicted this ongoing advocacy and deep commitment is evident in the following statement from the parent of a 6-year-old child: (P12):

> I know, and I fully believe without us walking so closely to this, my kid would fall off the rails, completely. I believe that. We're not going to let it happen because we're right there in the thick of it and we're not going anywhere, but you can see how kids struggle, right? If there isn't someone emotionally, physically, mentally able to do the advocating for them. We just shouldn't have to advocate this hard to treat and like a, like a diagnosable

condition like, it just shocks me. So you think about, you know, you kind of, you just wish it was different, right?

Family Stress. In addition to the burdens of constant advocacy, parents described how childhood ADHD reverberated throughout their households and families. As expressed by the parent of a 7-year-old (participant 7), “I’'s not just the parents and i’'s not just the individuals, but i’'s a family thing. This affects the whole family”. Parents described living in chaotic and unpredictable households where they regularly coped with behaviour challenges such as poor sleep, inability to maintain routines, “meltdowns”, and destructive behaviour. Parents described experimentation with countless strategies and interventions to try to bring a sense of calm, explaining how they would adjust all aspects of how their household functioned to try to help their children cope and to bring a sense of calm.

Parents also explained how the experience of childhood ADHD took a toll on their family relationships. Many parents shared how they felt judged and criticized by their own parents and other family members, and specifically being told that they were parenting their children the wrong way. Parents also shared how they wanted their children to get along, but they often “triggered each other” or “couldn’t work together”. Parents shared stress over how to balance the needs of one child over another, and not being sure when to change plans that would impact other children to meet the needs of their child with ADHD.

Several parents shared the experience of parenting their children without a partner, leading to feelings of stress, burnout, and an increased sense of burden. For parents who had a partner, they shared experiences of conflict and disagreement such as having different opinions about using medication to treat ADHD, or of having different understandings of ADHD altogether.

Personal Well Being. Perhaps one of the most common sentiments shared by parents were expressions of their own emotional suffering, and the tolls taken on their mental health. Parents expressed distress came in the form of guilt, and perceptions that they were not being a good parent. Parents additionally talked about feeling stigmatized on account of their children's ADHD. They described feeling misunderstood and judged by peers, and that their children were misunderstood in general. They expressed worry about the way other adults, such as teachers and family members, perceived their children, and this made it difficult for them to talk about what they were going through. An illustrative example of this emotional burden is conveyed in the following statement from the parent of a 10-year-old child (participant 13): "They make me feel, like my daughter, isn't normal, she needs medication to be like a normal human being. What's to say her normal isn't normal?"

Parents also shared a deep sense of worry and concern for their children's well-being, and their interviews conveyed a profound sense of sadness in watching their children struggle. Emotional struggles pertained to concerns for their children's mental health, including concerns about their children's self-esteem and feelings of depression. Parents also felt concerned about the ambiguity for their children's futures, and whether they would be able to live fulfilling and happy lives as adults.

Recognition and awareness for the multitude of parent's emotional burdens and needs while they navigate their children's ADHD diagnoses, and the impact of childhood ADHD on parent mental health and well-being, is thus an essential component of managing and treating childhood ADHD. As stated by the parent of a 6-year-old (participant 10):

You can't take care of anybody else if you don't take care of yourself. So especially with these exceptional kids, you can't take care of their needs if you don't take care of your own. Learn to love yourself. And that's a hard piece, it's a very hard piece.

Table 13.

Representative Quotations for Stressors and Burdens

Area	
Advocacy	We just have to get the right resources for her to help her be successful with the least amount of struggle. Slowly, it feels like it's coming. But we're working on almost a year from diagnosis and I'm like, ooofff. There's been lots of tears (P7)
Advocacy	I have to be an advocate. I have to make sure that he does well in school and taking his medication to get him through. So then he could maybe have a chance (P1)
Advocacy	How to properly advocate for him when I, in theory, know what to advocate for, but that part I feel that maybe I'm not as confident on is how to advocate for him (P9)
Family	Your house is usually like the wheels have come off, daily. It's wild, it's unhinged on a daily basis (P1)
Family	I was just in tears. I was desperate, like I was desperate by this point. Like our kid was like physically destroying our house. We were losing all control. We were just at the max in terms of capacity (P12)
Family	It's adjusting like everything really in your lifestyle to really help the child succeed, or at least just always having it sort of in the back of your mind (P3)
Family	You can't let them get away with this or you can't let them do this or whatever kind of thing, but not understanding what their needs are and what was needed (P2)
Family	Do I want to derail the entire day for everyone in the household? Or do I let her do the tough love, learn it the hard way lesson? (P7)
Family	It's hard learning how to be a parent to a child with ADHD as well as to a parent to a child that doesn't have ADHD and working out the differences (P12)
Family	My husband is pretty much undiagnosed ADHD, so he thinks there's nothing wrong with our daughter in the fact that she's just busy and she needs to be kept busy or she finds trouble. We went through a lot of arguing. We argued a lot (P7)
Family	Everybody is at a different place on the journey, and so, because I've done more research and learned more, I was kind of farther ahead than my husband. And so, some conflict around how we're managing (P2)

Parent Mental Health	I always felt like I was telling her to not be her. Don't be you. Don't be loud. Don't be goofy. Don't have fun. And it was hard. I just felt like I was being a crappy mom, telling my kid not to be herself (P7)
Parent Mental Health	I would feel guilty because I felt that I was a better teacher to my students who have ADHD than to my own son at home. It's like all the knowledge I know was only applicable in my classroom. And when I come home as a mom, I didn't apply it and it was very not OK for me or for him (P11)
Parent Mental Health	This stigma, the chatter. I've seen comments. I've heard from other people talking behind, behind my back. That's probably the biggest thing (P1)
Parent Mental Health	I just think there's such a stigma. I just didn't feel comfortable talking about anything. So I felt bad about it. It's hard when it comes to your kids (P7)
Parent Mental Health	It breaks my heart because I know there's another piece in there that says depression and that one is really hard to think about for my son (P1)
Parent Mental Health	Every parent has a desire that his child is successful. And successful I don't mean money and jobs. Successful means to settle as an adult, to have a family, to be happy, to be kind to people. That's what I mean for successful. And it makes me very emotional that I don't know what's going to happen to this child (P11)
Parent Mental Health	If there are ways that we can help them succeed and live a full life without having to struggle so much, then I want to do it. But I don't know how. And I don't know where to start (P6)

Note: Each of the 13 parent participants are identified in parentheses, P1 through P13.

COVID-19 and ADHD.

This study of parent information needs occurred during the COVID-19 pandemic and its associated public health restrictions. Some of these included limitations on in-person gatherings and a shift to provision of health care using virtual platforms. Schools were also subject to a range of public health restrictions, including online learning, limitations on the number of staff and students in schools, and classroom or school closures during COVID-19 outbreaks. Although the current investigation was not specifically intended to examine how COVID-19 impacted the experiences of parents navigating a diagnosis of childhood ADHD, it is important to recognize the environmental context of this study. Parents commonly reported that the COVID-19 pandemic influenced their experiences in terms of access to support, and in their

experiences of daily living. Representative quotations for each of these areas are presented in Table 14.

Access to Support. Parents experienced reduced availability and functionality of several types of ADHD supports. In terms of clinical services, parents felt that fewer appointments were being offered by clinical specialists. They also felt that online assessments and therapy were not capturing the extent of their children's difficulties. This was due to children's limited engagement with virtual assessment or therapy appointments, and concern that virtual or online appointments did not capture the range of their children's challenging behaviours. Parents also felt that their access to their own peer support was constrained. Although parents continued to talk with each other via text or messaging platforms, they missed the richness and sense of camaraderie that would have otherwise been afforded to them through face-to-face conversations with parents going through similar experiences.

Parents additionally shared how their children's school supports were negatively impacted by COVID-19 public health restrictions. Many parents shared that their children's ADHD symptoms made it difficult for them to adapt to learning changes that occurred due to public health restrictions. Parents reported that their children struggled to stay focused and engaged during online learning. They also felt that online classes necessitated a shift to written submitted work, with fewer opportunities for children to use their strengths in interactive and hands-on learning. Other school policy changes similarly exacerbated their children's difficulties. For instance, small group sizes and social cohorts resulted in children "blowing through" friendships and increasing their social stress, while strict "stay home when sick" policies enabled children who were school avoidant to stay home. Parents also shared that fewer resources were available within schools in general, resulting in limited ADHD accommodations

for their children, and a resulting concern that the COVID-19 pandemic may be having a disproportionate negative impact on children with special needs. As shared by the parent of a 6-year-old child (P12):

> It's been covid too, right? So there's been a lot of stuff going on. But my child just falls farther behind. And I'm very empathetic about the fact that this is an unusual year. But I also don't think my son should suffer any more than any other child, and he is. He's feeling this COVID more than anyone else that is neurotypical or doesn't have a disorder or something like that. Not to say it's not tough, but these kids with additional needs, I think are suffering more.

Daily Living. In addition to impacting the way that parents were able to access to ADHD-related resources and supports, parents also shared how COVID-19 pandemic restrictions impacted the everyday living experiences of their families. Parents mentioned how closures of extra-curricular activities and schools left their children without their usual structure and routine, and this seemed to exacerbate their ADHD symptoms. They reported concern about excessive use of screens due to children having little else to do. Parents also shared that closed activities, or activities that would open and then close again, left their children feeling confused and angry, with parents feeling powerless to change things to help their children feel better. Parents additionally recounted their own heightened stress levels, including layoffs from work and reduced access to their own outlets for stress relief such as time with peers or access to family caregivers, and this made it harder for them to help their children.

Although areas of difficulty posed by COVID-19 pandemic restrictions were numerous, parents also described instances of finding a silver lining within them. Parents recognized how novel approaches to service delivery sometimes had unanticipated and positive results. Some of

these included more convenient and time-effective appointments for relatively simple matters such as progress updates and medication checks. Virtual appointments were also helpful in reducing children's anticipatory anxiety. By being at home until the time they needed to be seen by their care provider, parents reported that their children often felt calmer, and this could help appointments happen more smoothly. In the area of school, parents also shared some unanticipated positive outcomes. With the change to remote learning, children were able to get a break from their social difficulties. With the shift to smaller numbers of children in each classroom, children were able to get more teacher attention, leading to improvements in their learning.

Perhaps most optimistically, parents shared how pandemic restrictions afforded them broader insight and understanding about their children. Specifically, by being at home with their children on the daily, parents felt they gained understanding of their children's needs. Awareness and understanding about their children took several forms. In some instances, the many changes and hardships associated with pandemic health restrictions facilitated dialogue about mental health and resiliency in general. In other instances, in being at home with their children, parents felt they were able to recognize the presence of ADHD symptoms, thus prompting them to seek out information about ADHD or pursue an ADHD diagnosis, rather than waiting. Parents also felt they were better able to identify factors that influenced expression of their children's ADHD symptoms. Examples of this included noticing improved behaviour in the context of lower social demands, and worsened behaviour with the absence of outlets for physical activity. An illustrative example of how the COVID-19 pandemic facilitated parental understanding of their children was expressed by the parent of a 9-year-old child (participant 3):

It just really shone a huge spotlight on her ADHD. All of the things that we can't give a name to, all of the changes from going from your routine to being at home, from being in the classroom to being scared, her dad lost his job during COVID, like all of the stressors that COVID piled on everyone shoulders. I think brought out a lot of things in people that either were under lots of layers or were sort of starting to develop. It was shone a light on it.

Table 14

Representative Quotations for COVID-19 and ADHD

Area	
Supports	I've said that talking to friends has been helpful and is important for me, just to get their experience, so I don't see my friends as much as I usually do. So that part, like maybe I would have more information from friends if it wasn't COVID (P9)
Supports	I think in any other year, it would have been better, because I could have gone for coffee with that mom and I could have said, we could have looked each other in the eye and had to cry over it. Like, you know, shared something, a moment, right? It's different when you're just texting with this person on messenger (P12)
Supports	This online schooling on the tablet isn't fun anymore because the novelty is gone. It's been a lot of screen time and she's just not interested. So that part we struggle with (P7)
Supports	A lot more of the content is put into writing and needs to then be produced and given back because there's less room for classroom discussions or presentations or other ways of doing things. So the mode that is the most problematic for producing work is now the primary mode of presenting all information and even classes (P2)
Supports	They do just a simple phone call where they don't even see them, they don't see his behaviors and what he does in that whole 20 minutes of having to sit there (P12)
Supports	I feel like stuff gets missed when you're not meeting with someone face to face (P6)
Supports	They’re online, it's over the phone, you can't come in person. So it's really hard to find some options available. Yeah, it's kind of where I'm at right now with all that. So it's a little hard (P5)
Living Experiences	Kids who need structure and routine and schedules, that all gets thrown out the window when you're going to school every other day or you go for a few days and then you don't go, or you have the sniffles, so now you need to stay home for a couple of days (P2)

Living Experiences	So having him home, having no routine or we're trying to instill the routines. We're trying to use a grandparent as well, even though that's not allowed. We need it, we're just trying to survive, right? (P12)
Living Experiences	I was forced to resign from my job because I had two kids. I was not allowed to work my job, so I was home schooling every day. It was very, very combative where he couldn't sit still, couldn't focus, all over the place, trying to do his school, fighting us, refusing to do it, trying to bribe it because a child with ADHD like him is very reward based. So it's like, we'll buy you a slurpee if you do this homework, we'll let you watch TV for X amount of minutes if you do this. And it was just like this ping pong of like, we cannot live like this (P1)
Living Experiences	My kid was going crazy because she couldn't do anything. Well I can't do anything about that. She's getting mad at me because she wants to go to indoor playgrounds. She wants to go here, she wants to go there. I can't do anything about that. That's out of my control. That's out of my hands. It's not fair. I don't think it's right, but I don't make the rules (P5)
Living Experiences	Where I've never thought of myself as being terribly social or personable, but now with COVID I realized, oh, I actually do need that connection (P9)
Living Experiences	My son, he really needs a structure. So I tried to implement like a military structure, time for breakfast, time for studying, time for exercising, time for arts. But it was so demanding for me. I was so anxious to follow these and try to keep him on track. It was harder on me than on him because I had no idea what to do with him (P11)
Living Experiences	Our appointments were by phone instead of in-person, but actually when we were just doing med reviews, I actually found that to be really helpful as opposed to the opposite. instead of me and my child having to block out an hour, an hour and a half t' go to a doctor's appointment, I can take a quick phone call while I'm at work and deal with the med review, if that's all we're doing (P2)
Living Experiences	The virtual was so fantastic because he has such bad anxiety. It would be like, do you know which way we're going, do you know where you're parking, how long are we going to be there for, are we going to be late? And it would ramp up at those appointments. And then when we went to virtual, it's like buddy, play, one minute, just come on over (P1)
Living Experiences	Probably the saving grace for my child is the remote learning right now, because she's done. She hated everyone in her class. Nobody was her friend. She was sick of the mall. And I don't blame her (P7)
Living Experiences	We realized in a smaller setting, I don't know what it was probably five not even 10 kids every day, he was like, I love class, I'm getting so much more attention. It's so much more one on one. And I went that makes sense. Instead of being a classroom size of 25 or 30 or whatever it would have been, he was now in a class size of like 5 to 10 and his grades flew through the roof (P1).
Living Experiences	I feel so horrible saying it but has been absolutely wonderful for us, because of the additional issues that all revolve around social anxieties and social behaviors. And 'because we haven't been able to be social, they all kind of went away. So, life at home is nice now (P4)

Living Experiences	I guess maybe it was the initial push for me to find out, because by then he was still not diagnosed (P11)
Living Experiences	Covid hit and it was remote learning. It was extremely evident that there was something going on. She couldn't sit and do a simple three times four equation without me sitting there guiding her through it, even though she knew the answer (P3)

Note: Each of the 13 parent participants are identified in parentheses, P1 through P13.

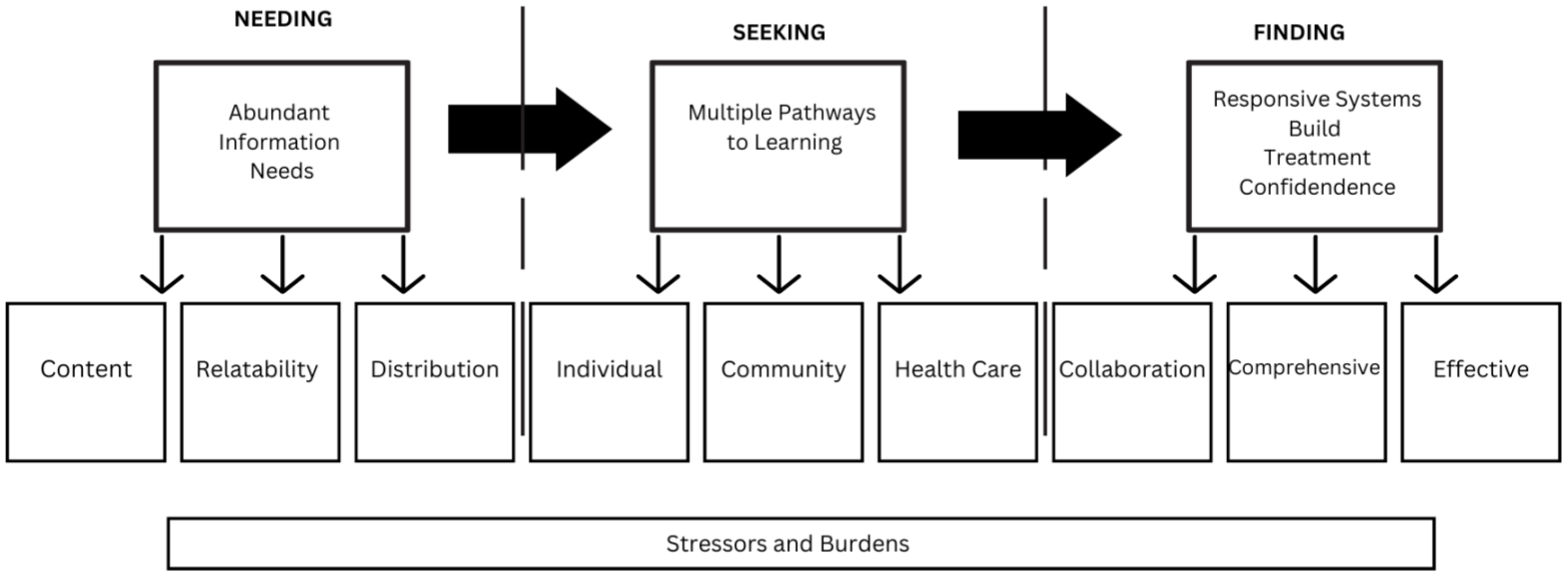
Qualitative Discussion

The objective of this qualitative strand of my research was to examine parental information needs and comfort with treatment decisions about childhood ADHD from the perspective of their lived experiences. I was interested in understanding how parents navigated their child's ADHD diagnosis within our local health-care context, with specific focus on understanding why specific types and sources of information are important to parents, how they interact with information sources to learn about ADHD, and how parents gain comfort with ADHD treatments. Results of my analysis yielded several themes that richly depict parental experiences, and which provide novel and important insights into key facilitators and barriers for how parents acquire ADHD related information.

These experiences may be linked together and conceptualized as a journey, where parents move through stages of needing information about ADHD, seeking information about ADHD, and then ultimately and hopefully finding comfort with their choice of treatment. Figure 8 depicts stages of this process, as described below.

Figure 8

A Journey of Parent Information and Treatment Needs for ADHD



Parents' information journey began with their need for an abundance of ADHD information. Parents reported how they sought information across a wide range of content areas, including recognizing potential ADHD symptoms, responding to ADHD symptoms with medication, behaviour, and academic strategies, and understanding help-seeking options and how to pursue them. They further reported many ways in which existing information about ADHD fell short of their needs, as it was often overly scientific, not relatable to their specific concerns and experiences, or not distributed in a way that was easily accessible or trustworthy. These findings thus update and provide additional support to previous quantitative findings that parents wish to receive ADHD information on a wide variety of topics (Sciberras et al.,2010), and qualitative findings that parents wish to receive information about ADHD that is non-technical and relevant to their life experiences (Ahmed et al., 2014; David et al., 2012). The breadth of content, and depth of content sought by parents suggests they seek a deep and holistic understanding of their children's experiences.

These findings offer a nuanced and enhanced understanding of what it means to acquire mental health literacy (MHL). It is notable that the types of important ADHD topics referenced by parents, such as symptom recognition and knowing how to access ADHD treatment, map directly onto Jorm's (1997, 2012) seminal definition of mental health literacy, thus providing validity to the MHL construct through an inductive, qualitative lens. However, in their interviews, parents also talked about their wish to understand ADHD at a deeper and less factual level, and they shared how existing ADHD content often didn't "fit" for their children. Parents shared their need for highly relatable information that was emotionally engaging, and which resonated with their experience of living with ADHD. As such, from a parent-based perspective, acquiring mental health literacy for ADHD may require providing parents with deeper and more

holistic understanding about what it means to have ADHD, and using novel forms of information delivery that promote a deeper level of interaction and engagement with information than previously thought.

In their position paper on using the knowledge to action model for childhood ADHD, Levesque and colleagues (2007) outlined how merely creating ADHD informational material is not sufficient to ensure effective knowledge translation. They discussed a need to develop targeted and specific informational materials that met the needs of resource infrastructures and target audiences. Through recounting their experiences, parents consistently offered novel and highly practical suggestions for creating more relatable and easily accessible ADHD informational materials. They suggested use of non-traditional and highly engaging formats such as podcasts and informational videos where ADHD information could be designed to meet with the needs of diverse audiences, and they suggested ways to make better use of existing and trusted information channels such as schools and pharmacies. The above-described results thusly hold promise for the creation and distribution of meaningful ADHD-related information for parents in accordance with the Knowledge to Action model (Straus et al., 2016).

Next in their search for ADHD information, parents described multiple and interacting pathways of learning. They recounted how individual characteristics (e.g., their social location, personality attributes), community networks (e.g., peer groups, schools), and health-care providers (e.g., primary care providers, specialists) each facilitated their learning about ADHD in unique but important ways. Parents also shared how these pathways were interactive and recursive, such that parents would use one pathway to gain access to another pathway (e.g., word of mouth from peers to access health care providers), to cross-reference information (e.g., checking-in with peers about a medical recommendation), or to return to a pathway as they

gained information (e.g., going back to independently re-visit or re-research a topic after diagnosis).

These interacting and recursive influences of individual, community and health care learning pathways are reminiscent of Pescosolido et al.'s (2013) NEM-II model of mental health service use, whereby the interplay between personal, social, and treatment system factors influence individual's health care trajectories. These findings are consistent with recent research that has similarly used the NEM-II to outline factors that influence the course of mental illness. For instance, Perry and Pescosolido (2015) interviewed with adults recovering from serious mental illness and found that a NEM-II framework helped explain aspects of their recovery process. More recently, Green and Pescosolido (2023) used the NEM-II model to frame a latent class analysis examining different pathways to mental health care in a large community sample. The current results add to this body of research, and they suggest that the NEM-II framework may provide a useful framework for studying how individuals come to acquire information about their mental health in the first place.

Parents feelings of confidence with their children's ADHD treatment represents a further step in their journey of navigating childhood ADHD. In this investigation, parents shared a range of factors that influenced their feelings about their children's treatment. Collaborative and supportive relationships with primary care providers were of high value to parents. They wanted health care providers to hear their perspective, present them with multiple treatment options, and give them time to decide on a treatment course. Parents' sentiments clearly reflect the essential components of shared decision making (Charles et al., 1997), thus adding support to the prevailing view that shared care is a fundamental component of health care delivery when a choice of treatments is available (Stiggelbout et al., 2015), and supporting current clinical

practice guidelines for best practices in ADHD treatment (Feldman et al., 2018). Unfortunately, within this investigation, many parents conveyed experiences suggesting that a shared decision-making framework did not transpire for them when they sought care for their children, resulting in dissatisfaction and a sense of ongoing concern about treatment options for their child. Accordingly, additional research into the barriers that hamper the ability of health care providers to use a shared decision-making approach when delivering ADHD treatment is an important topic for further research.

Parents also expressed how characteristics of the health care system in general impacted their feelings about their children's ADHD treatment. Even when parents were fortunate to have had positive experiences with individual health care providers, parents generally described a fragmented and chaotic health care system that was not responsive to their treatment needs. They described delays of care, gaps in care, and at times, refusal of care altogether. They described the lack of a coordinated and cohesive approach to treatment that did not meet the needs of their children. These sentiments and experiences are consistent with issues that have been documented within the recent provincial report on mental health care in Manitoba (Virgo, 2018), and they underscore the need for ongoing efforts to improve the accessibility and coordination of mental health service delivery in our province. These findings also underscore the notion that information per se is not enough to help parents feel comfortable and confident about ADHD treatment, and that it may in fact have iatrogenic effects if and when informed and educated parents become aware that they are unable to access the care that they know their children need.

As depicted along the bottom of the model, a powerful undercurrent of stress underlies parent's experiences navigating ADHD information and its treatments. This includes the burdens of constant advocacy to obtain treatment for their children, managing and balancing household

and family relationships and needs while responding to a child in distress, and numerous emotional worries about the short-term and long-term psychological well-being of their children. These types of stressors are all consistent with those that have been well-documented in previous studies (e.g., Brinkman et al. 2009; Davis et al., 2012; Leitch et al., 2019; Taylor et al., 2006). Future research that examines parental information needs will benefit from recognition and greater understanding of how this highly charged and emotional context affects parental capacity to acquire ADHD information, and to provide appropriate emotional and pragmatic supports for parents, both for their own well-being and so they can continue to support their children.

Finally, it is important to recognize the above-mentioned processes reflect the experiences of parents during the COVID-19 pandemic. Results must thus be understood within the context of some of the unique challenges that have occurred during this time, including reduced access to services, changes in service delivery and overall heightened levels of psychological stress. Although research into the COVID-19 pandemic and its impacts on ADHD is still within its infancy, preliminary research suggests that these types of changes are consistent with the difficulties that have been experienced by youth and their families during this time (Cost et al., 2022; Pickren et al., 2022; Stein, 2022; Zhang et al., 2020).

Chapter 5: Integration and General Discussion

The overarching objective of this research was to improve understanding of the pathways and processes through which parents acquire information about ADHD, and to explore the functional impacts of information acquisition on treatment decision-making. A primary goal from this work is to improve the calibre of local parent-directed knowledge translation initiatives on ADHD, so that information deemed important by parents can be more effectively designed and disseminated within our health care and mental health care communities. An additional goal of this work is to better understand the informational and treatment needs of parents in order to enhance elements of client-focused care within evidence-supported ADHD treatment initiatives.

This body of work used a concurrent mixed-methods design, thusly shedding insight on parents' information needs and their functional associations with treatment decisions from two different yet complementary perspectives. Quantitative data in the form of online surveys was used to identify broad trends in parents' information needs and preferences, to examine the extent to which access to various sources of information were associated with parents' ADHD literacy, and to examine the relationship between ADHD literacy and comfort with making treatment decisions. Qualitative data in the form of research interviews was used to explore the experiences of parents seeking childhood ADHD information and treatment in their own words, thus allowing for an atheoretical and experiential perspective about how and why specific types of information and treatment experiences were salient for them. Integration of these two complementary sets of data is organized around the four broad research questions of this project: (1) Are parents receiving adequate information about ADHD and its treatments?; (2) What information sources do parents use to understand ADHD and its treatments?; (3) What types of barriers make it difficult for parents to access the information they need to understand ADHD

and its treatments?; and (4) What is the relationship between access to information and comfort with ADHD treatments? Integrated data and discussion on each of these research questions is presented via joint displays, each of which include a summary of quantitative findings, a summary of qualitative findings (relevant themes and representative quotations), and an interpretation of how results from each strand of the investigation relate to each other.

Question 1: Are Parents Receiving Adequate Information about ADHD and its Treatments?

As presented in Table 15, quantitative and qualitative datasets each found that parents find a wide number of ADHD topics to be important. Likert-ratings of importance and representative quotations both reflect that parents want to obtain practical information that addresses their children's functional needs (e.g., behaviour management, academic strategies). These types of parental ADHD-information needs have previously been reported in quantitative investigations (Sciberras et al., 2010) as well as qualitative investigations (Ahmed et al., 2014). Broad information needs have also been reported among parents whose children struggle with anxiety (Mak et al., 2017).

With respect to accessibility, quantitative and qualitative findings each indicate that parents experience difficulties accessing needed information about childhood ADHD, and consequently, that many parental information needs are not being met. Quantitatively, access difficulties were indicated by non-overlapping confidence intervals between importance and accessibility for all queried ADHD content areas, as well as by parents' moderate and uneven ratings of their ADHD literacy across domains, such that topics where parents reported feeling least informed (e.g., information about treatments and how to seek help) were rated as mattering to them the most. Qualitatively, interview data confirmed and provided further insight into some

of the reasons for parents' low accessibility ratings, with parents sharing that ADHD information was often too technical, frequently unrelatable and generic, superficial, and difficult to find.

Recognition that parents are experiencing widespread difficulties in their access to ADHD information that they consider important is a novel and highly significant finding, and it has numerous worrisome implications for parent's engagement with help-seeking and their participation in treatment for their children. However, joint interpretation of these complementary sets of results has yielded new insights and understandings about the nature of parental information needs, and how they be better met. Notably, many of the ADHD topics rated as important by parents, and discussed by parents, map on to the core features of mental health literacy (Jorm, 2012), thus lending ongoing support for the importance and validity of this construct. Also notable, however, are the breadth of content areas and the types of information characteristics deemed important by parents during their interviews. These offer a parent-informed and inductive perspective on ADHD literacy, which includes a deeper and more holistic understanding about the nature and implications of ADHD, in addition to the traditional types of mental health literacy content such as symptom identification and how to seek help. Thus, through the eyes of parents, gaining ADHD literacy may require additional information than is typically provided via traditional educational outreach tools such as symptom checklists and informational pamphlets. Parent-informed and creative approaches to knowledge translation, such as through first-person videos, graphic novels, and podcasts, designed with target audiences in mind, could be of considerable utility in bringing greater understanding about ADHD to parents and their families.

Table 15

Integrated Results: Are Parents Receiving Adequate Information about ADHD and its Treatments?

Quantitative Findings	Qualitative Findings	Comparison	Interpretation
Parents rated all listed ADHD information topics at or near the "extremely important" anchor of the importance rating scales Most important ADHD topics: behaviour/emotional problems, educational supports, behaviour management Moderate levels of ADHD literacy, and uneven development of parents' ADHD literacy: ADHD signs and symptoms > causes of ADHD, types of professional help, how to access professional help (non-overlapping 95% confidence intervals)	*Abundant Information Needs: Content* • What I needed to learn about ADHD was everything • I think a lot of the stuff around executive functions, so like understanding that ADHD has to do with organization and motivation and timekeeping • I guess it's more or less strategies to help them just to be able to concentrate and to do the work that he has to do • The most important thing for me was really to understand what my daughter was going through and how to help her	Confirmation, Expansion	Quantitative and qualitative findings each indicate that parents wish to learn about a wide variety of ADHD topics related to the emotional and behavioral well-being of their children. Qualitative findings extend quantitative findings as the scope of topics shared by parents suggest they wish to understand ADHD deeply and holistically.
Significant differences between importance and accessibility for all ADHD content areas (non-overlapping 95% confidence intervals)	*Abundant Information Needs: Relatability, Distribution* • It's scientific stuff. It didn't really explain that's what he needed. Or at least not	Confirmation, Explanation	Qualitative findings confirm quantitative ratings of poor accessibility. Qualitative findings explain factors that underlie access difficulties. Poor

	in a way that I understood it • I was trying to find pamphlets, and there's no pamphlets about ADHD. • I feel like there should be somewhere from the health care system where we can access information that we need • Maybe personal experiences, either written stories or videos of just what parents' experiences were for their kids or kids directly saying what their experiences were		relatability and poor distribution of ADHD materials in general appear to underlie accessibility difficulties.

Question 2: What Information Sources do Parents Use to Understand ADHD and its Treatments?

As presented in Table 16, quantitative and qualitative research datasets each found that parents sought information about ADHD from a wide range of sources, with qualitative data supplementing and providing insight into why various sources of information were helpful, or why they weren't. Quantitatively, parents endorsed a wide number of different information sources to learn about ADHD, including through independent reading and research, through interactions with community networks with peers and their children's schools, and through interactions with health care providers. Qualitatively, parents shared how they gained different forms of understanding about ADHD through their interactions with these different types of information sources. Specifically, parents valued conversations and connections within their community networks because these offered relatable information about ADHD, and it provided a sense of validation and connection with other parents going through the same experience. These findings are consistent with previous studies indicating that peer support is highly valued by parents of children with complex needs (Sartore et al., 2021), as well as by parents of children with ADHD (Klein et al., 2022). Parents also shared that they valued conversations and connections to health-care providers, turning to them for their clinical expertise and high-level understanding about ADHD. Taken together, qualitative and quantitative findings illustrate how parents benefit from access to multiple types of information sources about childhood ADHD, and how both community and health-care information sources represent separate yet differently important pathways for ADHD learning. An important area for further research and development will comprise finding ways to better integrate these distinct informational pathways.

Quantitative and qualitative datasets also provided complementary understandings about parents' preference to access clinical sources of information when making treatment decisions. On surveys, parents ranked clinical information sources as their most used choice for treatment decisions. In interviews, parents shared several ways in which the types of information provided from health-care providers uniquely guided their treatment journeys, such as through providing diagnostic clarity and providing referrals for additional clinical specialists and interventions. Parents also shared an expectation that health care providers had the expertise to answer their questions, and they voiced disappointment when interactions with health care providers did not meet their needs. Together, these findings convey the exceptionally high value of health care providers as an information source for parents. This finding is consistent with previous studies (Ahmed et al., 2014; Sciberras et al., 2010), and speaks to the importance of ensuring that primary care providers, who often serve as parents' first touchpoint for access to specialist care, have sufficient training and expertise to provide support for parents who have a child with ADHD.

Although parents frequently endorsed the use of independent information sources on surveys, they did not frequently share about the relevance of these sources for their ADHD learning during interviews. There are several possibilities for this discrepant finding. One reason might be because independently sourced information has limited utility for parents in the absence of other information sources to help them contextualize what they read. Alternatively, parents may feel overwhelmed by the volume, and/or underwhelmed by the quality, of public domain information about ADHD, and ultimately learn more meaningfully when they obtain ADHD information through their interactions with others. Consistent with this notion, King and colleagues (2021) reviewed 31 ADHD themed websites that figure prominently on popular

Internet search engines. Results indicated a generally poor quality of online information, with difficulties that included poor alignment with clinical practice guidelines, higher than recommended reading levels, and poor discussion of psychosocial treatments. From this perspective, independently sourced information may be seen as a helpful starting point for parents as they start to learn about childhood ADHD, yet parents may ultimately require trusted relationships with community and health-care networks to access usable, relevant, and evidence-based ADHD information.

Table 16

Integrated Results: What Information Sources do Parents Use to Understand ADHD and its Treatments?

Quantitative Findings	Qualitative Findings	Comparison	Interpretation
Frequent access to clinical sources, independent sources, community sources, and schools for ADHD information (descriptive tallies)	*Learning through Multiple Pathways, Community and Clinical* • Community: It's very relatable, so it's easier to gain information from other people's experiences. • Community: It kind of helps that you know there's other people out there that are going through the same thing. • Clinical: I need some professionals to tell me, help tell me what we need because I only, we only know so much • Clinical: His behavior, in explaining to me, where does it come from and how we can deal with it our routine. It felt very good • Clinical: It's the hardest person to get, the hardest source to get information from, but it was the best information I found	Confirmation, Expansion	Qualitative findings confirm quantitative findings of parents using multiple information sources, and they provide additional insight into why each of these pathways is important to them. Independently sourced information may be of limited utility to parents in the absence of additional and interactive information sources.
Parents overwhelmingly prefer clinical sources to help with treatment decisions (descriptive rankings)	*Learning through Multiple Pathways, Clinical* • So it all starts with health care professionals, like the doctor being	Confirmation, Explanation	Qualitative findings confirm quantitative finding that clinical sources of information are important for parents.

	able to actually point you in the right direction • We know there's something going on and I just want confirmation that there is something going on • I feel left in the dark by all these professionals that are supposed to have these answers and have the time to answer, but they don't because they've got the next patient to deal with		Qualitative findings explain the uniquely important role of health care providers in guiding ADHD treatment.

Question 3: What Types of Barriers Make it Difficult for Parents to Access the Information They Need to Understand ADHD and its Treatments?

Table 17 presents integrated quantitative and qualitative data pertaining to barriers experienced by parents seeking information about ADHD and its treatments. In terms of personal barriers, quantitative and qualitative findings were synergistic, each offering a different lens on individual factors that may contribute to parents' learning. Survey data found that parents with higher education levels were more likely to independently seek out information about ADHD, which in turn was modestly associated with higher levels of ADHD literacy. A different yet complementary perspective was found through analysis of interview data, whereby parents with a more privileged social location (e.g., flexible workplace, experience with medical or research systems, financial security) reported having more opportunities to access ADHD information, as well as the ability to access to private practitioners for treatment. Taken together, these findings suggest that higher social-economic status facilitates the development of ADHD literacy, while lower socio-economic status may serve as a barrier.

Although it wasn't a focus of this investigation, parents also spontaneously shared a multitude of highly emotional and stressful experiences that accompanied their daily living, ranging from managing complex family relationships, to searching for supports and advocating for their children, to ongoing worry about their children's short-term and long-term psychological well-being. Some parents additionally described a sense of purpose and determination to find the information and supports that they needed, even though it was difficult and stressful. The experience of high parental stress in childhood ADHD is well-established (Theule et al.., 2013), and it is likely that parents who are poorly equipped to manage these

stressors may encounter additional difficulties when trying to access information about ADHD and its treatments.

Taken together, quantitative and qualitative results suggest that individual characteristics such as socio-economic status, education, and personality attributes may be personal determinants for the development of ADHD literacy. However, it is plausible that these represent different manifestations of a common underlying construct. The concept of self-efficacy is one example of a concept that illustrates this possibility. Representative quotations from parents about their determination and belief in themselves are consistent with self-efficacy, which is associated with academic achievement (Bandura et al., 1996; Caprara et al., 2011) as well as a wide variety of health behaviours and uptake of health education initiatives (Isa et al. 2017; Lawrance & McLeroy, 1986). The current investigation did not include quantitative measures of parents' personal attributes, such as their parenting self-efficacy or their parenting stress. Further research would benefit from inclusion of these sorts of individual level variables, so they can be examined in conjunction with the ways parents interact with health care and mental health care systems to acquire information and make treatment decisions.

In terms of whether the combination of socio-demographic characteristics, use of community networks, and health-care system access was associated with parents' ADHD literacy, as articulated by the NEM-II model, quantitative and qualitative findings were generally consistent. Survey data found that the usages of various information networks were positively inter-correlated, suggesting that parents gather information about ADHD from multiple sources in a dynamic and recursive process. Interview data similarly suggested a rich interplay between different information sources, with parents describing how information gained from one source could then help them gain information from other sources.

Other integrated findings had explanatory value with respect to information barriers, with interview data helping to explain quantitative results. Specifically, multiple regression analysis found that socio-demographic characteristics and use of various information sources explained only a modest portion of variance in ADHD literacy, and this was due mostly to a small trending effect of parents' use of independent information sources. However, in their interviews, parents shared a range of experiences and needs from their interactions with community and clinical sources of information, such that sometimes parents gained valuable information and understanding about ADHD during these interactions, while other times they did not. Together, these results suggest that mere access to information does not automatically bequeath meaningful ADHD information to parents, and that there are likely additional factors at play which influence whether parents will be able to make use of the information they find. In their interviews, parents described how specific dynamics of their interactions helped them learn about ADHD, such as whether they felt heard and understood within relationships. They also shared that they needed information to be presented in a way that made sense to them, suggesting that perhaps general literacy levels, stress, and/or information readiness may influence the explanatory value of information. These combined findings suggest a need for greater consideration of how intra-individual characteristics may operate in combination with social networks and treatment systems to influence the development of ADHD literacy.

Table 17

Integrated Results: What Barriers Make it Difficult for Parents to Access the Information They Need?

Quantitative Findings	Qualitative Findings	Comparison	Interpretation
Higher education associated with better ability to independently seek out ADHD information ($p < .05$). Use of independent information sources modestly associated with ADHD literacy ($p = .06$)	*Learning through Multiple Pathways, Personal* • I think partly it's my personality is that I just want to learn things and totally know what I'm getting into • And then I just thought, no, you're not powerless, you're the mom, you're her mom, so you're going to find information • I'm lucky because I work in an environment where I'm doing research often and I'm seeking information and writing proposals, so I'm able to kind of dig for information and know what sources to go to. *Stressors and Burdens* • I just think there's such a stigma. I just really just didn't feel comfortable talking about anything. • If there are ways that we can help them succeed and live a full life without having to struggle so much then I want to do it. But I don't know how. And I don't know where to start.	Synergistic	Quantitative and qualitative findings each provide complementary understandings of the personal barriers that make it difficult for parents to independently seek out information about ADHD. Parents with higher levels of education may also possess personality characteristics that facilitate their ability to manage stress and to learn about ADHD.
Use of independent, community network, and	*Learning through Multiple Pathways, Community and Clinical*	Explanatory	Qualitative findings offer an explanation to the quantitative finding that access to

clinical information sources are positively inter-correlated ($p < .05$).	• The school provided me with the resources I could look for. Like you can go to the audiologist, you can, you can go back to the pediatrician, you can try a psychologist. You can try an OT. • Once you get that diagnosis, then you can kind of dive back into the Internet and start looking again		community and clinical information sources is not associated with ADHD literacy. Qualitative findings suggest that nuanced features of each of these information sources influences whether they are useful in helping parents learn. Access to sources is necessary but not sufficient to help parents feel informed about ADHD.
Access to community and clinical information sources are not associated with ADHD literacy (multiple regression model, $p > .05$)	• I shouldn't have to, you know, ask, beg my doctor for over a year to see somebody, because apparently the family doctor can't diagnose ADHD		

Question 4: What is the Relationship between Access to Information and Comfort with ADHD Treatments?

Table 18 depicts integrated data about access to information and parents comfort making ADHD treatment decisions. Both quantitative and qualitative findings indicated parents' clear preference to work together with their care providers when making treatment decisions. On surveys, close to 90% of respondents endorsed a preference for collaboration in decision making, and this preference held regardless of parents' level of ADHD literacy. Similarly, in interviews, parents shared how they wanted to work in partnership with their health care providers as they decided on treatment plans, such that care providers listened to their perspectives and provided them with a range of treatment options. These findings are consistent with research indicating that parents have a favorable view of shared decision-making approaches in ADHD care (Brinkman et al., 2013; Fiks et al., 2011; Tan & King, 2022).

In terms of feeling comfortable about their children's treatment, quantitative and qualitative data yielded synergistic findings. Quantitative data indicated that ADHD literacy had a strong association with parents' decisional conflict, such that parents who reported higher levels of ADHD literacy felt less conflicted about their treatment decisions. This finding is consistent with previous studies indicating that providing parents with information that meets their needs improves their perceptions about ADHD treatment and treatment adherence (Bai et al., 2015; Monastra, 2014; Kolko et al., 2014). Qualitative data offered a different lens on parents' comfort with treatment decisions, however, whereby parents shared how their feelings about ADHD treatment were more related to broad systemic factors, such as whether their children were able to receive cohesive treatment across health-care professionals, whether information about their children was communicated to them and other adults who cared for them

in a timely and efficient way, and whether their children were able to receive comprehensive and holistic treatment that addressed their emotional well-being. Unfortunately, most parents described significant difficulties accessing the type of holistic and coordinated treatment they desired for their children, sharing many experiences of fragmented and disjointed approaches to treatment, or an inability to access treatment altogether. These types of experiences are consistent with some of the current shortcomings of our provincial mental health care system, and which are currently being addressed via recommendations within Manitoba's provincial mental health strategy (Virgo, 2018). Taken together, these findings suggest that parents may be able to feel relatively confident with their specific treatment choices when they feel sufficiently informed; however, when considered within a broader context, parents continue to experience ongoing concern and dissatisfaction about the overall level and type of ADHD care being provided to their children.

It is notable that parents with higher education levels, who tended to access more sources of information independently, also experienced greater levels of decisional conflict. One potential explanation for this finding is that higher education is associated with parents being more discerning and critical of what they read, with tendencies to overthink their treatment decisions. Additionally, it is possible that parents reach a point of diminishing return on their independent research, such that information becomes less helpful to them at higher volumes. However, qualitative data suggests an additional potential explanation for this finding. Specifically, parents who felt well-informed about ADHD expressed feelings of sadness and frustration once they recognized that the treatment needs of their children were not being met. Having ADHD literacy may have thus had the unintended consequence of making them feel less satisfied about their treatment options, rather than better. This suggests that even the most well-

crafted and perfectly distributed information about ADHD will be of limited utility unless it is provided within the context of a responsive and well-functioning treatment system.

Table 18

Integrated Results: What is the Relationship between Access to Information and Comfort with ADHD Treatments?

Quantitative Findings	Qualitative Findings	Comparison	Interpretation
89.1% of parents endorse collaborative approaches to making treatment decisions (TCP self-ratings). No significant differences in ADHD literacy between treatment control style groups ($p > .05$)	*Responsive Systems build Treatment Confidence, Collaborative Professionals* • She was so quick to suggest it. It's thrown me off a little bit, that I really question whether I want to keep her as a doctor or find one who's more, OK, well, let's figure this out together to help you • They were kind of blown back when I had suggested something not medicated related. And they were like, oh, well, I guess we can refer you to a psychologist type of thing. And I felt like right then it was them saying it's no longer our problem • Just being able to talk to her doctor and figure out what options she had, especially with the medication stuff, I think that was probably the most meaningful • As a parent that you feel more empowered to make better choices for what's going on with your child because you feel supported.	Consistent	Quantitative and qualitative findings both indicate that parents want to work in partnership with their health care providers to make treatment decisions, reinforcing the importance of a shared decision-making approach in ADHD treatment.
After controlling for ADHD symptoms, ADHD literacy and parent education each	*Responsive Systems build Treatment Confidence, Comprehensive Treatment and Coordinated Systems*	Synergistic.	Quantitative and qualitative findings each provide a complementary lens on the issue of treatment confidence.

have independent effects on parents' decisional conflict ($\Delta R^2 = .235$). Greater ADHD literacy is associated with less decisional conflict ($p < .001$)	• I think medication is quite often used not as a last resort, but as a first resort and without trying behavior modification or trying other things. • I need something hands on. I need something that my child can go to realize that she's not broken • We submitted paperwork to his, to our doctor who is supposed to pass it all on, but he's unreachable right now, so I don't even know what happened. • It's almost like once the diagnosis was done, they were done with the child and they had done their part, their portion of the cog in the wheel. And now we have to go and find our own way		Quantitative findings indicate that parents with higher levels of ADHD literacy report less decisional conflict about their choice of treatment, while qualitative data indicates that parents also require a comprehensive and coordinated approach to care to feel satisfied with their child's ADHD treatment in general.
Higher education is associated with increased decisional conflict ($p < .01$)	*Responsive Systems Build Treatment Confidence, Coordinated Systems* • We wanted a partner in the school, a culture of collaboration. Adaptations aren't happening. Once we had the diagnosis, we really thought it would make all the difference. • I would say it kind of feels like a lonely place to be. I feel like I've got this and I know this is the right way of going, but I need the support of the other people working with my kids to make this work. Unfortunately, it's made me more aware of the deficits	Synergistic	Quantitative and qualitative findings each provide an explanation for why parents feel unhappy about treatment choices. Quantitative data indicates that higher education is associated with more feelings of conflict, perhaps due to being more discerning and overthinking treatment choices. Qualitative data suggests that parents with higher levels of ADHD literacy feel disappointed and discouraged when the system doesn't show up for them.

	• He has no external supports because we haven't been able to get that wrap around approach for him. We are sitting and waiting on referrals bla bla bla So, you know, when I think about what difference the diagnosis has made, I'm not really sure.		

Chapter 6: Conclusions and Future Directions

Conclusions and Contribution

The current work was intended to provide enhanced understandings about the informational needs and preferences of parents whose children have recently been diagnosed with ADHD, the pathways and processes through which parents acquire information about ADHD, and how acquiring information about ADHD is related to parents' confidence making ADHD treatment decisions. The use of a concurrent mixed-methods design provided two complementary perspectives on this understudied area. Quantitative data obtained from online surveys examined broad trends in the types and sources of information used by parents to learn about ADHD, and it was also used to examine whether factors associated with mental health service use were also associated with parents' acquisition of ADHD literacy, and in turn, with their comfort making ADHD treatment decisions. Qualitative interview data explored these topics from an inductive and atheoretical perspective, providing a richly textured and contextual backdrop to these broad trends, and shedding insight into how and why specific types of information and experiences matter for parents as they navigate ADHD, and how they operate within our local environment. Results of this study thus offer a novel and nuanced appreciation into parents' information needs and their functional impact on treatment confidence.

Several conclusions resulted from merging these two sets of data. First, consistent with previous research (e.g., Ahmed et al., 2014; Sciberras et al., 2010), findings indicate that parents seek broad and holistic understanding about ADHD, with top information needs that pertain to understanding their children's emotional and behavioural difficulties, and in finding strategies to help them. However, despite parents actively seeking information about ADHD from a variety of sources, they described widespread challenges in accessing relevant information due to

difficulties with the readability, relatability, and distribution of publicly available informational materials. Parents additionally provided numerous suggestions and alternatives that could improve their experience learning about ADHD, such as creation of more in-depth and relatable materials that were less reliant on text. These latter results serve as an important extension to existing findings, as they address the accessibility of ADHD-related information for parents, and they also provide concrete and actionable steps which may be taken to improve the content and distribution of parent-focused ADHD informational materials.

Second, current findings indicate that parental acquisition of ADHD literacy likely results from a culmination of several pathways. Domains articulated within the NEM-II model, including personal factors, social networks, and treatment system characteristics each were implicated in how parents learn about ADHD and its treatments. Personal factors including higher education levels and other aspects of privileged social location (e.g., medical or research experience, financial stability, occupational flexibility) and the ability to persist during personal stress facilitated parents' ability to access needed information and supports, most notably in the form of using Internet-based information and private practitioners for ADHD treatment. Parents also placed high value on community networks and health-care providers as sources of ADHD information, and each of these were viewed by parents as offering uniquely valuable types of information and support. These findings are broadly consistent with previous research which indicates that higher SES, the presence of supportive networks, and treatment system availability are associated with greater ADHD service utilization (Bax et al., 2019; Corkum et al., 2015; Koerting et al., 2013), and suggest that models of mental health service use may be useful starting points for understanding the process of how individuals come to acquire mental health literacy. More broadly, however, these results are consistent with a social determinant of health

framework for mental health literacy and service utilization in general, such that personal characteristics and social resources each play in important role in the way that individuals can acquire and use resources to promote their well-being (Marmot, 2005). These perspectives may help further inform approaches to mitigating barriers in accessing ADHD information and treatment.

Third, as parents feel better informed about ADHD, they experience less conflict about their treatment decisions. This finding is consistent with several studies which have found greater degrees of treatment utilization and adherence when parents feel well-informed about their child's ADHD (e.g., Bai et al., 2015; Corkum et al., 2016; Monastra, 2005, Kolko et al., 2014). However, parents nonetheless remained dissatisfied with many aspects of their children's ADHD treatments, and they described ADHD treatment experiences that were largely unsatisfactory due to difficulties receiving timely, holistic, and coordinated care. These experiences have left parents feeling unhappy with ADHD treatment overall, and worried for their children's well-being. These findings mirror the conclusions of the recent report by the Virgo group (2018) and underscore the need for locally accessible and coordinated ADHD treatment. Information about ADHD will ultimately be of limited utility in the absence of effective treatment options.

This is the first known study to approach the topic of parental information needs in childhood ADHD from a knowledge translation framework, using the Knowledge-to-Action model (KTA; Graham et al., 2006) to approach the question of why parents struggle to obtain an accurate understanding about ADHD and its treatments. Findings from this investigation suggest there is an abundance of publicly available information about childhood ADHD. However, parents nonetheless report consistent difficulties accessing information that they consider to be relevant, trustworthy, and usable. Use of the KTA model has thus provided additional

understanding into some of the basis for this knowledge-to-action gap. Specifically, by examining the situational contexts of Manitoba parents (i.e., KTA action phase 2), this study has provided novel understanding about how and why specific settings and information sources are important for parents' learning. Though examination of barriers (i.e., KTA action phase 3), this study has identified some of the personal, social, and organizational barriers facing parents who have sought out ADHD information and treatment for their children, thus paving the way for the development of targeted and specific initiatives that can match their areas of need. Current findings highlight the utility of further interdisciplinary research that integrates knowledge translation frameworks within the study of mental health literacy and psychological treatment.

Implications

Findings of this study have meaningful implications at several levels. First, it is important that primary care providers such as family doctors and pediatricians appreciate the importance of their role in parents' diagnostic and treatment journeys. Results from both quantitative and qualitative datasets suggest that parents place a high level of value and trust in primary care providers for their expertise and as a first point of contact within the health care system. Accordingly, these providers need to be well-versed to counsel parents about a range of evidence-supported ADHD treatments, including psychosocial interventions as well as medication options. It is also important that providers are aware of the high levels of stress and distress facing parents, so that they can offer needed validation and emotional support during office visits. Primary care providers may perhaps consider themselves as long-term partners in ADHD care, rather than merely diagnosticians or prescribers. This is particularly important considering the capacity concerns and extensive wait times to specialists within our treatment systems. Having primary care providers who are highly knowledgeable and supportive about

ADHD will be important for meeting the information and treatment needs of parents early on, and it may increase the likelihood that they stay engaged in care.

Other health care providers in the community, such as psychologists, counsellors, and occupational therapists, likewise need to recognize the many information and emotional needs facing parents of children with ADHD, as well as the challenges they face in acquiring sufficient ADHD literacy. It is thusly important that clinicians create opportunities to provide parents with meaningful and relevant non-generic ADHD psychoeducation that specifically targets the needs of their children, as has been suggested by previous outcome research on the topic of psychoeducation (Bai et al., 2015, Kolko et al., 2014; Monastra 2014). With the high levels of emotional and psychological stress among parents whose children have a recent diagnosis of ADHD, articulated in the current study as well as in additional literature (e.g., Theule et al., 2013), clinicians may additionally wish to ensure that they offer evidence-based emotional and parenting support as part of their ADHD care. A final implication for ADHD clinicians is the need to incorporate a systems approach for ADHD treatment planning. In recognition of the many different environments that are impacted by the presence of ADHD symptoms, and as noted by many participants within this body of work, parents wish for co-ordination in ADHD treatment planning, including supporting children within family systems, working with medical doctors who prescribe ADHD medications, and collaborating with schools so children can receive appropriate ADHD adaptations and supports.

There are additional and broader health policy implications suggested by these findings. Results of the current study, together with Manitoba's recent provincial review of mental health care services (Virgo, 2018), indicate ongoing gaps in providing accessible and coordinated ADHD care to children and their families. This suggests a need to consider structural changes

within local health care delivery systems, such as creating more streamlined referral pathways and communication lines between specialists and primary care doctors, structured communication channels between care providers and community agencies, and methods to ensure collaboration and access to school supports once an ADHD diagnosis is confirmed.

Future Directions

Results of the current research suggest many areas of need pertaining to childhood ADHD within our local community. However, with the identification of need comes the impetus and potential for innovation, and the development of new approaches for parent-directed knowledge translation and service delivery. Several actionable steps are suggested by current findings.

Findings from this study conveyed a need for greater understanding on parent perspectives about what constitutes mental health literacy, and how mental health literacy can inform engagement with mental health care. Even within this initial exploratory study, parents offered numerous creative and imaginative solutions to address this information gap. Parents shared ideas about creating relatable informational materials via use of podcasts, graphic novels, and use of social media. They proposed mechanisms for better distribution of ADHD information within pharmacies, schools, and clinical settings. These suggestions speak to the utility of local level community research partnerships that could engage parents in ADHD knowledge translation research. A recent systematic review on patient engagement in research reported a compelling rationale for greater involvement of patients in research settings, including increased study enrollment rates, improved design of study protocols, and development of relevant study outcomes (Domecq et al., 2014). In this regard, one could easily envision the utility of parent focus-groups to help develop content and a viable dissemination strategy for a

series of ADHD informational materials. This could be a meaningful extension of this research and provide a new inroad for further development of locally based ADHD knowledge translation initiatives.

Another novel finding from this investigation was the rich depiction of how and why various sources of information were meaningful for parents, and specifically how community networks and clinical sources of information each informed parents understanding of ADHD in different ways. This finding speaks to a need for bridge building between these uniquely important information sources. For instance, creating opportunities for health care expert speakers to attend community groups could help parents receive evidence-informed information within a relatable and supportive peer context. Conversely, information-sharing and community collaboration between health care providers and community supports could facilitate providers' ability to provide information about local community supports and resources for ADHD, thus creating potential for more seamless and cohesive informational and treatment journey for parents. Notably absent in Manitoba are community-based ADHD agencies with protected funding, which could offer peer support, systems navigation, and evidence-based information to parents. These types of non-profit agencies already have a local presence in Manitoba, including the Mood Disorders Association of Manitoba, the Anxiety Disorders Association of Manitoba, the Manitoba Schizophrenia Society, and the Obsessive-Compulsive Disorder Centre Manitoba (Virgo, 2018). It is curious and unfortunate that a similar support agency for ADHD is not available to serve our local population. Given current study findings, creation of a formalized community-based ADHD support hub could have practical and tangible value.

Although the focus of this investigation was on parental information needs, current findings indicate that information in the absence of meaningful ADHD treatment has limited

value. Provision of information may even have iatrogenic effects if or when parents become knowledgeable about the types of services their children need, but they are unable to access them. Results from this investigation illustrate a clear need for ongoing capacity building for ADHD treatment within our health care systems and within our schools, so that children and their families can access coordinated and evidence-supported ADHD treatments within and across their communities.

Given that the intention of the proposed study is to increase awareness and knowledge about parents' information needs in ADHD treatment, post-study knowledge translation is an essential follow-up component of this work (Graham et al., 2013). There are several target audiences for current findings. For instance, health care providers may benefit from discussion about their highly trusted role, and the types of information parents most want to learn about. Additionally, local community agencies and schools may benefit from provision of evidence-based information about ADHD and its treatment interventions, and information about systems navigation. Several dissemination strategies will be helpful for these audiences, including user-friendly summaries (print and web-based) of current findings, and small-group educational outreach. As these target audiences have different roles in the treatment and management of ADHD, different time constraints on their service delivery, and different areas of background knowledge about ADHD, materials need to be contextualized and tailored so they can be maximally relevant for the needs of their users.

Limitations

As with any investigation, there are limitations to the current study. First, the effect of the COVID-19 pandemic must be acknowledged. As all data collection for this investigation took place online, participants in this study were limited to individuals with reliable internet access,

and who comprised a small, relatively well-educated, and financially stable sample of female parent respondents. Accordingly, this sample is admittedly not fully reflective of the general population of parents of children with a recent ADHD diagnosis. It is noteworthy that findings relating to poor accessibility of ADHD information, barriers to ADHD information and treatment, and dissatisfaction with ADHD treatments, emerged even within this high-functioning and small sample. It is likely that a more representative and diverse sample of parents would have experienced even greater levels of difficulty accessing information that was important for them. It also bears mention that a recent review of unmet needs among people with ADHD and/or their caregivers yielded similar findings as this study, including a desire for multi-modal treatment, greater access to clinical services and supports, and improved ADHD education (Sciberras et al., 2023). Nonetheless, a re-examination of some of the current questions during this post-pandemic period, including the ability to conduct in-person interviews with a larger and more diverse sample of parents, will be helpful in ensuring that results reflect the needs of a broad range of individuals.

The COVID-19 pandemic may have additionally influenced current findings in that the stressors associated with COVID-19 and resulting public health restrictions may have shaped the way parents experienced and understood their children's ADHD symptoms. For instance, with additional time spent at home and less time spent in school and/or extra-curricular activities, parents have been more likely to need information about the specific areas of functioning that they were exposed to on a daily basis (e.g., parenting strategies, academic strategies), and less likely to need information in areas of need that might have been occurring if children were spending more time outside of the home (e.g., social skills). It is also important to recognize that parents may have experienced heightened stress levels in general, which could also impact their

perceptions of their experiences. Recent research has also found that children experiencing ADHD suffered an increase in their symptoms during pandemic restrictions (Summerton et al., 2023). Current findings are largely consistent with the types of information needs and stressors that have been documented in other studies, thus somewhat minimizing generalizability concerns in this regard. However, it will be helpful and important to re-examine parents' information and treatment needs as our communities evolve away from the COVID-19 pandemic era.

Another important area of limitation involves the scope of the questions posed within the quantitative strand of this preliminary and exploratory study, and the range of factors that were examined as contributing to ADHD literacy. This investigation drew on research from the mental health service utilization literature, using the NEM-II model and access to various types of information sources to frame potential facilitators and barriers for information acquisition about ADHD. While domains of the NEM-II model were each implicated in how parents access ADHD information, quantitative results indicated that mere access to each of these various information sources did not account for significant portions of variance in parents' self-reported ADHD literacy. As such, there are likely other factors at play on this topic.

Other literature fields and conceptual models may be helpful in exploring how parents acquire understanding about ADHD and the conditions under which this is most likely to occur. For instance, within the child psychopathology literature, numerous individual-level variables have been linked to the provision of mental health supports for children, including parental motivation, self-efficacy, confidence, and a parent's own mental health needs (Smith et al., 2014). The child advocacy literature has also identified individual-level variables that influence the degree to which parents engage with treatment services, including sense of autonomy, communication skills, and role-identity (Siller, 2013; Goldman, 2020). Within the

implementation science literature, the Behaviour Change Wheel (Michie, Stralen & West, 2011) articulates a combination of individual and structural variables as contributing to knowledge uptake, including elements of individual capability, structural opportunities, and motivation.

For the current study, pragmatic concerns about survey length and participant burden precluded inclusion of the range of individual-level and structural-level variables which are likely associated with parental information acquisition about ADHD. As well, the small sample size in this study precluded a more sophisticated analysis of the range of potential variables and pathways within the NEM-II model. Incorporating diverse literatures into subsequent studies, with the specific inclusion of individual- and structural-level predictor variables, would be meaningful ways to extend the findings of the current project.

An additional consideration for this study involves the types of conclusions that may be drawn about parental treatment decision-making. This study explored factors associated with parents' comfort about their treatment decisions. However, it did not consider whether parents were making evidence-based treatment decisions, or if treatment decisions resulted in improved functioning for their child. It is possible that some parents may have felt comfortable making treatment decisions that are not supported by clinical practice guidelines, or they might have felt comfortable with their decisions even in the absence of their child's functional improvement. While this may be seen as a shortcoming if one were to consider how this study informs the clinical outcome literature, it is important to recognize that the intention of this study was to capture and understand the range of informational needs, experiences, and treatment decisions of parents. This understanding is a fundamental first step for ultimately creating greater levels of treatment engagement and understanding between parents and ADHD service providers.

Concluding Comments

ADHD is among the most highly diagnosed neurodevelopmental conditions in young children. The functional impacts of untreated ADHD are multiple, complex, and have the potential to be life-altering. The objectives of this investigation were to enhance understanding of parental information needs after their child's ADHD diagnosis, to understand how parents interact with various information sources, and to examine the functional impact of information on treatment confidence. Actionable goals of this study include the development of meaningful and usable informational materials for parents, and to enhance our delivery of ADHD-focused care. Results of this study provided novel understanding about the complexities faced by parents as they seek information to understand ADHD, and thusly shed light on why ADHD continues to be plagued by misunderstandings, stigma, and treatment reluctance or non-adherence. With further research, and with ongoing contributions from parents and from providers of care, we have promise to develop more systematic practices for providing parents with relevant and high-quality information that can inform their treatment decision-making, and ultimately yield positive outcomes for their children.

References

Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, A. (1999). Health literacy: Report of the Council on Scientific Affairs. *JAMA : The Journal of the American Medical Association*, 281(6), 552–557. https://doi.org/10.1001/jama.281.6.552

Ahmed, R., Borst, J., Yong, C., & Aslani, P. (2014). Do parents of children with attention-deficit/hyperactivity disorder (ADHD) receive adequate information about the disorder and its treatments? A qualitative investigation. *Patient Preference and Adherence*, 8, 661–670. https://doi.org/10.2147/PPA.S60164.

Altin, S., Finke, I., Kautz-Freimuth, S., & Stock, S. (2014). The evolution of health literacy assessment tools: a systematic review. *BMC Public Health*, 14(1), 1207–. https://doi.org/10.1186/1471-2458-14-1207

American Psychiatric Association. (2013). Neurodevelopmental Disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Author.

Andersen, R. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36(1), 1–10. https://doi.org/10.2307/2137284

Andersen, R. (2008). National health surveys and the behavioral model of health services use. *Medical Care*, 46(7), 647–653. https://doi.org/10.1097/mlr.0b013e31817a835d

Bai, G., Wang, Y., Yang, L., & Niu, W. (2015). Effectiveness of a focused, brief psychoeducation program for parents of ADHD children: Improvement of medication

adherence and symptoms. *Neuropsychiatric Disease and Treatment*, 11, 2721–2735. https://doi.org/10.2147/NDT.S88625

Bandura, A., Barbaranelli, C., Caprara, G. V., & Pastorelli, C. (1996). Multifaceted impact of self-efficacy beliefs on academic functioning. *Child Development*, 67(3), 1206–1222. https://doi.org/10.1111/j.1467-8624.1996.tb01791.x

Bard, D. E., Wolraich, M. L., Neas, B., Doffing, M., & Beck, L. (2013). The psychometric properties of the Vanderbilt attention-deficit hyperactivity disorder diagnostic parent rating scale in a community population. *Journal of Developmental and Behavioral Pediatrics*, 34(2), 72–82. https://doi.org/10.1097/DBP.0b013e31827a3a22

Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51*(6),* 1173–1182. https://doi.org/10.1037/0022-3514.51.6.1173

Bax, A.C., Bard, D.E., Cuffe, S.P, McKeown, R.E & Wolraich, M.L.. (2019). The association between race/ethnicity and socioeconomic factors and the diagnosis and treatment of children with attention-deficit hyperactivity disorder. *Journal of Developmental and Behavioral Pediatrics*, 40(2), 81–91. https://doi.org/10.1097/DBP.0000000000000626

Bélanger, S., Andrews, D., Gray, C., Korczak, D., & Bélanger, S. (2018). ADHD in children and youth: Part 1-Etiology, diagnosis, and comorbidity. *Paediatrics and Child Health*, 23(7), 447–453. https://doi.org/10.1093/pch/pxy109

Berkman, N., Sheridan, S., Donahue, K., Halpern, D., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine*, 155(2), 97–107. https://doi.org/10.7326/0003-4819-155-2-201107190-00005

Bisset, M., Brown, L. E., Bhide, S., Patel, P., Zendarski, N., Coghill, D., Payne, L., Bellgrove, M. A., Middeldorp, C. M., & Sciberras, E. (2023). Practitioner Review: It's time to bridge the gap – understanding the unmet needs of consumers with attention-deficit/hyperactivity disorder – a systematic review and recommendations. *Journal of Child Psychology and Psychiatry*, 64(6), 848–858. https://doi.org/10.1111/jcpp.13752

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3:2, 77-101, https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-Being*, 9(1), 26152–2. https://doi.org/10.3402/qhw.v9.26152

Braun, V., & Clarke, V. (2019). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, 1–16. https://doi.org/10.1080/2159676x.2019.1704846

Braun, V., Clarke, V., Hayfield, N., Terry, G. (2019). Thematic Analysis. In: Liamputtong, P. (Ed.) *Handbook of Research Methods in Health Social Sciences.* Springer, Singapore. https://doi-org.uml.idm.oclc.org/10.1007/978-981-10-5251-4_103

Braun, V., & Clarke, V. (2020). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, 1–25. https://doi.org/10.1080/14780887.2020.1769238

Brinkman, W., & Epstein, J. (2011). Treatment planning for children with attention-deficit/hyperactivity disorder: Treatment utilization and family preferences. *Patient Preference and Adherence*, 5, 45–56. https://doi.org/10.2147/PPA.S10647

Brinkman, W., Hartl Majcher, J., Poling, L., Shi, G., Zender, M., Sucharew, H., Britto, M., & Epstein, J. (2013). Shared decision-making to improve attention-deficit hyperactivity disorder care. *Patient Education and Counseling*, 93(1), 95–101. https://doi.org/10.1016/j.pec.2013.04.009

Brinkman, W., Sherman, S., Zmitrovich, A., Visscher, M., Crosby, L., Phelan, K., & Donovan, E. (2009). Parental angst making and revisiting decisions about treatment of attention-deficit/hyperactivity disorder. *Pediatrics*, 124(2), 580–589. https://doi.org/10.1542/peds.2008-2569

Brody, D. S. (1980). The patient's role in clinical decision-making. *Annals of Internal Medicine*, 93, 718-722.

Bussing, R, Meyer, J., Zima, B.T., Mason, D.M., Gary, F.A., & Garvan, C.W. (2015). Childhood ADHD symptoms: Association with parental social networks and mental health service use during adolescence. *International Journal of Environmental Research and Public Health*, 12(9), 11893–11909. https://doi.org/10.3390/ijerph120911893CADDRA (2020).

Bussing, R., Zima, B., Mason, D., Meyer, J., White, K., Garvan, C., & Bussing, R. (2012). ADHD knowledge, perceptions, and information sources: Perspectives from a community sample of adolescents and their parents. *Journal of Adolescent Health*, 51(6), 593–600. Retrieved from http://search.proquest.com/docview/1315886374/

Canadian ADHD Resource Alliance (2018). *Canadian ADHD Practice Guidelines, Fourth Edition.* https://www.caddra.ca/wp-content/uploads/CADDRA-Guidelines-4th-Edition_-Feb2018.pdf.

Canadian ADHD Resource Alliance (2020). *ADHD and COVID-19: Frequently Asked Questions.* https://www.caddra.ca/wp-content/uploads/CADDRA-ADHD-and-Virtual-Care-FAQ.pdf.

Charach, A., Carson, P., Fox, S., Ali, M., Beckett, J., & Lim, C. (2013). Interventions for preschool children at high risk for ADHD: A comparative effectiveness review. *Pediatrics* 131(5), e1584–e1604. https://doi.org/10.1542/peds.2012-0974

Chartier, M., Brownell, M., MacWilliam, L., Valdivia, J., Nie, Y., Ekuma, O., Burchill, C., Hu, M., Rajotte, C., & Kulbaba, C. (2016). *The mental health of Manitoba's children*. Wininpeg, MB. Manitoba Centre for Health Policy.

Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine*, 44(5), 681–692. https://doi.org/10.1016/s0277-9536(96)00221-3

Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine,* 49(5), 651–661. https://doi.org/10.1016/s0277-9536(99)00145-8

Chinn, D. (2011). Critical health literacy: A review and critical analysis. *Social Science & Medicine,* 73(1), 60–67. https://doi.org/10.1016/j.socscimed.2011.04.004

Climie, E., & Henley, L. (2018). Canadian parents and children's knowledge of ADHD. *Vulnerable Children and Youth Studies*, 13(3), 266–275. https://doi.org/10.1080/17450128.2018.1484975

Coletti, D. J., Pappadopulos, E., Katsiotas, N. J., Berest, A., Jensen, P. S., & Kafantaris, V. (2012). Parent perspectives on the decision to initiate medication treatment of attention-deficit/hyperactivity disorder. *Journal of Child and Adolescent Psychopharmacology*, 22(3), 226–237. https://doi.org/10.1089/cap.2011.0090

Collett, B.R., Ohan, J.L., & Myers, K.M. (2003). Ten-year review of rating scales. V: Scales assessing attention-deficit/hyperactivity disorder. *Journal of the American Academy of Child and Adolescent Psychiatry,* 42, 1015-1037.

Caprara, Vecchione, M., Alessandri, G., Gerbino, M., & Barbaranelli, C. (2011). The contribution of personality traits and self-efficacy beliefs to academic achievement: A longitudinal study. *British Journal of Educational Psychology*, 81(1), 78–96. https://doi.org/10.1348/2044-8279.002004

Corkum, P., Bessey, M., McGonnell, M., & Dorbeck, A. (2015). Barriers to evidence-based treatment for children with attention-deficit/hyperactivity disorder. *Attention Deficit and Hyperactivity Disorders*, 7(1), 49–74. https://doi.org/10.1007/s12402-014-0152-z

Corkum, P., Rimer, P., & Schachar, R. (2016). Parental knowledge of attention-deficit hyperactivity disorder and opinions of treatment options: Impact on enrolment and adherence to a 12-month treatment trial. *Canadian Journal of Psychiatry*, 44(10), 1043–1048. https://doi.org/10.1177/070674379904401011

Cost, K., Crosbie, J., Anagnostou, E., Birken, C., Charach, A., Monga, S., Kelley, E., Nicolson, R., Maguire, J., Burton, C., Schachar, R., Arnold, P., & Korczak, D. J. (2022). Mostly worse, occasionally better: Impact of COVID-19 pandemic on the mental health of Canadian children and adolescents. *European Child and Adolescent Psychiatry*, 31(4), 671–684. https://doi.org/10.1007/s00787-021-01744-3

Coulter, A., & Ellins, J. (2006). Patient-focused interventions: A review of the evidence (Vol. 1). London: Health Foundation. https://www.health.org.uk/sites/default/files/PatientFocusedInterventions_ReviewOfTheEvidence.pdf Accessed August 2019.

Coulter, A., & Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *British Medical Journal*, 335(7609), 24–27. https://doi.org/10.1136/bmj.39246.581169.80

Coulter, A. & Collins, A. (2011). Making shared decision making a reality: No decision about me, without me. The King's Fund. https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf Accessed December 26, 2019.

Creswell, J., & Plano Clark, V. (2018). *Designing and conducting mixed methods research* (3rd ed.). Sage., California.

Cumming, G. (2014). The new statistics: Why and how. *Psychological Science*, 25(1), 7–29. https://doi.org/10.1177/0956797613504966

Cumming, G., & Finch, S. (2005). Inference by eye: Confidence intervals and how to read pictures of data. *American Psychologist*, 60(2), 170–180. https://doi.org/10.1037/0003-066X.60.2.170

Cummings, P. & Koepsell, T. (2010). P Values vs estimates of association with confidence intervals. *Archives of Pediatrics and Adolescent Medicine*, 164(2), 193–196. https://doi.org/10.1001/archpediatrics.2009.266

Dahl, V., Ramakrishnan, A., Spears, A., Jorge, A., Lu, J., Bigio, N., & Chacko, A. (2019). Psychoeducation interventions for parents and teachers of children and adolescents with ADHD: A systematic review of the literature. *Journal of Developmental and Physical Disabilities*, 32(2), 257–292. https://doi.org/10.1007/s10882-019-09691-3

Daley, D., van der Oord, S., Ferrin, M., Danckaerts, M., Doepfner, M., Cortese, S., & Sonuga-Barke, E. (2014). Behavioral interventions in attention-deficit/hyperactivity disorder: A

meta-analysis of randomized controlled trials across multiple outcome domains. *Journal of the American Academy of Child and Adolescent Psychiatry*, 53(8), 835–847.e5. https://doi.org/10.1016/j.jaac.2014.05.013

Davis, C., Claudius, M., Palinkas, L., Wong, J., & Leslie, L. (2012). Putting families in the center: Family perspectives on decision making and ADHD and implications for ADHD Care. *Journal of Attention Disorders*, 16(8), 675–684. https://doi.org/10.1177/1087054711413077

Deber, R. (1994). Physicians in health care management: 7. The patient-physician partnership: Changing roles and the desire for information. *Canadian Medical Association Journal*, 151, 171-176.

Domecq, J., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., Brito, J. P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P., Eton, D., Sloan, J., Montori, V., Asi, N., Dabrh, A. M. A., & Murad, M. H. (2014). Patient engagement in research: a systematic review. *BMC Health Services Research*, 14(1), 89–89. https://doi.org/10.1186/1472-6963-14-89

Edwards, M., Davies, M., & Edwards, A. (2009). What are the external influences on information exchange and shared decision-making in healthcare consultations: A meta-synthesis of the literature. *Patient Education and Counseling*, 75(1), 37–52. https://doi.org/10.1016/j.pec.2008.09.025

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision

making: A model for clinical practice. *Journal of General Internal Medicine*, 27(10), 1361–1367. https://doi.org/10.1007/s11606-012-2077-6

Emanuel, E., & Emanuel, L. (1992). Four models of the physician-patient relationship. *JAMA: the Journal of the American Medical Association*, 267(16), 2221–2226. https://doi.org/10.1001/jama.1992.03480160079038

Feldman, M., Charach, A., & Bélanger, S. (2018). ADHD in children and youth: Part 2-Treatment. *Paediatrics and Child Health*, 23(7), 462–472. https://doi.org/10.1093/pch/pxy113

Ferrin, M., Perez-Ayala, V., El-Abd, S., Lax-Pericall, T., Jacobs, B., Bilbow, A., & Taylor, E. (2016). A randomized controlled trial evaluating the efficacy of a psychoeducation program for families of children and adolescents with ADHD in the United Kingdom: Results after a 6-month follow-up. *Journal of Attention Disorders*, 24(5), 768–779. https://doi.org/10.1177/1087054715626509

Ferrin, M., Moreno-Granados, J., Salcedo-Marin, M., Ruiz-Veguilla, M., Perez-Ayala, V., & Taylor, E. (2014). Evaluation of a psychoeducation programme for parents of children and adolescents with ADHD: Immediate and long-term effects using a blind randomized controlled trial. *European Child and Adolescent Psychiatry*, 23(8), 637–647. https://doi.org/10.1007/s00787-013-0494-7

Finch, S., & Cumming, G. (2009). Putting research in context: Understanding confidence intervals from one or more studies. *Journal of Pediatric Psychology*, 34(9), 903–916. https://doi.org/10.1093/jpepsy/jsn118

Fiks, A., Hughes, C., Gafen, A., Guevara, J., & Barg, F. (2011). Contrasting parents' and pediatricians' perspectives on shared decision-making in ADHD. *Pediatrics*, 127(1), 188–196. https://doi.org/10.1542/peds.2010-1510

Fiks, A. & Jimenez, M. (2010). The promise of shared decision-making in paediatrics. *Acta Paediatrica*, *99*(10), 1464–1466. https://doi.org/10.1111/j.1651-2227.2010.01978.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. https://doi.org/10.1037/ipp0000094

Gagnon, E. & Recklitis, C. (2003). Parents' decision-making preferences in pediatric oncology: The relationship to health care involvement and complementary therapy use. *Psycho-Oncology*, 12(5), 442–452. https://doi.org/10.1002/pon.655

Goldberg, D. & Huxley, P. (1980). *Mental illness in the community: The pathway to psychiatric care.* London: Tavistock Publications.

Graham, I., Logan, J., Harrison, M., Straus, S., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *Journal of Continuing Education in the Health Professions*, 26(1), 13–24. https://doi.org/10.1002/chp.47

Graham, I.D., Tetroe, J. & Gagnon, M. (2013). Knowledge dissemination: End of grant knowledge translation. In S.E. Straus, J. Tetroe, & Graham, I.D. (Eds.), *Knowledge translation in health care: Moving from evidence to practice*. Oxford: Wiley. (pp.75-92)

Green, H. & Pescosolido, B. A. (2023). Social pathways to care: how community-based network ties shape the health care response of individuals with mental health problems. *Social Psychiatry and Psychiatric Epidemiology*, 1–12. https://doi.org/10.1007/s00127-023-02476-2

Hadlaczky, G., Hökby, S., Mkrtchian, A., Carli, V., & Wasserman, D. (2014). Mental Health First Aid is an effective public health intervention for improving knowledge, attitudes, and behaviour: A meta-analysis. *International Review of Psychiatry*, 26(4), 467–475. https://doi.org/10.3109/09540261.2014.924910

Harrison, C. (2004). Treatment decisions regarding infants, children and adolescents. *Paediatrics and Child Health*, *9*(2), 99–114. https://doi.org/10.1093/pch/9.2.99

Henshaw, E., & Freedman-Doan, C. (2009). Conceptualizing mental health care utilization using the health belief model. *Clinical Psychology: Science and Practice*, 16(4), 420–439. https://doi.org/10.1111/j.1468-2850.2009.01181.x

Hesse-Biber, S. (2017). *The practice of qualitative research: engaging students in the research process* (3rd Ed). California, SAGE.

Institute of Medicine (US) Committee on Health Literacy; Nielsen-Bohlman L., Panzer A.M., & Kindig D.A., (Eds.). Health literacy: A prescription to end confusion. Washington (DC): National Academies Press (US); 2004. https://www.ncbi.nlm.nih.gov/books/NBK216032/ doi: 10.17226/10883. Accessed December 26, 2019.

Isa, A., Muhamad, N. A., Mustapha, N., Abdul Mutalip, M. H., Lodz, N. A., Mohd Royali, M. S., Baharin, M. F., Zaini, Z., & SM, S. (2017). Association between self-efficacy and health behaviour in disease control: A systematic review. *Global Journal of Health Science*, 10(1), 18–. https://doi.org/10.5539/gjhs.v10n1p18

Jorm, A. (2012). Mental health literacy. American Psychologist, 67(3), 231–243. https://doi.org/10.1037/a0025957

Jorm, A. (2015). Why we need the concept of "Mental health literacy." *Health Communication*, 30(12), 1166–1168. https://doi.org/10.1080/10410236.2015.1037423

Jorm, A., Korten, A., Jacomb, P., Christensen, H., Rodgers, B., & Pollitt, P. (1997). "Mental health literacy": A survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. *Medical Journal of Australia*, 166(4), 182–186. https://doi.org/10.5694/j.1326-5377.1997.tb140071.

Jefsen, O., Rohde, C., Nørremark, B., & Østergaard, S. (2020). Editorial perspective: COVID-19 pandemic-related psychopathology in children and adolescents with mental illness. *Journal of Child Psychology and Psychiatry*. https://doi.org/10.1111/jcpp.13292

King, S., Ritchie, K. C., McGonnell, M., Doe, C., Corkum, P. V., Côté, E., & Cox, A. (2021). Paging Dr. Google: Availability and Reliability of Online Evidence-Based Treatment Information about ADHD. *Evidence-Based Practice in Child and Adolescent Mental Health*, 6(2), 277–289. https://doi.org/10.1080/23794925.2021.1901632

Klein, Walker, C., Aumann, K., Anjos, K., & Terry, J. (2022). Peer support groups for parent-carers of children with attention deficit hyperactivity disorder: the importance of solidarity as care. *Disability and Society*, 34(9-10), 1445–1461. https://doi.org/10.1080/09687599.2019.1584090

Knapp, C., Huang, I., Madden, V., Vadaparampil, S., Quinn, G., & Shenkman, E. (2009). An evaluation of two decision-making scales for children with life-limiting illnesses. *Palliative Medicine*, 23(6), 518–525. https://doi.org/10.1177/0269216309104892

Knapp, C., Sberna-Hinojosa, M., Baron-Lee, J., Curtis, C., & Huang, I. (2014). Does decisional conflict differ across race and ethnicity groups? A study of parents whose children have a life-threatening illness. *Journal of Palliative Medicine*, 17(5), 559–567. https://doi.org/10.1089/jpm.2013.0604

Knopf, A. (2020). Telepsychiatry coming into its own with COVID-19. *The Brown University Child and Adolescent Psychopharmacology Update*, 22(5), 1–3. https://doi.org/10.1002/cpu.30487

Koerting, J., Smith, E., Knowles, M., Latter, S., Elsey, H., McCann, D., Thompson, M., & Sonuga-Barke, E. (2013). Barriers to, and facilitators of, parenting programmes for childhood behaviour problems: A qualitative synthesis of studies of parents' and professionals' perceptions. *European Child and Adolescent Psychiatry*, *22(11)*, 653–670. https://doi.org/10.1007/s00787-013-0401-2

Kolko, D., Campo, J., Kilbourne, A., Hart, J., Sakolsky, D., & Wisniewski, S. (2014). Collaborative care outcomes for pediatric behavioral health problems: A cluster randomized trial. *Pediatrics* 133(4), e981–e992. https://doi.org/10.1542/peds.2013-2516

Lawrance, L., & McLeroy, K. R. (1986). Self-efficacy and health education. *The Journal of School Health*, 56(8), 317–321. https://doi.org/10.1111/j.1746-1561.1986.tb05761.x

Leitch, S., Sciberras, E., Post, B., Gerner, B., Rinehart, N., Nicholson, J. & Evans, S. (2019) Experience of stress in parents of children with ADHD: A qualitative study. *International Journal of Qualitative Studies on Health and Well-being*, 14:1, https://doi.org/ 10.1080/17482631.2019.1690091

Leslie, L., Plemmons, D., Monn, A., & Palinkas, L. (2007). Investigating ADHD treatment trajectories: Listening to families' stories about medication use. *Journal of Developmental and Behavioral Pediatrics*, 28(3), 179–188. https://doi.org/10.1097/dbp.0b013e3180324d9a

Levesque, P., Davidson, S., Kidder, K., & Levesque, P. (2007). Knowledge exchange for attention-deficit/hyperactivity disorder research: An integrated evidence and knowledge exchange framework leading to more effective research dissemination practices. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 16(2), 51–56.

Liverpool, S., Pereira, B., Hayes, D., Wolpert, M., & Edbrooke-Childs, J. (2021). A scoping review and assessment of essential elements of shared decision-making of parent-involved

interventions in child and adolescent mental health. *European Child and Adolescent Psychiatry*, 30(9), 1319–1338. https://doi.org/10.1007/s00787-020-01530-7

Lo, K., Gupta, T., & Keating, J. (2018). Interventions to promote mental health literacy in university students and their clinical educators. A systematic review of randomised control trials. *Health Professions Education*, 4(3), 161–175. https://doi.org/10.1016/j.hpe.2017.08.001

Marmot., M. (2005). Social determinants of health inequalities. *The Lancet (British Edition),* 365(9464), 1099–1104. https://doi.org/10.1016/S0140-6736(05)71146-6

McGrath, J. (2020). ADHD and Covid-19: Current roadblocks and future opportunities. *Irish Journal of Psychological Medicine*, 1–22. https://doi.org/10.1017/ipm.2020.53

McKenna, K., Collier, J., Hewitt, M., & Blake, H. (2010). Parental involvement in paediatric cancer treatment decisions. *European Journal of Cancer Care*, 19(5), 621–630. https://doi.org/10.1111/j.1365-2354.2009.01116.x

Mak, L., Walker, J., Hiebert-Murphy, D., & Altman, G. (2017). Information needs and preferences of parents considering treatment of child anxiety. *Journal of Developmental and Behavioral Pediatrics*, 38(3), 173–180. https://doi.org/10.1097/dbp.0000000000000388

Makoul, G. & Clayman, M. (2006). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60(3), 301–312. https://doi.org/10.1016/j.pec.2005.06.010

Michie, S., van Stralen, M.M. & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science,* 6 (42), https://doi.org/10.1186/1748-5908-6-42

Moldavsky, M. & Sayal, K. (2013). Knowledge and attitudes about attention-deficit/hyperactivity disorder (ADHD) and its treatment: The views of children, adolescents, parents, teachers and healthcare professionals. *Current Psychiatry Reports*, 15(8), 1–7. https://doi.org/10.1007/s11920-013-0377-0

Monastra, V. (2005). Overcoming the barriers to effective treatment for attention-deficit/hyperactivity disorder: A neuro-educational approach. *International Journal of Psychophysiology*, 58(1), 71–80. https://doi.org/10.1016/j.ijpsycho.2005.03.010

Moumjid, N., Gafni, A., Brémond, A., & Carrère, M. (2007). Shared decision making in the medical encounter: Are we all talking about the same thing? *Medical Decision Making*, 27(5), 539–546. https://doi.org/10.1177/0272989X07306779

National Initiative for Children's Healthcare Quality (2002). *NICHQ Vanderbilt assessment scales.* https://www.nichq.org/project/attention-deficit-hyperactivity-disorder-adhd-learning-collaborative.

Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15(3), 259–267. https://doi.org/10.1093/heapro/15.3.259

O' Connor, A. M. (1994). Validation of a decisional conflict scale. *Medical Decision Making: An International Journal of the Society for Medical Decision Making*, 15(1), 25–30. http://dx.doi.org/10.1177/0272989X9501500105.

Osborne, R., Batterham, R., Elsworth, G., Hawkins, M., & Buchbinder, R. (2013). The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health*, 13(1), 658–658. https://doi.org/10.1186/1471-2458-13-658

Parsons, T. (1951). *The social system*. Glencoe, Il: Free Press.

Perry, B. L., & Pescosolido, B. A. (2015). Social network activation: The role of health discussion partners in recovery from mental illness. *Social Science and Medicine*, *125*, 116–128. https://doi.org/10.1016/j.socscimed.2013.12.033

Pescosolido, B. A., Boyer, C. A., & Medina, T. R. (2013). The social dynamics of responding to mental health problems. In C.S.Aneshensel (Ed.), *Handbook of the sociology of mental health* (2nd ed., pp. 505-523). New York: Springer Science.

Pickren, S., Harriott, E. M., Huerta, N. B., & Cutting, L. E. (2022). Impact of COVID-19 on children's attention deficit hyperactivity disorder symptomology, daily life, and problem behavior during virtual learning. *Mind, Brain and Education*, 16(4), 277–292. https://doi.org/10.1111/mbe.12337

Polanczyk, G., Willcutt, E., Salum, G., Kieling, C., & Rohde, L. (2014). ADHD prevalence estimates across three decades: An updated systematic review and meta-regression

analysis. *International Journal of Epidemiology*, 43(2), 434–442. https://doi.org/10.1093/ije/dyt261

Pyke-Grimm, K., Degner, L., Small, A., & Mueller, B. (1999). Preferences for participation in treatment decision making and information needs of parents of children with cancer: A pilot study. *Journal of Pediatric Oncology Nursing*, 16(1), 13–24. https://doi.org/10.1016/S1043-4542(99)90003-6

Rootman, I., & Gordon-El-Bihbety, D. (2008). A vision for a health literate Canada: Report of the Expert Panel on Health Literacy. Ottawa, ON: Canadian Public Health Association. https://www.cpha.ca/sites/default/files/uploads/resources/healthlit/report_e.pdf Accessed August 31, 2019.

Sartore, Pourliakas, A., & Lagioia, V. (2021). Peer support interventions for parents and carers of children with complex needs. *Cochrane Database of Systematic Reviews*, 12(12), CD010618–CD010618. https://doi.org/10.1002/14651858.CD010618.pub2

Sayal, K., Mills, J., White, K., Merrell, C., & Tymms, P. (2015). Predictors of and barriers to service use for children at risk of ADHD: Longitudinal study. *European Child and Adolescent Psychiatry*, 24(5), 545–552. https://doi.org/10.1007/s00787-014-0606-z

Sciutto, M. (2015). ADHD knowledge, misconceptions, and treatment acceptability. *Journal of Attention Disorders*, 19(2), 91–98. https://doi.org/10.1177/1087054713493316

Simonds, S. (1974). Health education as social policy. *Health Education Monographs*, 2(1_suppl), 1–10. https://doi.org/10.1177/10901981740020S102

Schatz, N. K., Fabiano, G. A., Cunningham, C. E., dosReis, S., Waschbusch, D. A., Jerome, S., Lupas, K., & Morris, K. L. (2015). Systematic review of patients' and parents' preferences for ADHD treatment options and processes of care. *The Patient*, 8(6), 483–497. https://doi.org/10.1007/s40271-015-0112-5

Sciberras, E., Iyer, S., Efron, D., & Green, J. (2010). Information needs of parents of children with attention-deficit/ hyperactivity disorder. *Clinical Pediatrics*, 49(2), 150–157. https://doi.org/10.1177/0009922809346730

Stein, M.A. (2022), Editorial perspective: COVID-19, ADHD management and telehealth: Uncertain path. *Journal of Child Psychology and Psychiatry*, 63(7): 829-831. https://doi-org.uml.idm.oclc.org/10.1111/jcpp.13584

Stewart, D.W., Walker, J.W., Beatie, B., Reynolds, K.A., Leonhart, M.,Tulloch, A., the Mobilizing Minds Research Group. (2014). Postsecondary students' information needs and pathways for help with stress, anxiety, and depression. *Canadian Journal of Counselling and Psychotherapy*, 48(3), 356-374.

Stiggelbout, A., Pieterse, A., & De Haes, J. (2015). Shared decision making: Concepts, evidence, and practice. *Patient Education and Counseling*, 98(10), 1172–1179. https://doi.org/10.1016/j.pec.2015.06.022

Straus S.E., Tetroe, J., & Graham, I.D. (2013) Knowledge translation: What it is and what it isn't. In S.E. Straus, J. Tetroe, & I.D Graham (Eds.). *Knowledge translation in health care: Moving from evidence to practice*, 2nd Ed. West Sussex, UK: Wiley Blackwell

Stremler, R., Haddad, S., Pullenayegum, E., & Parshuram, C. (2017). Psychological outcomes in parents of critically ill hospitalized children. *Journal of Pediatric Nursing*, 34, 36–43. https://doi.org/10.1016/j.pedn.2017.01.012

Sørensen, K., Van, d. B., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*, 12, 80. doi:http://dx.doi.org.uml.idm.oclc.org/10.1186/1471-2458-12-80

Summerton, A. Bellows, S. T., Westrupp, E. M., Stokes, M. A., Coghill, D., Bellgrove, M. A., Hutchinson, D., Becker, S. P., Melvin, G., Quach, J., Efron, D., Stringaris, A., Middeldorp, C. M., Banaschewski, T., & Sciberras, E. (2023). Longitudinal Associations Between COVID-19 Stress and the Mental Health of Children With ADHD. *Journal of Attention Disorders,* 10870547231168334–10870547231168334. https://doi.org/10.1177/10870547231168334

Swami, V. (2013). Mental health literacy of attention-deficit hyperactivity disorder. In R. Moore & D. Perry (Eds.). *Health literacy: Developments, issues and outcomes* (pp. 109-125). Nova Science Publishers, Incorporated.

Tan, D. & King, T. R. (2022). Finding the "Sweet Spot": Sharing the decision-making in ADHD treatment selection. *Annals of General Psychiatry*, 21(1), 14–14. https://doi.org/10.1186/s12991-022-00394-2

Tay, J.L., Tay, Y.F. & Klainin-Yobas, P. (2018). Effectiveness of information and communication technologies interventions to increase mental health literacy: A systematic

review. *Early Intervention in Psychiatry*, 12(6), 1024–1037. https://doi.org/10.1111/eip.12695

Taylor, M., O'Donoghue, T., & Houghton, S. (2006). To medicate or not to medicate? The decision-making process of Western Australian parents following their child's diagnosis with an Attention Deficit Hyperactivity Disorder. *International Journal of Disability, Development and Education: Attention Deficit Hyperactivity Disorder*-I, 53(1), 111–128. https://doi.org/10.1080/10349120500510115

Theule, J., Wiener, J., Tannock, R., & Jenkins, J. M. (2013). Parenting stress in families of children with ADHD: A Meta-Analysis. *Journal of Emotional and Behavioral Disorders*, 21(1), 3–17. https://doi-org.uml.idm.oclc.org/10.1177/1063426610387433

Unger, J. & Dyck, K. (2021, February 17). Issues with access to psychologists in Manitoba. https://mps.ca/wp-content/uploads/2021/04/Access-to-Psychologists-2021-Final-website-slides.pdf

Veatch, R. (1972). Models for ethical medicine in a revolutionary age. *The Hastings Center Report*, 2(3), 5–7. https://doi.org/10.2307/3560825

Virgo Planning and Evaluation Consultants (2018). Improving Access and Coordination of Mental Health and Addiction Services: A Provincial Strategy for all Manitobans. https://www.gov.mb.ca/mh/mh/docs/mha_strategic_plan.pdf

Wright, N., Moldavsky, M., Schneider, J., Chakrabarti, I., Coates, J., Daley, D., Kochhar, P., Mills, J., Sorour, W., & Sayal, K. (2015). Practitioner Review: Pathways to care for ADHD

- A systematic review of barriers and facilitators. *Journal of Child Psychology and Psychiatry*, 56(6), 598–617. https://doi.org/10.1111/jcpp.12398

Wolraich, M.L., Lambert, W., Doffing, M.A., Bickman, L.B., Simmons, T., & Worley, K. (2003). Psychometric properties of the Vanderbilt ADHD diagnostic parent rating scale in a referred population. *Journal of Pediatric Psychology*, 28. 559-568.

Wong, S., Walker, J., Carr, R., Graff, L., Clara, I., Promislow, S., Rogala, L., Miller, N., Rawsthorne, P., & Bernstein, C. (2012). The information needs and preferences of persons with longstanding inflammatory bowel disease. *Canadian Journal of Gastroenterology*, 26(8), 525–531. https://doi.org/10.1155/2012/735386

Wyatt, K., List, B., Brinkman, W., Lopez, G., Asi, N., Erwin, P., (...) & LeBlanc, A. (2015). Shared decision making in pediatrics: a systematic review and meta-analysis. *Academic pediatrics*, *15*(6), 573-583.

Zhang, J., Shuai, L., Yu, H., Wang, Z., Qiu, M., Lu, L., Cao, X., Xia, W., Wang, Y., & Chen, R. (2020). Acute stress, behavioural symptoms and mood states among school-age children with attention-deficit/hyperactive disorder during the COVID-19 outbreak. *Asian Journal of Psychiatry*, 51, 102077–102077. https://doi.org/10.1016/j.ajp.2020.102077

Appendix A: ADHD Survey Screening Items

Thank you for your interest in our study. Please answer the following brief questions to confirm your eligibility for participating:

Are you parenting a child who has been diagnosed with ADHD?

- ○ Yes
- ○ No

Is this child between the ages of 6 and 12 years old (6 years or older, but under 13)?

- ○ Yes
- ○ No

Has this child been diagnosed with ADHD since the onset of COVID-19 pandemic restrictions (March 2020, up until the present day?)

- ○ Yes
- ○ No

To the best of your knowledge, was the person who diagnosed your child with ADHD a medical doctor, a clinical psychologist (working in a clinic), or a psychologist working in a school?

- ○ Yes
- ○ No

Have you needed to learn more about ADHD since the time of your child's diagnosis?

- ○ Yes
- ○ No

Are you able to understand and complete without assistance an online survey written in the English language?

○ Yes

○ No

Thank you for your interest in our study. The circumstances around your child's diagnosis of ADHD do not meet the eligibility criteria we need for this study. Please see the next page for a list of ADHD-related information materials and supports.

Please note the following evidence-based sources of information about ADHD and its treatments.

Centre for ADHD Awareness Canada (CADDAC) https://caddac.ca

The Canadian ADHD Resource Alliance (CADDRA) https://www.caddra.ca

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
https://chadd.org

Centres for Disease Control and Prevention: ADHD
https://www.cdc.gov/ncbddd/adhd/index.html

Learning Disorders Association of Manitoba
https://www.ldamanitoba.org/ 204-774-1821

Psychological Service Centre, University of Manitoba
https://umanitoba.ca/faculties/arts/departments/psych_services/ 204-474-9222

Psychological Association of Manitoba, Electronic Directory of Psychologists
https://www.cpmb.ca/directory.php

Manitoba Adolescent Treatment Centre: ADHD Service
https://matc.ca/services/adhd/
204-958-6270

Clinical support services offered through your child's school. Contact a member of your child's school team for information on how to access.

Your family doctor and/or your child's pediatrician has the ability to refer your child to ADHD specialists, including WRHA psychologists and psychiatrists.

Appendix B: Electronic Informed Consent Form (Survey Battery)

Title of Research: Listening to parents' perspectives about childhood ADHD: How can we improve access to information and support?

Principal Investigator:
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Dr. Kristin Reynolds, Ph.D. University of Manitoba, Department of Psychology and Psychiatry.
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The present study is being conducted as part of an interdisciplinary PhD thesis in psychology and community health sciences. This consent form, a copy of which you may maintain for your records and reference, is part of the process of informed consent. It should give you the basic idea of what this study is about and what your participation will involve. If you would like more detail about something mentioned here, or information that is not included here, you should feel free to ask. Please take the time to read this carefully and to understand it. This study is being conducted by University of Manitoba Ph.D. student Jennifer Ritter, and is supervised by Dr. Barry Mallin, PhD. Dr. Mallin is a Senior Scholar in the Psychology Department at the University of Manitoba.

Purpose of the Study: The purpose of this study is to help us understand the information needs of parents whose children have recently been diagnosed with ADHD, and to understand how access to information is related to parents feeling confident about ADHD-related treatment decisions for their children. We want to use this information to help develop informational tools about ADHD that are helpful, meaningful, and accessible for parents and families.

Study Procedures: In this study, you will be asked to complete a brief online survey. We will ask your perspectives on the importance and accessibility of information for various ADHD topics, sources of information about ADHD that you consider helpful, and your comfort with making ADHD treatment decisions. We will also collect some demographic information and some details about your child's ADHD treatment history. The survey will take approximately 20 minutes to complete. All information from this survey will be anonymized and confidential such that your identity cannot be linked to your responses, as described further below.

Potential Benefits of the Research: There are no direct benefits that would come to you for sharing this information and completing this survey for research purposes. We hope that a greater understanding of parent's information needs and perspectives about ADHD will help us to develop high quality and accessible information materials for parents. This in turn would be a benefit for other children and families.

Risks or Costs Associated with the Research: There is no cost to you in sharing this information and the likelihood of any personal discomfort is very low. Your participation in this study is voluntary and you may choose to answer only the questions that you feel comfortable answering. A list of support resources for ADHD will be provided at the end of this survey.

Voluntary Participation: Participation in this study is voluntary and your decision to participate or not will not influence any treatment or supports that you may receive at MATC, or elsewhere. Investigators in this study are not involved with treatment assignment at MATC, or any other treatment agency. Should you decide to participate, you will have the option to receive compensation of a $15.00 Superstore gift certificate in recognition of your participation. You also have the option to enter your name for draw prizes, including an Apple iPad and two sets of Apple AirPods. You may claim compensation and/or enter the draw even if you choose to withdraw from the survey. Any contact information you provide will be stored separately from the survey data, on a password-protected file on a password protected network within the University of Manitoba One Drive.

This study includes an option to participate in one of a limited number of individual follow-up interviews. The intention of the interview is to help us better understand your perspectives and experiences obtaining ADHD information and your comfort with making treatment decisions for your child. These interviews will be confidential and anonymized, and you may choose to receive additional compensation for participating. You will be given additional information about the interview~~s~~ at the conclusion of this study. You will have the option to provide your contact information if you wish for a researcher to contact you at a later date.

You may participate in this survey whether or not you decide to participate in an individual interview.

Freedom to Withdraw: It is your choice whether or not to share your information for research purposes. Participation is voluntary and you may withdraw from this study at any time without penalty. If you wish to withdraw from the study and still claim compensation, you may do so by proceeding to the conclusion of the survey to provide a mailing address. You may also withdraw by simply exiting the survey platform. If you withdraw from the study, your data will be destroyed.

Confidentiality: Your participation in this research is confidential. That means that we cannot identify you or your family members as participating in this research unless required by law. The information that you give us will be treated as confidential in accordance with the Personal Health Information Act (PHIA), meaning that we cannot share it with anyone who is not a member of the research team.

If you choose to provide your contact information to receive compensation, or to get results from this survey, this information will be kept separate from your survey data, and it will be stored in a separate password-protected file on a password protected network within the University of Manitoba One Drive. Your contact information will not be associated with your responses to the survey. Jennifer Ritter and Dr. Barry Mallin will have access to your mailing address and/or your email address, and they will only use it to mail out your compensation and/or study findings. If you receive clinical services at MATC, Jennifer Ritter may recognize your name and/or contact information, but she will not be able to link your information to your survey responses.

If you choose to provide your contact information because you are interested in learning about a follow-up interview, we will assign a temporary random code number to your information. Only Jennifer Ritter and Dr. Barry Mallin will have access to your contact information and code number, which will be stored in a separate password-protected file on a password-protected network within the University of Manitoba One Drive. If you are contacted and decide to participate in an

interview, we can use this code to locate your survey responses to use as part of your interview. If you decide to decline an interview, or if we do not contact you for an interview, your contact information and code number will be deleted. If you decide to participate in an interview, the code linking your personal information to your responses will be deleted as soon as the interview session has concluded.

The only external agency that may have access to our research records are the Research Ethics Board at the University of Manitoba, Fort Garry campus, which may review our records to ensure that we maintain their standards. The results of this study may be published or presented in public forums such as academic journals and professional conferences. However, your name will not be used. No information revealing any personal information such as your name, address, email address, or telephone number will leave our research computer files. Results will be reported for all survey participants as a group, not for individuals. This study will conclude in December 2021. We will destroy any personally identifying information that you have provided to us once the study has concluded. Anonymized data obtained from this study may be stored indefinitely on a password-protected file on a password-protected network within the University of Manitoba One Drive, and available only to the study researchers.

Feedback About the Research: Findings from this research will be available by December 2021. A non-technical summary of our findings will be sent to those parents who wish to receive this information. If you wish to receive a summary of results, you will have the opportunity to provide your email address and a summary will be sent to you. If you choose to provide your email address, this will be stored in a password protected file on a password protected network within the University of Manitoba One Drive, and it will not be linked to your survey data. A summary of study results will also be posted at URL.

Statement of Consent: Checking the box below indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. Research records that contain your identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba (PHIA). All records will be kept in a locked secure area and only those persons identified as requiring access to your records will have opportunity to review or copy your research records.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Officer at 204-474-7122 or HumanEthics@umanitoba.ca. A copy of this consent form can be retained by you to keep for your records and reference.

Clicking the box below labeled “agree” indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate.

Questions or Concerns: If you have any questions, please do not hesitate to contact Jennifer Ritter by email at ritterj@myumanitoba.ca or by phone at 204-474-8257.

Appendix C: ADHD Survey

The information we gather today will be used to help understand parents' perspectives and information needs when making ADHD treatment decisions for their children. There are no right or wrong answers to the questions below. We are interested in your honest and candid opinions.

We hope you answer all of the questions within this survey. However, you are free to answer only the questions you feel comfortable answering. You may complete this survey in multiple sessions by re-entering it from the link on our webpage. Incomplete surveys will be deleted one week after they have been started.

You may discontinue this survey at any time without penalty. If you wish to discontinue and still receive compensation, you may proceed to the end of this survey to provide your mailing address. Thank you for your participation.

Please tell us a bit about yourself:

What is your current age (years)?

_____

What is your identified gender?

- ○ Male
- ○ Female
- ○ Non-binary /third gender
- ○ Prefer not to say

So we can better understand parents' experiences in different communities, please provide the first 3 characters of your postal code (letter, number, letter)

_____

What is your relationship to your child diagnosed with ADHD?

- ○ Birth parent
- ○ Step parent
- ○ Adoptive parent
- ○ Legal guardian
- ○ Other (please indicate): _____

What is your current marital status?

- ○ Married
- ○ Common-Law
- ○ Living with a partner
- ○ Single (never married)
- ○ Widowed
- ○ Separated
- ○ Divorced

What is the total number of children in your home (under 18 years of age)?

_____

What is the total number of people who regularly live in your home (including all adults and children)?

_____

People living in Canada come from many different racial and/or cultural backgrounds. Please select all that apply to your background:

- [ ] White/Caucasian
- [ ] Indigenous (First-Nations, Metis, or Inuit)
- [ ] Filipino
- [ ] Asian
- [ ] Black
- [ ] East Indian
- [ ] Hispanic
- [ ] Other (please specify) _____
- [ ] Prefer not to say

Which of the following categories best describes your total household annual income before taxes:

- ○ $40,000 or lower
- ○ $40,000 to $60,000
- ○ $60,000 to $85,000
- ○ $85,000 to $125,000
- ○ $125,000 or higher
- ○ Prefer not to say

What is your highest level of education obtained? Please select one.

- ○ Some high school
- ○ High school diploma or GED
- ○ College or technical program
- ○ Bachelors degree
- ○ Masters degree
- ○ Professional degree
- ○ PhD

Please tell us about your child and their ADHD treatment history.

What is your child's age?

- ○ 6
- ○ 7
- ○ 8
- ○ 9
- ○ 10
- ○ 11
- ○ 12

What is your child's identified gender?

- ○ Male
- ○ Female
- ○ Non-binary / third gender
- ○ Prefer not to say

To your best recollection, how long was the time period between when you first became concerned about your child's ADHD symptoms and your child's official ADHD diagnosis?

- ○ More than two years
- ○ Between one and two years
- ○ Between six months to one year
- ○ Between three to six months
- ○ Between one to three months
- ○ Less than a month
- ○ I did not notice any ADHD symptoms before my child was diagnosed

---

To your best recollection, when was your child diagnosed with ADHD?

- ○ Month _____
- ○ Year _____

Please indicate which professional(s) provided the diagnosis (please select all that apply)

- ☐ Family physician
- ☐ Pediatrician
- ☐ Psychiatrist
- ☐ Clinical psychologist
- ☐ School psychologist
- ☐ Other type of professional (indicate their title, do not provide their name): _____

Is your child currently taking medication for their ADHD symptoms?

- ○ Yes
- ○ No

If your child has any additional diagnoses beside ADHD, please list them below. If your child does not have any additional diagnoses beside ADHD, please click on the next button.

_____

Please indicate which health care providers have **ever** provided treatment, in-person or online, for you and/or your child for your child's ADHD symptoms. Treatments may include medications, behaviour support, school support, and counselling. Please select all that apply.

- [ ] Family physician
- [ ] Pediatrician
- [ ] Child psychiatrist
- [ ] Clinical psychologist
- [ ] School psychologist
- [ ] Occupational therapist
- [ ] Therapist/counsellor
- [ ] Other type of professional (indicate their title; do not provide a name):

_____

How many appointments (including in-person and/or virtual appointments) have you and your child had with a ${lm://Field/1} for specific discussion and/or management of your child's ADHD symptoms

- ○ Only one appointments
- ○ 2 to 5 appointments
- ○ Between 5 to 10 appointments
- ○ More than 10 appointments

End of Block: Appointment Number Loop

Has your child **ever** received any of these types of supports for their ADHD? Please check all that apply:

- ☐ Medications
- ☐ Parenting strategies (e.g., consequence system, reward system, visual aids)
- ☐ Occupational therapy (e.g., self-regulation, manage information from the senses)
- ☐ Supports at school (e.g., resource time, adapted education plan, IEP)
- ☐ Counselling services (to the child or to the parent to help the child)
- ☐ Diet changes
- ☐ Exercises
- ☐ Neurofeedback
- ☐ Other: _____

We would like to understand what kinds of information are most important to you when making decisions about ADHD treatment for your child. We also want to know how easily you can find the information that is most important to you. Below are questions about ten different topics related to ADHD. For each topic, please rate how important or unimportant that topic is for you, and how easily or uneasily you have been able to find information about it. Please answer each question to the best of your ability.

Recognizing the symptoms of ADHD

- ○ Prefer not to respond
- ○ Not important at all 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately important 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very important 8

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Understanding what causes ADHD

- ○ Prefer not to respond
- ○ Not important at all 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately important 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very important 8

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Behaviour and/or emotional problems that may occur with ADHD

- ○ Prefer not to respond
- ○ Not important at all 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately important 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very important 8

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Medication treatments for ADHD

- ○ Prefer not to respond
- ○ Not important at all 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately important 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very important 8

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Behaviour management/parenting strategies for ADHD

- ○ Prefer not to respond
- ○ Not important at all 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately important 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very important 8

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Educational supports and strategies to accommodate symptoms of ADHD

- ○ Prefer not to respond
- ○ Not important at all 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately important 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very important 8

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Alternative interventions for ADHD (e.g., neurofeedback, diet, supplements, exercise)

- ○ Prefer not to respond
- ○ Not important at all 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately important 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very important 8

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Developmental concerns about how ADHD symptoms change over time

- ○ Prefer not to respond
- ○ Not important at all 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately important 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very important 8

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

How to talk with my child about ADHD

- ○ Prefer not to respond
- ○ Not important at all 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately important 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very important 8

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Where I can find supports for my child and family for ADHD

- ○ Prefer not to respond
- ○ Not important at all 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately important 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very important 8

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

We are interested to know if there any other topics about ADHD that are important to you, but have not been mentioned so far. If so, please list one topic here:

- ○ Yes (please indicate) _____
- ○ No, all topics that are important to me have been mentioned

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Is there any other topic about ADHD that is important to you that has not been mentioned so far?

- ○ Yes (please list): _____
- ○ No, all topics that are important to me have been mentioned

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Is there any other topic about ADHD that is important to you that has not been mentioned so far?

- ○ Yes (please list): _____
- ○ No, all topics that are important to me have been mentioned

Have you been able to find helpful information on this topic?

- ○ Have not looked
- ○ Not at all easily 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately easily 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very easily 8

Overall, how satisfied or dissatisfied are you with the information you have been able to find about ADHD?

- ○ Prefer not to respond
- ○ Not at all satisfied 0
- ○ 1
- ○ 2
- ○ 3
- ○ Moderately satisfied 4
- ○ 5
- ○ 6
- ○ 7
- ○ Very satisfied 8

Based on your experiences so far, please indicate how knowledgeable you feel in the following areas:

	Prefer not to respond	Not at all knowledgeable 1	2	3	4	Extremely knowledgeable 5
Recognizing the signs and symptoms of ADHD	○	○	○	○	○	○
Understanding the possible causes of ADHD	○	○	○	○	○	○
The types of professional help available for ADHD	○	○	○	○	○	○
How to go about seeking professional help for ADHD	○	○	○	○	○	○

Please select **ALL** the sources of information that you have ever used in learning about ADHD.

- ☐ Family doctor
- ☐ Pediatrician
- ☐ Child psychiatrist
- ☐ Clinical psychologist
- ☐ Therapist (e.g., family therapist, psychotherapist, counsellor)
- ☐ Social worker
- ☐ Occupational therapist
- ☐ Other office-based provider (please indicate their title; do not provide their name):

_____

- ☐ School psychologist
- ☐ Classroom teacher
- ☐ Resource teacher
- ☐ School guidance counsellor
- ☐ Other school staff (please indicate their title; do not provide their name):

_____

- ☐ ADHD support group (in person or on-line)
- ☐ Perspectives and experiences from friends
- ☐ Perspectives and experiences from family members
- ☐ Religious beliefs about ADHD

- ☐ Cultural beliefs about ADHD
- ☐ General internet information (e.g., Facebook, Buzzfeed)
- ☐ ADHD websites
- ☐ TV news coverage
- ☐ Books
- ☐ Magazines
- ☐ Informational pamphlets
- ☐ Informational CDs/DVDs/video
- ☐ Informational podcasts
- ☐ Other source of information (please indicate; do not provide a personal name):

_____

Using 1 through 3, please rank order the top 3 sources of information that have been most helpful for you *in making treatment decisions* about ADHD. Start with "1" for your most helpful source.

_____ Family doctor
_____ Pediatrician
_____ Child psychiatrist
_____ Clinical psychologist
_____ Therapist (e.g., family therapist, psychotherapist, counsellor)
_____ Social worker
_____ Occupational therapist
_____ Other office-based provider (please indicate their title; do not provide their name):
_____ School psychologist
_____ Classroom teacher
_____ Resource teacher
_____ School guidance counsellor
_____ Other school staff (please indicate their title; do not provide their name):
_____ ADHD support group (in person or on-line)
_____ Perspectives and experiences from friends
_____ Perspectives and experiences from family members
_____ Religious beliefs about ADHD
_____ Cultural beliefs about ADHD
_____ General internet information (e.g., Facebook, Buzzfeed)
_____ ADHD websites
_____ TV news coverage
_____ Books
_____ Magazines
_____ Informational pamphlets
_____ Informational CDs/DVDs/video
_____ Informational podcasts
_____ Other source of information (please indicate; do not provide a personal name):

There are many treatment choices available for ADHD. The choice of treatment is personal to every family. Of the different treatments available, which option have you most recently chosen for your child? Please select one:

- ○ Medications
- ○ Behaviour-based therapies (e.g., counseling, parenting support, school supports)
- ○ A combination of medication and behaviour therapies
- ○ No treatment/monitor how my child is doing
- ○ Unsure
- ○ Something else (please indicate): _____
- ○ Prefer not to say

Thinking back on the treatment choice you have made for your child, please answer the following questions. Please answer every question to the best of your abilities.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. I know which options are available to me.	○	○	○	○	○
2. I know the benefits of each option.	○	○	○	○	○
3. I know the risks and side effects of each option.	○	○	○	○	○
4. I am clear about which benefits matter most to me.	○	○	○	○	○
5. I am clear about which risks and side effects matter most.	○	○	○	○	○
6. I am clear about which is more important to me (the benefits or the risks and side effects).	○	○	○	○	○
7. I have enough support from others to make a choice.	○	○	○	○	○
8. I am choosing without pressure from others.	○	○	○	○	○
9. I have enough advice to make a choice.	○	○	○	○	○

10. I am clear about the best choice for me.	○	○	○	○	○
11. I feel sure about what to choose.	○	○	○	○	○
12. This decision is easy for me to make.	○	○	○	○	○
13. I feel I have made an informed choice.	○	○	○	○	○
14. My decision shows what is important to me.	○	○	○	○	○
15. I expect to stick with my decision.	○	○	○	○	○
16. I am satisfied with my decision.	○	○	○	○	○

The following statements describe different preferences for how to be involved in treatment decisions. Please select the ONE statement that best describes your preferred role in decision-making for your child's ADHD treatment.

- ○ I prefer to make the final decision about which treatment my child will receieve.
- ○ I prefer to make the final decision of my child's treatment after seriously considering my child's health-care provider's opinion.
- ○ I prefer that my child's health-care provider and I share responsibility for deciding which treatment is best for my child.
- ○ I prefer that my child's health-care provider makes the final decision about which treatment will be used, but seriously considers my opinion.
- ○ I prefer to leave all decisions regarding my child's treatment to my child's health-care provider.
- ○ Prefer not to say

How would you rate your child's behaviours in the following areas over the **past month**. Please try to answer every question to the best of your abilities.

	Never	Occasionally	Often	Very Often	Prefer not to answer
1. Does not pay attention to details or makes careless mistakes with, for example, homework	○	○	○	○	○
2.Has difficulty keeping attention to what needs to be done	○	○	○	○	○
3. Does not seem to listen when spoken to directly	○	○	○	○	○
4. Does not follow through when given directions and fails to finish activities (not due to refusal or failure to understand)	○	○	○	○	○
5. Has difficulty organizing tasks and activities	○	○	○	○	○
6. Avoids, dislikes, or does not want to start tasks that require ongoing mental effort	○	○	○	○	○

7. Loses things necessary for tasks or activities (e.g., toys, assignments, pencils, or books)	○	○	○	○	○
8. Is easily distracted by noises or other stimuli	○	○	○	○	○
9. Is forgetful in daily activities	○	○	○	○	○
10. Fidgets with hands or feet or squirms in seat	○	○	○	○	○
11. Leaves seat when remaining seated is expected	○	○	○	○	○
12. Runs about or climbs too much when remaining seated is expected	○	○	○	○	○
13. Has difficulty playing or beginning quiet play activities	○	○	○	○	○
14. Is “on the go” or often acts as if “driven by a motor”	○	○	○	○	○
15. Talks too much	○	○	○	○	○

16. Blurts out answers before questions have been completed	○	○	○	○	○
17. Has difficulty awaiting his or her turn	○	○	○	○	○
18. Interrupts or intrudes in on others' conversations and/or activities.	○	○	○	○	○

How would you rate your child's behaviours in the following areas over the past month:

	Excellent	Above Average	Average	Somewhat of a Problem	Problematic	Does not apply	Prefer not to say
19. Overall school performance	○	○	○	○	○	○	○
20. Reading	○	○	○	○	○	○	○
21. Writing	○	○	○	○	○	○	○
22. Mathematics	○	○	○	○	○	○	○
23. Relationship with parents	○	○	○	○	○	○	○
24. Relationship with siblings	○	○	○	○	○	○	○
25. Relationship with peers	○	○	○	○	○	○	○
26. Participation in organized activities	○	○	○	○	○	○	○

This is the conclusion of our survey. Thank you for participating in our study. We are very grateful for the time you took to share your perspectives and experiences. Through your involvement in our research, we hope to develop better ways to help parents learn about ADHD, so they can feel more confident and comfortable with their treatment decisions. In exchange for your time spent completing our survey, we would like to offer you a $15.00 Superstore gift card. If you would like to receive a gift card, please provide your mailing address below. Your mailing address will be processed and stored separately from your survey responses.

If you are not interested in compensation, you may leave these items blank and proceed to the next page.

- ○ Name _____
- ○ Address _____
- ○ Address 2 _____
- ○ City _____
- ○ Province _____
- ○ Postal code _____

We are also offering three separate draw prizes for our survey respondents, including an Apple iPad mini 4, and two sets of Apple AirPods (model A2032). If you would like to be entered into the draws for these prizes, please provide your preferred contact information (email or phone number) below. Your contact information will be processed and stored separately from your survey responses. The anticipated date for the draw is September 2021.

If you are not interested in the draw prizes, please proceed to the next page.

○ Contact information: _____

If you would like to receive an email summary of results from this research, please enter your email address below. Your email address will be processed and stored separately from your survey responses. Results of this research will also be posted at our study webpage, www.adhdinfostudy.com. The anticipated date for results is December 2021. If you do not wish to provide your email address, please proceed to the next page.

○ Email: _____

We are conducting a limited number of individual follow-up interviews with a portion of our survey respondents, who have accessed or are accessing services for ADHD within Manitoba. ***We are interested in hearing in your own words what challenges and benefits parents have experienced when they are trying to learn about ADHD and make treatment decisions for their child.***

Your decision to participate in or decline an interview is completely voluntary and it will not influence receiving your current compensation. Additional compensation is offered if you decide to participate in an interview.

If you choose to hear more about an interview, we will assign a temporary random code number to your information, and store this securely and separately from your survey responses. Only Jennifer Ritter and Dr. Barry Mallin will have access to your contact information and code number. If you are contacted and decide to participate in an interview, we can use this code to locate your survey responses to conduct a more meaningful interview. After you complete the interview, the code linking your personal information to your responses will be deleted. If you choose to decline an interview, your interview contact information will be deleted immediately, and we will not be able to associate your survey responses with you in any way.

If you agree to be contacted by Jennifer Ritter to learn about a follow-up interview, please choose from the contact options below. If you do not wish to be contacted, please leave this item blank and proceed to the next page.

- ○ YES, by phone at the following number:
  _____
- ○ May we text you at this number (yes or no)?
  _____
- ○ May we leave a voice message at this number (yes or no?)
  _____
- ○ YES, at the following email address:
  _____

Please note the following evidence-based sources of information about ADHD and its treatments.

Centre for ADHD Awareness Canada (CADDAC) https://caddac.ca

The Canadian ADHD Resource Alliance (CADDRA) https://www.caddra.ca

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
https://chadd.org

Centres for Disease Control and Prevention: ADHD
https://www.cdc.gov/ncbddd/adhd/index.html

Learning Disorders Association of Manitoba
https://www.ldamanitoba.org/ 204-774-1821

Psychological Service Centre, University of Manitoba
https://umanitoba.ca/faculties/arts/departments/psych_services/ 204-474-9222

Psychological Association of Manitoba, Electronic Directory of Psychologists
https://www.cpmb.ca/directory.php

Manitoba Adolescent Treatment Centre: ADHD Service
https://matc.ca/services/adhd/ 204-958-6270

Clinical support services offered through your child's school. Contact a member of your child's school team for information on how to access.

Your family doctor and/or your child's pediatrician has the ability to refer your child to ADHD specialists, including WRHA psychologists and psychiatrists.

Appendix D: Telephone Script – Recruiting Interview Participants

Hello, my name is Jennifer Ritter, and I am an interdisciplinary PhD student in psychology and community health sciences at the University of Manitoba, working with Drs. Barry Mallin and Mariette Chartier. I'm phoning because you completed our online ADHD survey, and expressed interest in participating in a follow-up interview. Is this a good time to talk?

[IF NO] When is best time to call back?
[IF YES] Ok wonderful. First of all, I want to thank you for participating in the online survey. We are grateful for your input and the time you spent. May I tell you more about the purpose of the interview and how it will work?

[IF YES] The purpose of the interview is to gain additional insight about parents' experiences learning about ADHD and making treatment decisions. In the survey you recently completed, you kindly gave us some ratings about the specific types of information and experiences you may have had. This interview is meant to give us a more in-depth understanding about the experiences you shared in the survey, and to give you a chance to explain in your own words the types of information and sources of information that are most important to you. We will also have a chance to talk about how information helps you with your treatment decisions, and for you to give us your opinions about how this experience could be made easier for parents. This information will be used to develop a better understanding of what parents need to feel comfortable choosing an ADHD treatment for their child. We also hope to develop user-friendly and relevant materials for parents about ADHD, and to provide those materials at accessible places within our local community.

Do you have any questions so far? [ANSWER ANY QUESTIONS]

The interview will be approximately one-hour long. Due to our current public health restrictions and safety concerns, I will do the interview with you on a secure online platform, such as Zoom, and we can schedule the interview at a time that is convenient for you. The interview meeting will be completely confidential, between us. The virtual meeting room will be password protected and by invitation only. You will have the opportunity to provide informed consent prior to the interview starting, and you can withdraw from the interview at any time without penalty. I will audio-record the interview so that our conversation can be transcribed into a typed document. However, I will not record anything that identifies you personally, so your responses will not be tied to you directly. You also have the right to ask me to stop recording at any time. Once we finish the interview, the audio recording of our interview will be transcribed into a typed document, either by me or a professional transcriber who has signed an Oath of Confidentiality. This typed document will only be identified by a code number, and it will be held in a password-protected file on on a password protected network within the University of Manitoba One Drive. The audio recording of our conversation will be destroyed as soon as it is transcribed.

If you wish, you will have an opportunity to provide me with feedback about preliminary results of the study by completing a brief and anonymous emailed questionnaire, and you will also be able to get the final results of this study. In exchange for your time and participation during the interview, you have the option to receive a $45.00 Superstore gift card, and also have the option to be entered in a draw for an Apple iPad or one of two sets of AirPods.

Do you have any questions so far? [ANSWER ANY QUESTIONS]

Because I also work as a psychological associate at the Manitoba Adolescent Treatment Centre in Winnipeg, and because we will not be anonymous to each other after the interview, I have taken steps to

assure that the information you share with me during our interview stays confidential and will not impact any services that you may be receiving or may receive in future at this agency. I do not have any involvement with treatment assignment at MATC, so your decision to participate in this research or not will have no bearing on services you may receive there, or when you receive them. To further protect your privacy and the confidentiality of the information you share with me, I will proactively excuse myself from any treatment discussions if I recognize your name. MATC is aware of this research project and can provide the same level of service through another clinician in such instances.

Do you have any questions about this? [ANSWER ANY QUESTIONS]

Would you be interested in participating in the study?

[IF NO] Thank you for your time. Just to let you know, this study will be ongoing over the next few months. If you change your mind and would like to participate at a later time, please feel free to call me back or email me using the contact information on the study's website. If you would like to think about it more, I can call you back to re-check in a couple of weeks.

[IF YES] Great, can I schedule a time for us to do the Zoom interview? What days and times work best for you? Also, I will email in advance with a general interview guide, so you will have an idea about the types of questions I will ask you. I will also email you a copy of the study's informed consent form. Please read it over in advance and make a note of any questions you might have. We will review it together before we start the interview, and make sure that any questions that you may have are answered before we start.

Set date and time and make sure they have instructions on how to download the zoom app. Also, give my contact information if they want to contact me directly.

Appendix E: Informed Consent, Qualitative Strand (semi-structured interview)

Title of Research: Listening to parents' perspectives about childhood ADHD: How can we improve access to information and support?

Principal Investigators:
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Dr. Mariette Chartier, PhD. University of Manitoba, Department of Community Health Sciences.
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The present study is being conducted as part of an interdisciplinary PhD thesis in psychology and community health sciences. This consent form, a copy of which you may retain for your records and reference, is part of the process of informed consent. It should give you the basic idea of what this study is about and what your participation will involve. If you would like more detail about something mentioned here, or information that is not included here, you should feel free to ask. Please take the time to read this carefully and to understand it. This study is being conducted by University of Manitoba Ph.D. student Jennifer Ritter, under the supervision Dr. Barry Mallin. Dr. Mallin is a Senior Scholar in the Psychology Department at the University of Manitoba.

Purpose of the Study: The purpose of this study is to help us understand the information needs of parents whose children have recently been diagnosed with ADHD, and to understand how access to information is related to parents feeling confident about ADHD treatment decisions for their children. We want to use this information to help develop informational tools about ADHD that are helpful, meaningful, and accessible for parents and families.

Study Procedures: The study will involve a confidential one-on-one interview with a Ph.D. student researcher, conducted on the Zoom platform. In the interview, you will be asked to reflect about your experiences obtaining information about ADHD and making treatment decisions for your child. The results from this interview study will be analyzed in combination with the online survey that you have previously completed. The interview will take approximately one hour. The interview will be audio recorded so that our conversation can be reviewed and transcribed into a text document, after which the audio recording will be deleted.

Potential Benefits of the Research: There are no direct benefits that would come to you for sharing your information and completing this interview for research purposes. We hope to develop greater insight into parent's information needs and perspectives after one of their children receives a diagnosis of ADHD. This information will help us to develop high quality and accessible ADHD information materials for

parents, and also help professional and community-based providers provide meaningful support for parents. This in turn would be a benefit for other children and families.

Risks or Costs Associated with the Research: There is no cost to you in sharing this information and the likelihood of any personal discomfort is very low. Your participation in this interview is voluntary and you may choose to answer only the questions that you feel comfortable answering. You will be notified when the researcher starts and stops audio-recording the interview, and you may ask the researcher to stop the audio-recording at any time during the interview. A list of support resources for ADHD will be provided at the end of the interview, if you wish to receive them.

Voluntary Participation: Participation in this study is voluntary and your decision to participate or not will not influence any treatment or supports that you may be receiving. Should you decide to participate, you will have the option to receive compensation of a $45.00 Superstore gift certificate in recognition of your participation. You will also have the option to be entered in three separate random draws for an Apple iPad 4(A1474) or one of two sets of Apple AirPods (A2032). You may indicate if you wish to be notified of the results of the draw. The draw will take place at the conclusion of the study, in December, 2021. If you wish to receive a gift card and/or be entered in the draw, you will be given an opportunity to provide your contact information before we start the interview. Any contact information you provide will be stored separately from the interview data, on a password-protected file on a password protected network within the University of Manitoba One Drive.

Freedom to Withdraw: It is your choice whether or not to share your information for research purposes. Participation is voluntary. You will be able to discontinue your participation at any point during the Zoom session without penalty. After the Zoom session concludes, we will not be able to re-link your interview material with your identifying information to delete your data. If you decide to withdraw from the study during the Zoom session, your responses will be destroyed, and we will not use your information in any data analyses. You will still receive compensation if requested.

Confidentiality: Your participation in this research is confidential. That means that we cannot identify you or your family members as participating in this research unless required by law. If, through the course of the study, we uncover concerns regarding abuse of a child or other vulnerable individual, we are obligated by law to report this to legal authorities. Other than this, the information that you give us will be treated in accordance with the Personal Health Information Act (PHIA), meaning that we cannot share it with anyone who is not a member of the research team.

In agreeing to an online interview, you are temporarily waiving your anonymity only to the interviewer, and only for the duration of the interview. We will not audio-record any of your personally identifying information, such as your full name, your child's full name, mailing address, email address, or phone number. Audio-recordings of interview conversations will be transcribed into anonymized text documents by the principal investigator of this study, and/or a professional transcriber who has signed an Oath of Confidentiality. Audio-recordings of interview conversations will be immediately and permanently deleted once they are transcribed into text documents. These text documents will be anonymized, identified by a code number that corresponds with your survey responses. Anonymized text documents will be kept confidential, stored in a password-protected file on a password protected network within the University of Manitoba One Drive. Once you have concluded your interview, we will destroy links between your personal information and your participant code number. Your name and/or other personally identifying information will not be associated with your interview responses.

We may consult with other University of Manitoba researchers about the best way to analyze anonymized interview and survey data. The only external agency that may have access to our research records is the Research Ethics Board at the University of Manitoba, Fort Garry campus, which may review our records

to ensure that we maintain their standards. The University of Manitoba may review information gathered during this study for quality assurance purposes.

The results of this study may be published or presented in public forums, such as academic journals and/or professional conferences. This may include direct quotations from your interview that represent general trends, themes, and sentiments expressed by many participants. However, your name or other unique identifiers will not be used. No information revealing any personal information such as your name, address, email address, or telephone number will leave our research computer files. Results will be reported as a group for all interview participants, not for individuals. The study will conclude in December 2021. We will destroy any retained personally identifying information that you have provided to us once the study has concluded. Anonymized data obtained from this study, including anonymized interview transcripts, may be stored indefinitely on a password-protected file on a password-protected network within the University of Manitoba One Drive, and available only to the study researchers.

Feedback About the Research: You will have an opportunity to provide feedback on preliminary findings from this study by responding to a brief emailed questionnaire. If you wish to do this, you will be given the option to provide your email address at the end of the interview. The anticipated date for the feedback questionnaire is September 2021. If you wish to receive a non-technical summary of final results from this study, you will have the opportunity to provide your email address and a summary will be sent to you. If you choose to provide your email address, this will be stored separately from survey data. A summary of study results will also be posted at URL.

Statement of Consent: Your verbal consent indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. Medical/research records that contain your identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba (PHIA). All records will be kept in a locked secure area and only those persons identified as requiring access to your records will have opportunity to review or copy your medical / research records.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Officer at 204-474-7122 or HumanEthics@umanitoba.ca. A copy of this consent form can be kept for your records and reference.

Questions or Concerns: If you have any questions, please do not hesitate to contact Jennifer Ritter by email at info@adhdinfostudy.com or by phone at 204-474-8257

You may wish to print a copy of this electronic consent form to keep for your records and reference. Do not sign agree to this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Appendix F: Interview Guide

1. What has been your experience in learning about ADHD?

2. What types of ADHD information are most important to you?

3. What kinds of information sources have you used to learn about ADHD?
    a) What sources of information have been most helpful? Why?
    b) What sources of information have not been helpful? Why?

4. Did anything make it hard for you to learn about ADHD?

5. How could the process of learning about ADHD be easier?

6. What has it been like for you to make ADHD treatment decisions for your child?

7. Has there been any particular experience or situation that stands out for you when you think back on your decision-making process? What made it so meaningful?

8. How has the COVID pandemic impacted the way you are learning about ADHD?

9. Is there anything else that you would like to say related to learning about ADHD and making treatment decisions that we haven't discussed?

Appendix G: Member Checking, Preliminary Results

Jennifer Ritter conducted online interviews with parents of 13 children to learn about their ADHD information needs and preferences, and their treatment decisions. Topics of the interviews included:

- parent's experiences learning about ADHD
- parent's perspectives about the types of ADHD information that is important to them
- the sources parents use to learn about ADHD
- how parents use information to make treatment decisions
- how the COVID-19 pandemic impacted parent's learning about and managing ADHD.

This is a general summary of key findings from the interviews. Please review this summary and let us know your opinions by answering the three short questions that follow. Your responses will be anonymous.

SUMMARY OF KEY FINDINGS:

1. Parents have many information needs. They want information that helps them better understand and manage ADHD symptoms, and information that they can relate to. They also want easy ways to access information they can trust.

2. Parents learn about ADHD differently and from many sources. Community networks (e.g., ADHD support groups, trusted friends or family) and health care providers are each important sources of information for parents.

3. Responsive treatment systems help parents feel confident with their treatment choices. Parents want health care providers who listen to their concerns and who can provide wrap-around treatment for their children.

4. Parents face many stressors when managing childhood ADHD, including family stress, and their own emotional stress and worry for their children.

5. The COVID-19 pandemic has been a mixed blessing for parents. For some families, restrictions meant less access to supports and worsening ADHD symptoms. Other times, children benefitted from time away from in-person school and the chance to work at their own pace.

How understandable was the summary of findings?

- ○ Not understandable 1
- ○ 2
- ○ 3
- ○ 4
- ○ Moderately Understandable 5
- ○ 6
- ○ 8
- ○ 9
- ○ Extremely Understandable 10

How much do you agree with the findings? (E.g., Do they ring true for you?)

- ○ Strongly disagree 1
- ○ 2
- ○ 3
- ○ 4
- ○ Mildly Agree 5
- ○ 6
- ○ 7
- ○ 8
- ○ 9
- ○ Strongly Agree 10

How reasonable are the conclusions of the findings?

- ○ 1 Not reasonable
- ○ 2
- ○ 3
- ○ 4
- ○ Moderately Reasonable 5
- ○ 6
- ○ 7
- ○ 8
- ○ 9
- ○ Extremely Reasonable 10

Please provide any additional comments below, if you wish

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