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Buzanko, Caroline

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Parents' Experiences of the Assessment Process that Resulted in their Son's Diagnosis of ADHD

by

Caroline Buzanko

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Abstract

In general, little is known about parents' experiences of the entire assessment process that led to their child's diagnosis of ADHD. The purpose of this study was to investigate parents' experiences of the assessment process, conducted by a psychologist in private practice, that resulted in their child's diagnosis of ADHD. Fifteen parents participated in semi-structured interviews that were recorded, transcribed, and analyzed using thematic analysis. The five themes identified from the interviews of this study were: (a) Hoops and barriers (i.e., the journey that led parents to their son's assessment), (b) What does this tell me about my son? (i.e., parents' experiences with the communication of the diagnosis), (c) We're not coming for labels. We're not coming for drugs. We're coming for roadmaps. (i.e., the need for support to manage their child's difficulties), (d) It's such a big journey (i.e., important aspects pervasive throughout the assessment, including the relationship with the psychologist and the emotional journey parents experienced), and (e) Rich insights: I want parents to know… (i.e., parent wisdom gained from the assessment that they can share with other parents new to the process). The results of the study emphasized the importance of the working alliance between psychologists and parents, along with the need for follow-up support, to promote quality services that address the parents' and child's needs. As an extension to this study, a parent intake form was developed to translate the knowledge generated from the parent interviews in a way that can be used in clinical practice. This form was developed in collaboration with parents to ensure that it addressed topics that were meaningful for them, as well as in collaboration with psychologists working in private practice who conduct assessments for ADHD to promote its feasibility and use in clinical practice. The implications and recommendations for practice and future research, based on the findings from this study, are discussed.

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Chapter 1: Introduction

Attention Deficit/Hyperactivity Disorder (ADHD) is believed to be one of the most common disorders in childhood (Durak et al., 2014; Golubchik, Sever, & Weizman, 2014; Marusich & Gilden, 2014; Vitulano et al., 2014), affecting approximately 5% of children (America Psychiatric Association [APA], 2013; Vitulano et al., 2014). ADHD is the term used to describe a neurodevelopmental condition that is characterized by a "persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development" (APA, 2013, p. 61). In North America, the diagnosis of ADHD is generally based on the criteria established in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5*; APA, 2013). Specifically, to be diagnosed, children must present with associated symptoms of inattention and/or impulsivity/hyperactivity that are developmentally inappropriate for at least six months and before they are 12-years-old (APA, 2013). Children with ADHD must also display significant impairments across a variety of domains of functioning (e.g., social, educational and/or occupational) and settings (e.g., home, school, social contexts; National Institute for Health and Clinical Excellence [NICE], 2013).

Currently, there is a dearth of research on what parents' experience was like throughout the entire assessment process that resulted in their child's diagnosis of ADHD. Researchers investigating parents' experiences of assessment processes that resulted in other diagnoses, such as autism, have revealed that most parents expressed dissatisfaction with the process (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Hackett, Shaikh, & Theodosiou, 2009; Hilton, Turner, Krebs, Volz & Heyman, 2012; Mansell & Morris, 2004). Many parental complaints included long wait times to begin the assessment (Hilton et al., 2012), not knowing what to expect (Bennett-Levy, Klein-Boonschate, Batchelor, McCarter, & Walton, 1994; Hackett et al., 2009), lack of collaboration with their clinician (Mulligan, MacCulloch, Good, & Nicholas, 2012), and uncertainty around how their child's diagnosis was made (Chamak et al., 2011; Mansell & Morris, 2004; Mulligan et al., 2012). Parent dissatisfaction with the assessment process has important implications because the assessment is often the first contact parents have with professionals and the process can influence how parents perceive their child's needs (Bennet, Power, Rostain & Carr, 1996). When dissatisfied with the assessment process, parents may be left with doubts about their child's diagnosis (Bussing & Gary, 2001) and they may not engage in their child's treatment (Dreyer, O'Laughlin, Moore, & Milam, 2010; McKay, McCadam & Gonzales, 1996). As such, it is important for clinicians to obtain parent input and to understand parents' experiences of their child's assessment process (Braiden, Bothwell & Duffy, 2010; Larsen, Munoz, DesGeorges, Nelson & Kennedy, 2012; Mental Health Commission of Canada, 2012). To this end, this study explores parents' experiences of the assessment process that resulted in their child's diagnosis of ADHD.

Statement of the Problem

As indicated above, there is a scarcity of research exploring parents' experiences of the entire assessment process that resulted in their child's diagnosis of ADHD. Much of the research done in this area has focused on parents' experiences of the assessment process for other disorders, particularly for medical disorders and for autism spectrum disorders. Importantly, exploring parents' experiences of the entire assessment process remains a neglected area of research, as the focus has been primarily on their experiences of receiving a diagnosis for their child (e.g., Brogan & Knussen, 2003; Chamak et al., 2011), with little attention given to the entire assessment process, from initial contact with the psychologist to the final feedback meeting. Taken together, there is little information about parents' experiences of the assessment process that resulted in their child's diagnosis of ADHD. Thus, there is a need to explore, describe, and document the experiences of parents who have had an assessment completed for their child diagnosed with ADHD.

Purpose of Study and Research Question

The purpose of this exploratory qualitative study was to understand parents' experiences of the assessment process, conducted by a psychologist in private practice, that resulted in their child's diagnosis of ADHD – Combined Presentation. In doing so, parents were given the opportunity to have their voices heard and to share their experiences in a way that is not addressed in the extant literature. The primary research question guiding this study was: *What are parents' lived experiences of the assessment process that resulted in their child's diagnosis of ADHD?* The extension of the study is practical in nature; to develop an input form to translate the knowledge generated from the parent interviews in a way that can be used in clinical practice. This form was developed in collaboration with parents to ensure that it addressed topics that were meaningful for them. The form was also developed in collaboration with psychologists who conduct assessments for ADHD to promote its feasibility and use in clinical practice. Overall, this study aimed to: 1) contribute to the literature that acknowledges parents' experiences and the need for their input in their child's assessment process, 2) enable parents to contribute to identifying ways to enhance their experience of their child's assessment process for ADHD, and; 3) translate the knowledge obtained from the interviews in an applied way through the parent input form.

The methodological approach used in this study was a pragmatic qualitative inquiry approach (Butler-Kisber, 2010; Creswell, 2009) utilizing thematic analysis (Braun & Clarke, 2006). This approach was considered to be the best fit for this study because it offers the means to explore parents’ lived experiences in-depth while also allowing for the opportunity to enhance the usefulness and accessibility of the study’s results through the process of knowledge translation to develop the parent input form.

Significance of the Study

Given the paucity of research in this area, there is a significant need to obtain parent input and to understand parents’ experiences of the assessment process that has resulted in their child’s diagnosis of ADHD. This study addresses that void in the literature. The anticipated significance of the study is that eliciting a better understanding of parents’ experiences may help to improve assessment practices in clinical practice. Specifically, obtaining parent input regarding the assessment process is important because it may: facilitate parent collaboration, which has the potential to improve parent involvement in the assessment process (Dreyer et al., 2010); promote positive assessment experiences for parents (Graungaard & Skov, 2006; Miller & Hanft, 1998); and promote parents’ engagement in their child’s treatment (Dreyer et al., 2010; Fantini, Aschieri, & Bertrando, 2013; McKay et al., 1996). Furthermore, obtaining information about parents’ experiences of the assessment process may provide valuable information that can inform a framework for potentially improving quality service provision (Larsen et al., 2012). Indeed, parents are considered “central to designing, monitoring and modifying service delivery” (Braiden et al., p. 378). A major goal in collecting parent feedback is to enhance “person-centred” services (i.e., focusing on what is important for the individual; Williams, Coyle, & Healy, 1998) to provide quality services. By asking parents for input regarding their experiences, it is anticipated that the researcher will elicit detailed information regarding what was involved in the assessment process and the specific interactions parents had with psychologists. In turn, their input can be incorporated into future assessment practices to facilitate the delivery of quality services that directly address what parents indicate is important for them.

In general, there is a growing emphasis on obtaining user/parent input. For instance, government policies in the United Kingdom have stipulated that services must be shaped around the concerns of the service users and that users must be involved in all aspects of the service, including evaluation (Department of Health, 2000). In the mental health field in Canada, individuals and their families have been considered “experts by experience” (Mental Health Commission of Canada, 2012, p. 31), a framework that highlights the importance of their involvement in service delivery. Additionally, the key to enhancing quality services is considered to actively include individuals and their family members at all levels of service provision (Mental Health Commission of Canada, 2012). Other Canadian organizations serving young people and their families have specified that services should be “driven by, and responsive to” (Kutcher & McLuckie, 2010, p. 16) the needs of children and their families. Practice guidelines have also affirmed the need to consider the family’s perspectives and to involve them throughout the assessment process in diagnosing ADHD (NICE, 2013). In brief, there is an identified need to involve parents to inform quality service provision and person-centred services (Graungaard & Skov, 2006; Larsen et al., 2012; Williams et al., 1998). Growing out of the need for person-centred services, this study is based on the premise that obtaining information regarding parents’ experiences is critical to promote positive experiences for parents (Graungaard & Skov, 2006), to enhance quality service delivery (e.g., Giannoulis, Beresford, Davis, Baird, & Sclare, 2004), and to promote parent collaboration (e.g., Barkley & Mash, 2007; Hoagwood, 2005) by addressing issues that parents deem to be important.

Personal and Professional Reflections

Having worked as a psychologist for several years before returning to pursue my doctoral degree, I chose a dissertation topic that was relevant to my clinical work. As a psychologist, I discovered that most parents I worked with who had a child diagnosed with ADHD expressed dissatisfaction with their child's assessment process. Additionally, approximately a third of these parents doubted their child's diagnosis and therefore chose to not implement the recommended treatment plan. In reading the literature, it was found that there is widespread parental dissatisfaction with their child's assessment process (e.g., Hackett et al., 2009; Hilton et al., 2012). After listening to parents' complaints about their experiences and reading through the literature about parents' negative experiences, I reflected on the assessment practices we conduct as psychologists and how those services are evaluated. Although I have worked with agencies that have collected client feedback regarding counselling services, no such feedback was ever obtained for any of the assessment services I have seen provided over the years and across contexts. While we, as clinicians, may follow assessment guidelines and may believe we are providing quality services, this does not necessarily mean that parents are satisfied with the process. In all my years doing assessments, the subjective perspective of parents involved in the assessment process was missing. I was motivated to learn more about parents' experiences.

This interest led me to the current study. Because I wanted to learn more about parents' real life experiences of the assessment process in-depth, I decided to conduct a qualitative study. Additionally, as a practicing clinician, I wanted to take my findings one step further to inform practices. As such, I chose to translate the knowledge gained from this study and utilize my understanding in a useful and applied way for clinical practice by creating a parent input form that could be used by psychologists with parents as part of the assessment process.

Overview of Dissertation

This dissertation is comprised of five chapters. Chapter one presents an overview of the study that includes the purpose of the study, research questions, and personal reflections. Chapter two presents a review of the relevant background literature including a detailed discussion of ADHD; the assessment process in diagnosing ADHD; traditional models of assessment as compared to other models and therapeutic assessment specifically; as well as parents' experiences of their child's assessment process. The chapter also includes a discussion of limitations in the current empirical literature and concludes with a section that presents the purpose of the study and specific research question. Chapter three presents the methodology and specific methods used for this study, including its design, selection of participants, and the phases of data analysis. Additionally, validity, limitations and data analysis are discussed. Chapter four reports the research findings. Finally, chapter five provides a discussion of the results and the empirical and practical implications of this research, as well as directions for future research.

Chapter 2: Literature Review

This literature review provides background for my study, the purpose of which is to understand parents' lived experiences of the assessment process that resulted in their child's diagnosis of ADHD. This chapter begins with an overview of ADHD, including its diagnostic classification, etiology, theoretical framework, and associated impairments. Next, a review of the established guidelines in the assessment and diagnosis of ADHD and the common phases of the assessment process is provided. A discussion about traditional assessment practices and therapeutic approaches follows. The subsequent section addresses the need to obtain parent input. Issues with respect to our current understanding of parents' experiences of the assessment process are presented, staging the purpose of this study. The chapter concludes with the overarching research question guiding this study. It is important to note that, because this research project includes children diagnosed specifically with ADHD - Combined Presentation, which is the most prevalent presentation of the disorder, the focus of this literature review is primarily on this population.

Attention Deficit/Hyperactivity Disorder

As discussed in the previous chapter, ADHD is known as a chronic, neurodevelopmental condition that impairs one's functioning and development (American Psychiatric Association [APA], 2013; Ramsay, 2010). The *DSM-5* (APA, 2013) classifies three interrelated presentations of ADHD. First, a predominantly inattentive presentation, is evident in children's problems with attention. This presentation is associated with at least six difficulties such as sustaining attention to complete tasks (often those considered boring or difficult), sustaining attention in play activities, making careless mistakes, listening when spoken to, following instructions, resisting distraction, remembering daily activities, keeping track of their belongings, and organization.

Second, a predominantly hyperactive-impulsive presentation is evident in high levels of physical activity and impulsivity. This presentation is associated with at least six problematic behaviours such as excessive fidgetiness, playing noisily, interrupting others, failing to remain seated when it is expected, running or climbing in situations where this behaviour is inappropriate (e.g., at the doctor's office), moving constantly, talking excessively, blurting out answers, and waiting in lines. Third, an ADHD combined presentation involves the presence of at least six symptoms of both inattention and hyperactivity/impulsivity.

To be diagnosed with ADHD, according to the *DSM-5* (APA, 2013), the following are required: a) the child must exhibit six or more symptoms of inattention and/or hyperactivity-impulsivity that have interfered with the child's functioning and/or development for at least six months; b) some symptoms causing impairment were present before the child was twelve years of age; c) several of the impairing symptoms are present in two or more settings (e.g., home, school, social contexts); d) there is clear evidence of clinically significant impairment in the child's functioning; and (e) the symptoms are not better explained by another mental disorder, such as a mood disorder, and do not occur exclusively during the course of schizophrenia, or other psychotic disorders.

The behavioural presentation of hyperactivity, impulsivity, and inattention appear early in life; however, evidence suggests that ADHD persists into adulthood in an average of 50% of cases (Lara et al., 2009). Hyperactive-impulsive behaviours tend to appear first in development and are more predictive of acting out and antisocial behaviours, but decrease significantly as the child develops (Barkley, 2005). Inattentive behaviours, on the other hand, tend to develop somewhat later and remain relatively stable and are more predictive of academic difficulties (Barkley, 2005).

Etiology of ADHD

Currently, there are no known causes of primary ADHD, except in cases of physical trauma or toxic insult to the brain (considered a secondary form of ADHD). However, researchers have implicated a number of factors as indirect forms of etiology. In their critical review of ADHD, Biederman and Faraone (2005) presented a multifactorial model of ADHD, suggesting that ADHD emerges from “the confluence of many different types of risk factors” (p. 243). Specifically, they associated genetic, neurological, environmental (e.g., toxins, prenatal exposure to alcohol and nicotine), and psychosocial factors (e.g., parenting stress, marital conflict, abuse, parent psychopathology) as potential contributing factors to the disorder. Although psychosocial and environmental risks may influence a particular child’s outcome, some have argued that these factors are not considered a critical component in the primary emergence of ADHD (e.g., Barkley, 2005; Biederman, 2005). Instead, they have suggested that biological factors (i.e., genetic and neurological factors) have the most scientific evidence as being the potential root of ADHD (Barkley, 2005).

Genetic factors. Researchers have demonstrated that genetic factors are a major contributing risk factor to ADHD (e.g., Biederman, 2005; Stevenson et al., 2005). Parents of children with ADHD are two- to eight-times more likely to present with symptoms of ADHD than parents of children without ADHD (Franke, Neale, & Faraone, 2009). Numerous adoption, twin and family studies have also demonstrated the genetic link to ADHD (e.g., Kuntsi et al., 2004; Lasky-Su et al., 2008; Levy, Hay, McStephen, Wood, & Waldman, 1997; Ouellet-Morin et al., 2008). In their investigation into the genetic and environmental contributions to overactive behaviour and attention problems in twin pairs, Rietveld, Hudziak, Bartels, van Beijsterveldt, and Boomsma (2003) found high genetic influences on overactive behaviour and attention problems across an age span from preschool to elementary school ages. Additionally, using an adoption study design, Sprich, Biederman, Crawford, Mundy, and Faraone (2000) compared adopted and non-adopted individuals diagnosed with ADHD. In this study, they found that ADHD was familial in biological parents and siblings of the biological ADHD group, with biological relatives presenting with high rates of ADHD and associated disorders. Furthermore, ADHD did not occur any more frequently in adoptive relatives of the adopted ADHD group when compared to biological relatives of the non-ADHD control group. Their results indicated that there is no familial aggregation of ADHD in relatives of adoptees with ADHD, thus supporting the genetic hypothesis for the disorder.

Regardless of whether the underlying mechanisms in the emergence of ADHD are genetic, environmental, or the interaction of both, it has been believed that “these effects are presumably expressed in the brain” (Nigg, 2013, p. 385). As such, an overview of the neurological factors that are strongly associated with ADHD is provided.

Neurological factors. There is increasing evidence indicating that children with ADHD have abnormalities in the structure and function of a part of the brain known as the prefrontal cortex (e.g., Aguiar, Eubig, & Schantz, 2010; Barkley, 2015; Ferrin & Vance, 2012; Nigg & Nikolas, 2008; Swanson et al., 2007) and the neural circuitry between the prefrontal cortex and the striatum, which is important in response output control (Dickstein, Bannon, Castellanos, & Milham, 2006). In terms of neuropsychological functioning, researchers have suggested that the prefrontal cortex mediates key executive functions (EF; Diamond & Amos, 2008). In sum, much of the findings from neuropsychological studies suggest that ADHD is a disorder of EF, as discussed next.

Theoretical Framework for ADHD

Research has increasingly provided evidence that a central problem for ADHD is deficits in self-regulation and EF (Barkley, 2015; Goldstein & Naglieri, 2008). Currently, a respected model of ADHD theory in the literature is offered by Barkley (2015). Barkley (2015) suggested that ADHD involves a deficit in self-regulation and that behavioural disinhibition is the primary cause of the behavioural difficulties children with ADHD exhibit. He argued that children with ADHD have difficulties because they are unable to inhibit their prepotent responses (i.e., responses for which immediate reinforcement is available or responses that have a strong history of reinforcement). In turn, this initial reaction affects the other cognitive abilities related to effective executive functioning, namely, nonverbal working memory (e.g., self-awareness, hind- and fore-sight so as to sustain chains of goal-directed actions); verbal working memory (e.g., self-questioning and problem solving); the self-regulation of affect/motivation/arousal (e.g., exerting control over emotional reactions to external stimuli); and reconstitution (e.g., behavioural analysis and synthesis, behavioural flexibility and diversity) that would otherwise normally help guide behaviour. Taken together, Barkley (2015) argued that these deficits limit children's ability to control and organize their goal-directed behaviour over time. Barkley (2005) also noted that children with ADHD have difficulty performing at the point of performance. Said differently, these children likely know what they are supposed to do, but have difficulty doing what they need to do when they need to do it, such as remaining seated when the expectation is to sit and attend to the teacher. Thus, children with ADHD do not necessarily have a skill deficit, but they have difficulty enacting the skills when they need them and often demonstrate inconsistent, unpredictable behaviour patterns (Barkley, 2005). Given their difficulties with behavioural inhibition, children with ADHD present with patterns of behaviour that negatively impair their functioning across several domains (APA, 2013). The following section provides an overview of some of the common outcomes associated with ADHD.

Outcomes Associated with ADHD

Children with ADHD present with patterns of behaviours that are often considered problematic and impair their functioning across various domains of their daily life. Academically, children with ADHD are at greater risk for poor academic achievement and lower grades (Wilson & Marcotte, 1996), poor motivation, difficulty completing assignments (Carlson, Booth, Shin, & Cnau, 2002), school dropout (Barkley, 2005), comorbid learning disabilities (Hinshaw, Carte, Sami, Treuting, & Zupan, 2002), and overall poor academic achievement (Rapport, Scanlan, & Denney, 1999). They also often cause classroom disruptions (Rapport et al., 1999) and have difficulty sustaining attention to classroom activities (Rapport, Kofler, Alderson, Timko, & DuPaul, 2009).

ADHD is also associated with cognitive impairments that affect a range of abilities, such as motor coordination, sequencing and mental computation (Barkley, 1997); working memory and processing speed (Mayes & Calhoun, 2007); story recall (Lorch et al., 2000); self-monitoring (Clark, Prior & Kinsella, 2000); and self-regulation of emotion (Barkley, 2005). Children also have difficulty with attention, which often results in complaints about their ability to concentrate, to resist distraction, to finish tasks, and to follow instructions (Culbertson & Krull, 1996). Difficulties with impulsivity also affect their adaptive functioning, such as completing self-care tasks (Stein, Szumowski, Blondis, & Roizen, 1995).

Children with ADHD are also at greater risk for social difficulties (Wolraich et al., 2005), as most exhibit clinically significant impairments in their social functioning (Huang-Pollock, Mikami, Pfiffner, & McBurnett, 2009). Children with ADHD often present with impaired social conduct, such as difficulties waiting their turn and interrupting others (APA, 2013). They often have conflicts with peers, can be socially intrusive and aggressive in their interactions, and are at greater risk for social rejection and lack of friendships (Hoza et al., 2005). Within thirty minutes of interacting with peers, children with ADHD can be identified as disruptive, aggressive, and unpredictable by their peers, which can lead to criticism and withdrawal (Pilham & Milich, 1984). Researchers have demonstrated that the social challenges children with ADHD experience are associated to long-term difficulties, such as academic, occupational, marital, legal and psychological problems (Hoza et al., 2005a).

Additionally, children with ADHD, particularly those who present with combined presentation, are at greater risk of developing comorbid behaviour disorders (Barkley, 2015). It has been estimated that 87% of children with ADHD also meet the diagnostic criteria for at least one other disorder (Canadian ADHD Resource Alliance; CADDRA, 2011). Common comorbid disorders include learning disabilities, oppositional defiant disorder, conduct disorder, anxiety, and mood disorders (Biederman, 2005) as well as Autism Spectrum Disorder (Craig et al., 2015) and Tourette Syndrome (Freeman, 2007). Furthermore, researchers suggested that children with ADHD who are also diagnosed with a comorbid disorder are at an even greater risk for increased symptom severity and persistence of both disorders (Barkley, 2003; Drabick, Gadow, & Sprafkin, 2006) and maladaptive outcomes into adulthood (Wilson & Marcotte, 1996).

Finally, children diagnosed with ADHD are at greater risk for numerous other difficulties later in life, including unemployment (Barkley, 2015), low income (Kessler et al., 2006), psychological maladjustment, driving risks (Murphy & Barkley, 1996), personality disorders, delinquency (von Polier, Vloet, & Herpertz-Dahlmann, 2012), antisocial behaviour, risky sexual behaviour (e.g., multiple sex partners with unknown sexual history; Hosain, Berenson, Tennen, Bauer, & Wu, 2012), early sexual activity and partner pregnancies (Flory, Molina, Pelham, Gnagy, & Smith, 2006), sexually transmitted diseases (Reid & Johnson, 2012), involvement in the criminal justice system including arrest and incarceration (Schilling & Walsh, 2011) and substance abuse (Rothenberger, Becker, Breuer, & Dopfner, 2011). These problems contribute to an overall decreased quality of life (Rothenberger et al., 2011) and increased mortality rates (Barbaresi et al., 2013). Given the significant impairments exhibited by children with ADHD, valid and reliable assessments are critical to identify children with ADHD. The following section provides an overview of recommended guidelines in assessing children for ADHD.

Assessment and Diagnosis of ADHD

ADHD is heterogeneous, intricate in nature and often overlaps with other disorders (Barkley, 2015). Coupled with the fact that there are no singular definitive tests for diagnosing ADHD, it is challenging to come to a conclusive clinical diagnosis (Koonce, 2007). Currently, the diagnosis of ADHD is based on the behavioural functioning of the individual (APA, 2013). Although there is no gold standard test (Koonce, 2007), professional bodies have established empirically supported guidelines for the assessment of ADHD, including, but not limited to, the American Academy of Pediatrics (AAP), NICE, and CADDRA.

In general, these guidelines delineate a comprehensive approach to diagnosing ADHD, in which a broad range of information is gathered from multiple sources (e.g., different people who know the child well, such as caregivers and school professionals), using multiple measures (e.g., interviews, observations, and validated DSM rating scales), about the child’s functioning across multiple settings (e.g., home, school, and social contexts). Guidelines noted the need to obtain evidence regarding the child’s core symptoms, duration of symptoms, impairment, and coexisting difficulties. These guidelines also indicated that the child should be tested for hearing and vision and evaluated for any comorbid conditions, such as anxiety, depression, learning disorders, and/or oppositional defiant and conduct disorders. Additionally, guidelines specified that clinicians should use the criteria published in the *DSM* (the most recent being *DSM-5;* APA, 2013) to diagnose ADHD. NICE (2013) also included the recommendation that clinicians should evaluate for additional information, such as the child's caregivers' personal, social, and mental health needs. Finally, these guidelines identified the need for clinicians to work collaboratively with parents and to obtain their input as part of service delivery.

In addition to the recommended guidelines described above, guidelines regarding evidence-based assessments in diagnosing ADHD are established within the research literature (e.g., Pelham, Fabiano & Massetti, 2005; Sowerby & Tripp, 2009). Evidence-based assessments are defined as the processes that "emphasizes the use of research and theory to inform the selection of assessment targets, the methods and measures used in assessment, and the assessment process" (Hunsley & Mash, 2007, p. 29). Similar to the guidelines set forth by the organizations described above, when diagnosing ADHD, evidence-based practice indicates that psychologists must determine whether the *DSM-5* criteria are met, including the number and duration of symptoms, and age of onset. Information regarding the child's developmental and medical history is important in gathering a comprehensive understanding of the child (Sowerby & Tripp, 2009). Information regarding the frequency and severity of symptoms is beneficial to determine whether the behaviours are consistent with the child's developmental level (Sowerby & Tripp, 2009). Factors such as frequency and severity also help the clinician to make the judgement whether an individual criterion is significant enough to warrant endorsement as an ADHD symptom.

Although children need to meet a certain symptom count to meet criteria for a diagnosis of ADHD, symptom count itself has somewhat limited utility and should not be the sole criterion used to diagnose. Indeed, children are not generally referred for an assessment because of symptoms; rather, they are often referred because of the impairments teachers and parents observe in the child’s adaptive functioning (e.g., academics, social contexts, family functioning; Angold, Costelio, Farmer, Burns, & Erkanli, 1999). Furthermore, their impairments in functioning, rather than symptoms, predict long-term outcomes. To explain, children with ADHD often present with numerous maladaptive behaviours in the classroom, such as failing to complete schoolwork and creating disruptions in the classroom, that negatively affects their long-term academic success (e.g., increased rates of dropout; Barkley, 2005). Similarly, researchers have suggested that disruptions in the peer relationships of children diagnosed with ADHD are a strong predictor of adverse adult social outcomes (Pelham et al., 2005). For instance, children with ADHD can be socially intrusive and aggressive in their peer relationships (Hoza et al., 2005; Nijmeijer et al., 2008), which can lead to later difficulties as adults. Indeed, in their longitudinal study spanning 22 years, Huesmann, Eron, Lefkowitz and Walder (1984) found that peer-reported aggressiveness in childhood (e.g., pushing peers) was predictive of later severe antisocial aggressiveness in adults (e.g., criminal behaviour, aggression, spouse abuse). Given the increased risk of poor long-term outcomes for children with ADHD, clinicians must go beyond symptom counts and assess the child’s level of impairment. Specifically, the child’s level of adaptive functioning in each of the affected domains (e.g., academic, social, emotional, and daily living) must be evaluated.

In addition, as established in the aforementioned guidelines, information must be obtained from multiple informants, which could include the child, his or her caregivers and other adults who know the child, such as teachers, other school personnel, other professionals, and coaches. Information may be obtained using a variety of methods, such as clinical interviews, empirically supported behaviour rating scales, behavioural observations, functional behaviour analyses, a review of the child's files and report cards, and results from formal assessment measures (Barkley, 2015; Sayal, Letch, & El Abd, 2008; Wright, Waschbusch, & Frankland, 2007). As indicated previously, children should also undergo hearing and vision tests, as well as medical check-ups to rule out any other conditions that may contribute to the manifestation of ADHD symptoms, such as FASD, lead poisoning, neurofibromatosis, thyroid disorder, or sleep disorders (Sowerby & Tripp, 2009).

Although not included in the recommendations for routine assessments of ADHD, additional clinical tests may be important to identify comorbid conditions (e.g., learning or behaviour difficulties) and/or to rule out other difficulties that may cause the presentation of symptoms that are similar to ADHD, such as low cognitive ability (Sowerby & Tripp, 2009). Additional clinical tests may include standardized instruments that measure intellectual ability and academic achievement. Assessments measuring children's EF abilities may also be valuable, as well as symptoms of attention and impulsivity (Sowerby & Tripp, 2009). In general, clinicians must take care to create as complete a picture of the child as possible before diagnosing ADHD.

Reaching a differential diagnosis is essential because there are several disorders that may mimic symptoms associated with ADHD (Barkley & Mash, 2007), such as anxiety disorders, mood disorders, behavioural disorders, learning disabilities, personality disorders, and medical conditions (e.g., sleep disorders). Thus, clinicians must assess for the inclusion criteria for ADHD, and also exclude other disorders that could better explain the child's difficulties to come to a differentiated diagnosis. In doing so, clinicians must review potential problems the child exhibits in multiple developmental domains, including motor, language, social/emotional, intellectual, and academic (Barkley & Mash, 2007). Careful consideration of the symptom type, onset, duration, strength and quality must also be made (Barkley & Mash, 2007).

As part of a comprehensive assessment, it is also important for clinicians to consider the child's family context and factors that may affect the persistence and severity of the child's ADHD, including family history of ADHD (Biederman, 2005). Assessing parents' mental health may also be important, particularly since parents of children with ADHD tend to experience significant levels of parenting stress and psychopathology (Johnston & Mash, 2001; Theule, Wiener, Tannock, & Jenkins, 2013; Tzang, Chang, & Liu, 2009). By evaluating family variables such as these, clinicians can obtain a comprehensive understanding of both the family's functioning and child's needs. Having a complete picture of the child's functioning and context is necessary to provide recommendations that are appropriate for the child and his or her family, which is an important goal in conducting an assessment in the first place (Sowerby & Tripp, 2009). In sum, a comprehensive assessment looking at the child's overall cognitive, learning, social/emotional profile, and contextual influences, is important to ensure that clinicians do not misattribute other difficulties with ADHD and consequently misdiagnose (Rey & Sawyer, 2003).

The Psychological Assessment Process for ADHD

For the purpose of this study, the assessment process refers to the period of time that starts with the first contact made with the psychologist's office (e.g., to book the first appointment for an assessment), until the final meeting when the results of the assessment are shared with the parents. The psychological assessment process generally involves three phases (e.g., Barkley & Mash, 2007; Finn & Tonsager, 1997; Gorske & Smith, 2009), as depicted in Figure 1. The initial phase includes the initial contact with the psychologist's office in booking the appointment, any information exchanged prior to meeting, (e.g., developmental history forms), and the initial intake meeting with parents to review their child's developmental history and current levels of functioning. The middle phase involves the formal assessment phase, which may include the administration of standardized tests (e.g., cognitive and academic) and rating scales, observations of the child in natural and clinical settings, additional interviews with other adults (e.g., teachers and school professionals), and ongoing communication with the parents. After the formal assessment is completed, the third phase of the process involves meeting with the parents to review the results from the assessment and to communicate the diagnosis. A written report is often also provided in the third stage of the assessment, along with recommendations and intervention strategies.

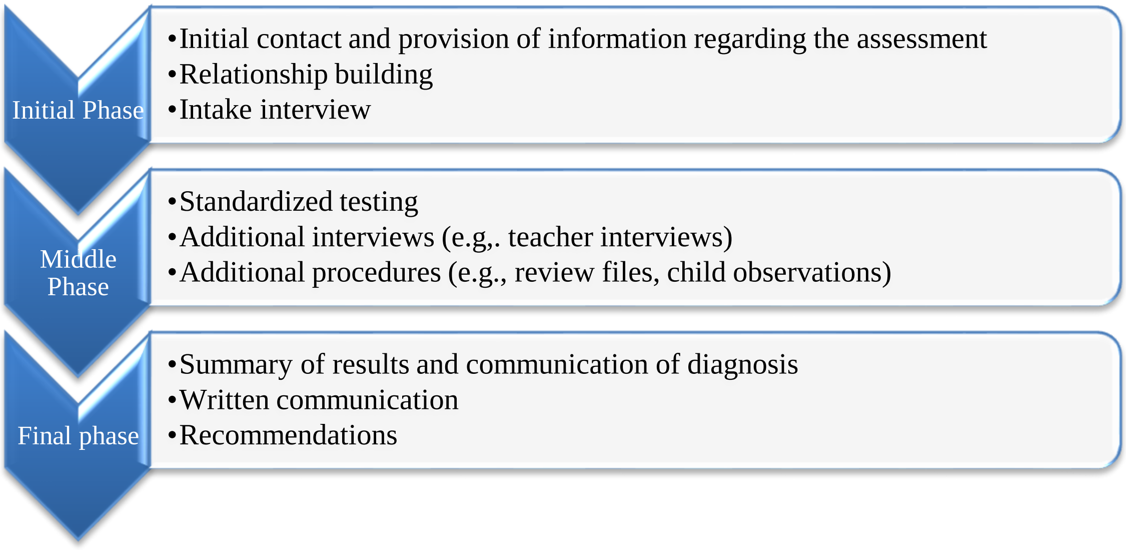

Figure 1. Phases of the Assessment Process

Shifting Paradigms in Assessment

Historically, psychological assessments were conducted within a traditional paradigm of assessment; also known as diagnostic psychological testing (Korchin & Chuldberg, 1981;

Tallent, 1992) or the information-gathering model (Finn & Tonsager, 1997). The traditional approach to assessment is largely objective in nature, in which test reliability and validity are paramount (Finn & Tonsager, 1997; Korchin & Chuldberg, 1981). In this model, psychologists value standardized assessment instruments to compare individuals "along empirically well-defined trait dimensions" (Korchin & Chuldberg, 1981; p. 1148). A significant portion of the assessment is "done outside of the human encounter" (Korchin & Chuldberg, 1981; p. 1149), as psychologists focus primarily on the test protocols to make sense of the scores. Thus, the focus is test-centred and psychologists use assessment instruments to help diagnose and to "guide subsequent treatment" (Finn & Tonsager, 1997, p. 377). During each step of the assessment, psychologists utilize a science-practitioner framework whereby they use clinical judgment to evaluate and confirm/refute the collected data in the process of case conceptualization (Lilienfeld, Ammirati, & David, 2012).

Although the traditional methods of information gathering are still prevalent in psychological assessments, over the past few decades, there has been a shift in thinking about how assessments should be conducted. For instance, Engel (1977) proposed a biopsychosocial model to promote health and wellness in a holistic manner. In this regard, he argued that individuals must be understood within their broader context. Similarly, Bronfenbrenner (1979) presented an ecological system's perspective, and later a bio-ecological model (Bronfenbrenner & Ceci, 1994), which further emphasized the need to understand individuals within their ecological context. He asserted that one's lifespan development is largely shaped by the multiple interacting contexts in which the person is situated. Since then, ecological theorists have continued to implicate broad external contexts (e.g., parent-child relationships, social, cultural, and political contexts) as important influencers in a child's externalizing profile (Bronfenbrenner

& Morris, 2006; Luthar & Zelazo, 2003; Lyons-Ruth, Alpern, & Repacholi, 1993; Sroufe, 1997) and developmental outcomes (Aunola, & Nurmi, 2005; Chan, 2011). From this body of work, a biopsychosocial model of assessment emerged that extended beyond the traditional assessment procedures by focusing on the investigation of biological, psychological, and socio-cultural factors that influence an individual's functioning (World Health Organization, 2007). Given the complexity of ADHD, the biopsychosocial approach provides a broader understanding of the child's difficulties than what is typically obtained in a traditional model. Having a more comprehensive understanding of the child and the specific factors that affect his or her success across environments helps psychologists to identify the specific needs of the child and family, and therefore specific interventions to address those needs, such as behaviour management, social skills, social supports, emotion regulation, and parent training (Pham, 2015).

Additionally, there has been a rise of humanistic orientations in psychology over the years, with an emphasis that moves away from test-centred, traditional approaches towards more client-centred approaches (Dana & Leech, 1974, as cited in Korchin & Chuldberg, 1981). This shift in approach includes the client as an active collaborator within the assessment process, rather than a passive participant that is being studied, to extend psychologists' understanding of the client (Korchin & Chuldberg, 1981). Fischer (1970) was instrumental in formulating the notion of collaborative assessment, in which the psychologist seeks to understand the individual client above and beyond test scores. As such, he considered clients as critical collaborators within the assessment process. Fischer (2000) later fostered the idea of using intervention within assessment, such as interrupting standardized testing to include breaks for intervention after each subtest, thus promoting a remediative component to assessment. Similarly, other assessment approaches, such as dynamic assessment, invites active collaboration between the assessor and child, while also integrating intervention strategies into standardized testing procedures to better understand how a child learns to promote his or her success with learning (Hill, 2015; Lauchlan & Carrigan, 2013). Using this dynamic approach, psychologists can explore how extra supports, such as prompts, feedback, or questions, help improve the child's performance in the classroom.

This significant shift in thinking emphasized the point that assessments could benefit individuals, rather than simply draw conclusions about them. Fischer (2000) was not the only one to highlight the therapeutic potential of the assessment process. Almost two decades earlier, Allen (1981) described assessment as a form of treatment; as did Korchin and Childberg (1981), who contended that assessment is a "human endeavour that has as its ultimate purpose helping individuals in distress" (p. 1157). Numerous researchers have further supported the notion that the assessment process should go beyond simply diagnosing clients to also benefit them (e.g., Allen, Montgomery, Tubman, Frazier & Escovar, 2003; Hilsenroth, Peters & Ackerman, 2004; Holm et al., 2008; Meyer et al., 2001; Newman & Greenway, 1997; Pegg, 2005; Poston et al., 2010; Ward, 2008).

Finn and Tonsager (1997) developed a form of collaborative psychological assessment that they called Therapeutic Assessment. The primary focus of this model is on making psychological assessments a positive and beneficial experience for clients. Within this approach, these researchers worked collaboratively with clients and added an intervention phase, in which intervention strategies are embedded in the middle of the assessment process. In his case study, Fischer (2000) demonstrated how, by engaging in intervention breaks within formal testing, and collaborating with his client throughout the assessment process, he and his client were able to create an intervention plan that the client could incorporate into daily life at the end of the assessment. Fischer also demonstrated how the assessment session could be used as an opportunity to practice skills, such as asking questions for clarification for clients who are generally passive, that can then be generalized more confidently in the individual's everyday life.

Therapeutic assessment is considered an innovative and flexible approach to child-centered assessment (Fantini et al., 2013; Finn, 2007; Hamilton et al., 2009; Smith, Wolf, Handler, & Nash, 2009; Tharinger et al., 2009; Tharinger et al., 2012). For instance, in their case study, Tharinger and colleagues (2007) noted that parents exhibited an increase in positive feelings, a decrease in negative feelings towards their child, and an overall positive change in the entire family system after participating in a therapeutic assessment. Researchers have also demonstrated that therapeutic assessment helps parents to develop a better understanding of their child and to better manage their child's difficulties, while also promoting improvements in the child's behavioural, emotional, and social presentation (e.g., Aschieri, Fantini & Bertrando, 2013; DuBose, 2002; Finn, 2007; Gart, Zamora & Williams, 2016; Michel, 2002; Smith et al., 2010; Tharinger et al., 2012).

A Comparison of Traditional Assessment and Therapeutic Assessment

The previous section provided a general introduction to the shifting paradigms in psychological assessment over the years. Although different assessment models have emerged over the years, this section offers a more detailed comparison of traditional approaches and therapeutic assessment approaches specifically, to highlight examples of some of the shifts in how assessments are conducted. The goals, process, view of tests, focus of attention, role of the psychologist, and assessment success of each model are discussed.

Goals of assessment. The referral question is important to both the traditional and therapeutic assessment, and both approaches focus on addressing that question. However, the way they do so differs. Within the traditional model of assessment, it has been argued that the main goal of assessment is to collect data to “facilitate communication between professionals” (Finn & Tonsager, 1997, p. 378), in which clients can be easily understood and described by pre-existing categories, such as the diagnostic labels offered in the DSM-5 (APA, 2013). Test scores can be used to make comparisons of the individual to the norm, or to other clinical populations, to make important decisions such as determining the most appropriate treatment approaches (Finn & Tonsager, 1997).

Whereas the information collected from the traditional assessment approach is intended to primarily help facilitate communication between professionals, information collected in therapeutic assessment is meant to facilitate communication with the clients. Rather than categorizing clients, the test scores are used to “provide access to the clients’ life worlds” (Fischer & Finn, 2008, p. 399). The goals of therapeutic assessment focus on ensuring clients leave the assessment with new insights or experiences to promote positive changes in their/their child’s life (Aschieri et al., 2013; Finn & Tonsager, 1997; Gart et al., 2016; Smith, Finn, Swain, & Handler, 2010; Tharinger et al., 2012). Thus, the assessment is considered an intervention in and of itself.

Assessment process. Psychologists who followed the traditional model of assessment typically engaged in three major steps: collecting data, making deductive interpretations of the data, and offering recommendations based on the data (Finn & Tonsager, 1997; Smith et al., 2010). There is often little back-and-forth collaboration between the psychologist and client in this process. Rather, in this approach, the assessment is largely one-sided, as the psychologist takes information from the client, but gives little in return until the end of the assessment (Finn & Tonsager, 1997).

The therapeutic assessment approach extends beyond the traditional model and generally includes six major steps: an initial session, initial testing sessions, an assessment intervention session, summary and discussion sessions, a written report, and a follow-up session (Aschieri, et al. 2013; Fantini et al., 2013; Smith et al., 2010; Tharinger et al., 2012). Although there is an overlap regarding certain procedures with traditional and therapeutic assessments (e.g., initial intake interview and use of standardized tests), the latter approach includes a number of unique procedures, such as the intervention sessions and discussions in which clients are invited to reflect on the results as part of the interpretation process. The collaborative nature of the relationship and working alliance is also paramount throughout the process (Fantini et al., 2013; Smith et al., 2010; Tharinger et al., 2012). As such, psychologists focus on establishing and maintaining a strong collaborative relationship with the client throughout the entire assessment, from developing goals for the assessment to helping develop subsequent recommendations (Fantini et al., 2013; Finn, 2012; Finn & Tonsager, 1997).

View of tests. The tests used in traditional and therapeutic assessments are often very similar. However, how they are used differs between the two models. Within the traditional model, the psychometric properties are paramount so that the psychologist can make nomothetic comparisons of the client based on the test scores and formulate conclusions about the individual’s functioning (Finn & Tonsager, 1997). Psychologists conducting therapeutic assessments can make nomothetic comparisons; however, there is also an idiographic approach to develop a deeper understanding of the clients’ experiences and perspectives. Within the therapeutic assessment, psychologists can also use test results to engage in a discussion with the client to gain a deeper understanding of the client in context, rather than to make absolute truths about the client (Fantini et al., 2013; Finn & Tonsager, 1997; Smith et al., 2010). For instance, the results can open discussions about how the client responded to certain questions and their experiences. Test results can then be interpreted in light of the client's thoughts and experiences of the assessment, as well as the psychologist's own observations and experiences.

Focus of attention and role of the psychologist. Within the traditional model, psychologists purport to maintain an objective stance and focus primarily on the test scores and final outcome, with little consideration for the client's subjective experiences of the assessment process (Finn & Tonsager, 1997). Psychologists thus take on the expert role as objective observers within a highly structured context. Their interactions with clients are largely one-sided and consist of asking questions and recording responses, thereby not only limiting clients to a passive role within the process, but also limiting their expertise (Finn & Tonsager, 1997). Within therapeutic assessment, what happens within and throughout the assessment is just as important as the final outcome (Finn & Tonsager, 1997). A key goal here is to maintain the working alliance and to develop as rich an understanding of the client as possible. In this regard, the subjective experiences of both the client and psychologist are important, as well as the relationship between the two (Fantini et al., 2013; Finn, 2012; Finn & Tonsager, 1997; Smith et al., 2010). Psychologists assume the role of a participant observer in the assessment. They also have a large influence in shaping and adapting the assessment process, particularly in terms of maintaining the working alliance, collaborating with clients, understanding the client's subjective experiences, ensuring clients understand the assessment process, and helping support change (Finn & Tonsager, 1997; Smith et al., 2010; Tharinger et al., 2009). Here, the relationship has been described as egalitarian and clients are considered experts in their own lives (Gart et al., 2016). Thus, client involvement in the assessment process is critical because the client "will always know more about himself and his own life than [the psychologist] can or does"

(Bugental, 1999, p. 89). As such, their role is more active as co-assessor (Clair & Pendergast, 1994; Finn, 1996; Fischer, 1970); as such, ongoing collaboration and feedback is elicited from the client throughout the assessment process.

Assessment success. Within the traditional assessment model, the assessment is considered successful if valid and reliable information is collected, if the final conclusions are accurate, and if the recommendations are useful for the client (Finn & Tonsager, 1997). Within therapeutic assessment, assessment success is determined by whether clients' goals and needs were met (Finn & Tonsager, 1997; Tharinger et al., 2012). The focus is on success with the relationship (e.g., collaboration and empathy from the psychologist), with the intervention/therapeutic aspect of the assessment (e.g., clients learn something new from the assessment), and/or with the client's intrapsychic experiences (e.g., clients feel empowered after the assessment; Finn & Tonsager, 1997; Smith et al., 2010). At the end of the assessment, the client should come away with a greater understanding of themselves and a new way of being. In helping support this end goal, the working alliance and collaborative nature is critical throughout the assessment process (Dana, 1985; Finn, 2012; Gart et al., 2016; Smith et al., 2010).

The Working Alliance in the Assessment Process

As highlighted in the previous discussion, the working alliance and collaboration is paramount throughout therapeutic assessments. The working alliance in psychology is not a new concept (Horvath & Luborsky, 1993; Luborsky, Barber, Siqueland, McLellan, & Woody, 1997). Over the past few decades, aspects of the human-relationship have become increasingly explicit in the psychological literature, with a focus on the professional's personality traits (e.g., Beck & Butler, 2005; Corey, 2009; Rogers, 1992; Yalom, 1980). In particular, the professional's genuineness, empathy, and unconditional positive regard were considered more important than client and situational factors (Rogers, 1992). However, the professional's personal qualities are not the only important aspect to a working alliance; so too is their collaborative relationship with their client (Clair & Pendergast, 1994).

Luborsky (1976) defined two alliances: The first alliance is the nurturant alliance, which focuses on the client's perceptions of the professional as supportive and helpful, pointing to the importance of the professional's qualities, as discussed above. The second alliance is the collaborative alliance, which focuses on a sense of working together, with an emphasis on shared responsibility for working on goals: a sense of "we-ness." Taken together, the nurturant alliance and the collaborative alliance form the overarching concept of the working alliance (Bachelor, 1995). Over the years, researchers have suggested that these two alliances are the single factor, above all others, most strongly and consistently associated with positive outcome for clients within a therapeutic environment (Horvath, 2000; Horvath, Del Re, Fluckiger, & Symonds, 2011; Horvath & Greenberg, 1989; Horvath & Luborsky, 1993; Howard, Krasner & Saunders, 2000; Krupnick et al., 1996; Winston & Winston, 2001).

Although most of the literature has focused on the working alliance with respect to counselling type situations, researchers have highlighted the need for psychologists to demonstrate empathy and support towards the client within psychological assessments (Finn & Tonsager, 2002; Fischer, 2000). Finn and Tonsager (1992; 1997; 2002) are strong advocates for the working alliance in assessment, asserting that this alliance helps to positively affect the assessment process. For instance, in their studies investigating client's perspectives of assessments, Finn and Tonsager (1992) found that clients expressed positive experiences of the assessment when they had a positive relationship with the assessor and felt respected and liked by the assessor. Conversely, clients felt negatively about the assessment process when they did not have a positive relationship with the assessor or felt judged by the assessor. Additionally, Finn (2012, 2007) reported that clients are more actively engaged in the assessment and more open to completing test protocols when they have a strong working alliance with their psychologist than those who do not.

Other researchers have provided commensurate results. In their investigation of the relationship between the working alliance during psychological assessment and subsequent therapy, Ackerman, Hilsenroth, Baity, and Blagys (2000) found that that a positive working alliance was related to positive assessment feedback experiences within the assessment process, as well as to positive working alliances and overall success within therapy. Similarly, Hilsenroth, Peters & Ackerman (2004) longitudinally examined the relationship of the working alliance during psychological assessment with the alliance later in therapy, comparing assessment as usual practices with therapeutic assessment practices. Their findings indicated that establishing a working alliance during the psychological assessment persisted throughout the course of therapy and promoted therapy success. In general, a working alliance and collaborative relationship between the psychologist and client is considered important to help clients gain a deeper understanding of their difficulties and to empower clients to create positive change in their life (Finn, 1996; Hilsenroth et al., 2004). A working alliance can also help reduce client anxiety in the assessment, and allow clients to engage in developing goals for the assessment, thereby maximizing the usefulness of the assessment process (Finn, 1996; Finn & Tonsager, 2002).

The studies reported above focused on the working alliance success with individual adult clients. Nonetheless, researchers have also emphasized the need for a collaborative relationship between psychologists and parents with respect to a child’s assessment (e.g., Barkley & Mash, 2007; Dreyer et al., 2010; McKay & Chesson, 1991). McLaughlin (2005) noted that the working alliance between parents and examiners is important to facilitate proper diagnosis of the child, particularly with obtaining detailed and accurate information. Maintaining the working alliance can also help psychologists deepen their understanding of the child, which further aids in the accurate interpretation of the assessment results (Byers, 2002; Fischer, 2000).

Although collaboration with parents is suggested in the guidelines for the assessment of ADHD (e.g., NICE, 2013), very little research has specifically investigated and reported on the working alliance and assessment of ADHD. Nonetheless, the results of the work that was done are similar to those reported above. For instance, in their investigation of parents' perceptions of their child's diagnosis of ADHD, Concannon and Tang (2005) found that parents reported negative assessment experiences when their assessor failed to establish a collaborative relationship with them and seemed uninterested in the family's needs.

In sum, the studies presented here suggest that the working alliance with regards to assessment is important for numerous reasons, such as to help reduce client anxiety within the assessment, to show empathy to the clients, to help promote goal formulation and ongoing collaboration throughout the assessment process, to develop rich understandings of the client, to contribute to accurate diagnosis, to promote client change, and to promote positive experiences of the assessment process.

The Need for Parent Input: An Empirical Context and Implications for Practice

Just as the working alliance and collaboration is an important part of the assessment process for individual clients and families, obtaining information about how parents describe what the experience of their child's assessment process was like for them may prove to be useful in clinical practice. Indeed, parent insight could be used to promote the collaborative nature of the assessment, and can also inform a framework for potential improvement in quality service provision by identifying what they consider contribute to, or detract from, their experiences (Larsen et al., 2012). To demonstrate, researchers exploring clients' experiences with their assessment process identified that consumer experiences may "provide a valuable source of quality assurance data" (Bennett-Levy et al., 1994, p. 220) and that understanding their experiences has helped improve "the understanding of what constitutes effective clinical practice" (Bennett-Levy et al., 1994, p. 220). By obtaining parent input and incorporating their feedback into assessment practices, clinicians may better provide quality services that address what parents indicate is important for them (Larsen, Attkinson, Hargreaves & Nguyen, 1979).

As indicated elsewhere, parents are experts in their daily lives and bring valuable information to the assessment process. As such, to enhance quality services, parents must be actively involved in all levels of service provision (Mental Health Commission of Canada, 2012). Practice guidelines have also affirmed the need to consider the family's perspectives and to involve them throughout the assessment process in diagnosing ADHD (NICE, 2013). Failure to obtain parent input regarding the assessment process may lead to bias if only the service provider's perspective is considered. This is because parents may have different, but equally important, perspectives regarding the services (Larsen et al., 1979). Failing to obtain client input may result in services being administered *to* the client, rather than *for* the client (Clark & Stewart, 1985, as cited in Griffey, 1989). As such, researchers highlighted the need for clinicians "to identify users' service values and what issues *they* find important, rather than make assumptions based on *professional* beliefs" (Giannoulis et al., 2004, p. 65) to ensure the provision of quality, person-centred services.

Recognizing the importance of obtaining parent input, researchers demonstrated how parent feedback can be used to improve services provision. For example, Giannoulis and colleagues (2004) investigated parents' experiences of assessment services provided in a specialist clinic for neurodevelopmental disorders. These researchers used the information they collected from parents in their study to modify services to better address parents' needs and to increase parent satisfaction with the services. Specifically, based on parent feedback, the clinic: a) developed a service leaflet with an overview of what parents could expect from the assessment, b) hired an additional psychologist to help with behavioural interventions, c) created a library of books and resources for parents regarding relevant neurodevelopmental disorders, and d) introduced a one-way screen so parents could observe their child being assessed.

Likewise, Mansell and Morris (2004) revealed that parent ratings of their child's assessment increased significantly when their input regarding the assessment process was used to make changes to service provision, again highlighting the value of using parent input in the assessment process to improve their satisfaction. Similar findings were obtained in earlier work by Cunningham, Morgan and McGucken (1984), who demonstrated that only 20% of parents were satisfied with the services provided to their families but that, after incorporating parent feedback into service provision, all parents expressed satisfaction. Furthermore, Piper and Howlin (1992) revealed that parent satisfaction with assessment services improved when clinicians obtained a list of topics parents wanted to discuss regarding the assessment prior to conducting the assessment. By obtaining parent input and incorporating their feedback into assessment practices, clinicians enhance the quality of services by directly addressing what parents indicate is important and helpful for them (Larsen et al., 1979).

Obtaining parent input regarding the assessment process may also promote parent collaboration and parent involvement throughout the process. This assertion is supported by the guidelines Hoagwood (2005) proposed in her review of empirically supported approaches to working with families in mental health. Specifically, she identified that establishing a collaborative relationship with families and engaging them from the initial session by obtaining their input regarding the services offered are two key areas of best practice in working with families. These guidelines stemmed from the work of several researchers that demonstrated the association between obtaining parent input and their subsequent engagement in the services offered by clinicians. In their seminal work evaluating the efficacy of engagement strategies (e.g., inquiring about family interactions, problems, values and interests, and supporting and establishing an alliance with families) to support drug abusers and their families to complete therapy, Szapocznik et al. (1988) revealed that the experimental group that received engagement strategies engaged in therapy at a dramatically higher rate (93%) than those in the control group (42%). The significance of the engagement strategies employed was that the families were engaged from the initial contact with clinicians, even before treatment commenced. Within this initial engagement, the clinician focused on establishing a working alliance with family members, while also obtaining input from the family regarding a range of issues, such as their values, interests, attitudes (e.g., towards treatment), areas of difficulty, and potential obstacles in completing therapy. Researchers concluded that clinicians who used engagement strategies increased family engagement in services substantially more than families who did not receive such strategies (e.g., McKay, McCadam, & Gonzales, 1996; Szapocznik et al., 1988). Similarly, Dreyer and colleagues (2010) found that the parents’ relationship with the clinician conducting their child’s psychological assessment is an important factor influencing parent engagement in the assessment process. They also highlighted the need to establish a collaborative relationship with parents and supported the recommendation to obtain parent input to increase parent engagement (Dreyer et al., 2010). When considering assessments for the diagnosis of ADHD specifically, Barkley and Mash (2007) highlighted the need to obtain parent feedback before commencing the assessment to ensure there is connection between parents' concerns and the assessment. In doing so, they noted that, by obtaining parent input, parents become engaged in the assessment process and clinicians are better able to promote a positive working relationship with them. Overall, these researchers emphasized that obtaining input from families is an important step in developing collaborative relationships with clinicians and facilitating family engagement in the services provided.

Furthermore, obtaining parent input and establishing collaborative relationships with parents may promote positive experiences for parents (Graungaard & Skov, 2006; Miller & Hanft, 1998). In exploring mothers' experiences of the assessment process for their child's learning disability, Stephenson, McKay and Chesson (1991) found that parents reported negative experiences when they had minimal opportunity to offer input into the process. Similarly, Keenan Dillenburger, Doherty, Byrne, and Gallagher (2010) noted that parents who expressed negative experiences with their child's assessment reported that their expertise about their own child was disregarded and that the professionals acted like the expert. In exploring parent perceptions of their child's diagnosis and treatment of ADHD specifically, Concannon and Tang (2005) also demonstrated that the parents who reported negative experiences were the ones who indicated that the clinicians they worked with failed to establish a collaborative relationship with parents and appeared to be uninterested in the family's needs.

Establishing a collaborative relationship with parents and obtaining their input is important and can transform the assessment process "into a positive discovery experience," (Miller & Hanft, 1997, p. 55) and can be individualized to meet the needs of the family. Unfortunately, "poor relationships and lack of communication between [clinicians] and parents can hamper diagnosis as symptoms are missed" (McLaughlin, 2005, p. 285). Additionally, the assessment "is the beginning of a family's journey" (Miller & Hanft, p. 50) and can affect how parents perceive their child's needs (Bennet, Power, Rostain & Carr, 1996) and diagnosis (Bussing & Gary, 2001). In their exploration of parents' decision-making process about whether to medicate their child diagnosed with ADHD, Taylor, O'Donoghue and Houghton (2006) found that a collaborative relationship with the clinician facilitated parents' acceptance of their child's diagnosis. Parents who did not have a collaborative relationship with their clinician denied their child's diagnosis and engaged in "doctor-shopping" (Taylor et al., 2006, p. 117). Others also identified that parents reported feelings of dissatisfaction with the assessment and doubts about their child's diagnosis when clinicians failed to obtain their input (Bussing & Gary, 2001). Unfortunately, parents who are unaccepting of their child's diagnosis may not cope well with the diagnosis, which may breed insecurity, isolation, and frustration within the family unit (Taanila, Syrjala, Kokkonen, & Jarvelin, 2002). Indeed, the assessment process can be emotionally stressful for parents, and their experiences with clinicians can "have a major, lasting influence on the parents' ability to cope with their child's condition" (Graungaard & Skov, 2006). For instance, Taanila and colleagues (2002) demonstrated that a major difference between high and low-coping families was their initial experience of learning of their child's diagnosis. These researchers again stressed the importance of collaboration between professionals and parents during the assessment process to help facilitate adaptive coping within the family.

As discussed throughout this paper, investigating parents' experiences of the services they use, including assessment services, is an important part of establishing a collaborative relationship and may help to inform service provision. The following section offers a more detailed review of the work done by researchers who investigated parents' experiences of their child’s assessment process. It is important to note that, because the typical assessment process for the assessment of ADHD is conducted within three phases, parents’ experiences of these three phases of assessment are discussed.

Parents’ Experiences of their Child’s Assessment Process: An Empirical Review

The following section provides an overview of the literature exploring parents’ experiences of their children’s assessment process. Because there is scant research exploring parents’ experiences of the assessment process for the diagnosis of ADHD specifically, much of information in this section draws from parents’ experiences of the assessment process for other disorders, such as autism spectrum disorders (ASD). As noted above, given the prevalence of how assessments are conducted, this segment is divided into three sections that directly reflect the three general phases of the assessment process. That is, the initial phase of the assessment, which includes the intake process (e.g., scheduling the appointment, conducting the initial interview); the middle phase, which may include standardized testing and/or observations; and the final phase, in which parents are provided feedback regarding the results of the assessment.

Initial Phase

In general, no studies have specifically sought out information related to parents’ experiences with the initial intake phase of the assessment process. Nonetheless, as discussed below, a few researchers have made note of elements of the assessment process that influenced parents’ experiences and that are relevant to this phase of the assessment. These elements include the wait times to see clinicians, parent preparedness for the assessment, and the establishment of a collaborative relationship between parents and clinicians.

In their study exploring parents’ experiences of the assessment process for their child’s mental health concerns, Hilton and colleagues (2012) noted that almost half of the parents in their study expressed dissatisfaction with the length of time they had to wait before attending their first appointment for their child's assessment. This finding echoed previous work done by Hackett et al. (2009), who also found parent dissatisfaction with the lengthy waiting period before their child's assessment to investigate autism spectrum disorders. However, neither study explicated exactly how long parents had to wait before their initial appointment, so further research is needed on this point.

In their exploration of client experiences of the neuropsychological assessment process, Bennett-Levy et al. (1994) noted that a significant majority of clients were not prepared for their assessment in that they did not know what to expect, which contributed to feelings of anxiety and overall negative experiences of the assessment process. These researchers concluded that helping clients understand the assessment process is important to help reduce their anxiety. Furthermore, they noted that clients may find the experience to be more worthwhile when given the chance to identify what information they would like to learn from the assessment. They also indicated that clients may be better able to provide the psychologist with a more comprehensive background history if they are prepared for the assessment, which can in turn aid in diagnosis. Bennett-Levy et al. (1997) concluded that, because client preparation for the assessment is highly related to their overall experience of the assessment process, clinicians should take the time to adequately educate and prepare clients for the assessment to promote positive experiences. This contention was supported in earlier work done by Webster (1992), who found that clients reported more positive experiences with the assessment process when they received detailed information about the assessment process (e.g., what to expect and how decisions are made) as compared to the control group who did not receive such information. Webster (1992) also indicated that clients who received pre-assessment information perceived that the clinicians listened to them better and felt more understood than the control group.

Hackett et al. (2009) found that many parents in their study expressed uncertainty about what their child’s assessment process entailed or how long the assessment would take. Parents indicated that they were uncertain about the purpose of the initial interview and that they would have appreciated being invited to bring a list of questions for the clinicians to the first meeting. Parents in Braiden and colleagues’ (2010) study also identified that they would have benefitted from learning about what types of questions they would be asked in the interviews so that they could be better prepared to provide more accurate and detailed information about their child.

Finally, in their exploration of parents’ experiences of the assessment process that resulted in their child’s diagnosis of autism, Braiden et al. (2010) found that the parents who reported having a negative experience with the assessment process were those who found the assessment to be a “daunting and difficult-to-understand process” (p. 385). Parents reported a limited communication with the professionals involved, which contributed to their uncertainty of the process, noting that they did not know what was going on in the assessment (Braiden et al., 2010). Thus, parents may face heightened levels of stress and anxiety and an overall negative experience of the assessment process (Braiden et al., 2010; Hackett et al., 2009). The field would benefit from additional qualitative research exploring parents’ experiences in this area, particularly about what clinicians can do to better prepare parents for their child’s assessment and to promote positive experiences.

Despite these negative experiences, parents have reported positive experiences as well. For instance, Braiden et al. (2010) revealed that parents reported positive assessment experiences, and also later accepted their child’s diagnostic outcome, when clinicians gave them the opportunity to provide feedback about the assessment. This point highlights the benefit of working collaboratively and obtaining parental input. Additional research investigating what promotes parents' positive experiences is important to help inform future assessment practices. This research is particularly relevant to the assessment process for ADHD, as there is currently a paucity of information in this area.

Middle Phase

As with the initial phase of the assessment process, little attention has been devoted specifically to exploring parents' experiences of the middle phase of the process. However, as above, researchers have identified elements from within this phase of the assessment process that may influence parents' experiences. Similar to findings in the initial phase, parents reported negative experiences when they were unsure about what their child was being assessed for (e.g., Chamak et al., 2011). Additional assessment practices influencing parents' experiences in this middle phase included collaboration, the length of testing, the comprehensiveness of the testing, and the wait time between the middle and final phases of the assessment process. Each of these elements is reviewed in the remainder of this section.

In terms of uncertainty, Braiden et al. (2010) shared a clear example of how one family believed their child was getting help for a phobia but were later told their child had an autism spectrum disorder. The parents were left feeling shocked. Likewise, Mulligan and colleagues (2012) found that parents reported negative experiences of their child's assessment process for ASD when they were uninformed about what their child was assessed for. The parents from this study expressed feeling upset with the "lack of perceived transparency on the part of the team in clearly conveying the purpose and potential outcome of the assessment process" (p. 318). Researchers have recommended that parents receive information regarding what their child is being assessed for, even if only based on a hypothesis, to better prepare them for the diagnostic outcomes (Braiden et al., 2010; Nissenbaum, Tollefson & Reese, 2002). However, this recommendation was made for clinicians who conduct assessments for ASD: there is little understanding about whether these recommendations are appropriate for parents of children with ADHD. For this reason, qualitative research exploring parents' experiences of their child's ADHD assessments is needed to better understand what assessment practices contribute to those experiences and what recommendations are appropriate.

An additional element influencing parents' experiences with the assessment process is whether parents had the opportunity to collaborate with clinicians. For instance, Mulligan and colleagues (2012) indicated that parents reported feelings of frustration with the "arduous and largely one-sided process" (p. 318) of diagnostic interviews. That is, parents expressed dissatisfaction with having to respond to a multitude of questions from the clinicians, but with no opportunity to ask questions themselves. In contrast, Hilton et al. (2012) found that parents who reported positive experiences also reported that their clinicians made time for the family throughout the assessment and gave parents the opportunity to discuss any concerns they had during their scheduled appointments.

Wait times between appointments (Braiden et al., 2010) and the lengthiness of this middle phase of the assessment process proved to be another element influencing parents' experiences. Indeed, many parents in both Hackett et al. (2009) and Keenan et al.'s (2010) studies that explored parents' experiences of their child's assessment for ASD stated that the formal testing phase took too long and was not completed in a timely manner. Furthermore, parents in Mulligan and colleagues (2012) study described the middle phase of the assessment process as not only lengthy, but also intense, particularly the diagnostic interviews. Parents in

Braiden et al.'s (2010) study remarked about the amount of work that needed to be done in this phase, expressing specific feelings of being overwhelmed with the amount of paperwork they needed to complete for their child's assessment. As is discussed elsewhere in this paper, assessments investigating the diagnosis of ADHD rely heavily on parent report and often include comprehensive interviews and rating scales. Thus, further inquiry is needed to identify parents' experiences within this second phase of assessment to see if they have similar experiences as those identified by parents in the studies mentioned here.

Although Hilton et al. (2012) found that parents in their study generally reported that the formal testing phase of the assessment was quite long, other parents nonetheless stated that they would have valued a longer assessment to ensure the thoroughness of the assessment. For instance, Braiden et al. (2010) noted that parents were dissatisfied with their child's assessment when they perceived that clinicians made "snap judgments" about their child, suggesting that they did not believe clinicians collected enough information. This concern was commensurate with work done by Concannon and Tang (2005), who investigated parents' perceptions of their child's diagnosis of ADHD. They noted that parents expressed concern when the clinicians working with their family failed to collect information from multiple sources and did not seem to have a complete understanding of their child's problems. Conversely, parents in Hackett et al.'s (2009) study reported positive experiences when they believed that their child's assessments were comprehensive and individualized to meet the needs of their child. Given the complaints with the middle phase of the assessment process, Bennett-Levy et al. (1994) suggested that clients' experiences may be enhanced if clinicians take the time to explain the relevance and rationale for the various tests they use and relate their purpose to the client's situation. The field would benefit from further qualitative research exploring parents' accounts about what clinicians can do to promote positive parents' experiences of this phase of their child's assessment, particularly when assessing for ADHD.

Final Phase

The wait time between the final testing session and the feedback meeting proved to be influential in parents' experiences with the assessment process. Indeed, parents from both Hackett et al. (2009) and Mulligan et al.'s (2012) studies expressed negative experiences with the assessment when they reported that this waiting period was too long. Mulligan et al. (2012) explained that the wait time was difficult for parents, who reported feeling "overwhelmed with worry and concern for their child" (p. 317) while also feeling "stalled," unsure as to what to do to help their child until they received the final results.

Although wait times can influence parents' experiences, a significant part of the final phase of the assessment is the moment parents receive their child's diagnosis. Indeed, receiving a diagnosis for their child is considered a critical event in parents' lives (Cottrell & Summers, 1990; Hasnat & Graves, 2000) and greatly influences how they perceive the entire assessment process. Researchers have indicated that many parents whose child received a diagnosis, such as autism, reported negative experiences with the assessment process due to aspects surrounding the communication of their child's diagnosis. Indeed, Chamak et al. (2011) revealed that 63% of parents were dissatisfied with the process; Mansell and Morris (2004) found that over 60% of participating parents were not satisfied; and Cunningham et al. (1984) revealed that 80% of parents were dissatisfied. In analyzing reasons for the negative experiences parents reported, several indicators were identified: the professional manner of the clinicians communicating the diagnosis, the context in which the diagnosis was communicated, and the information imparted about their child's diagnosis. Each of these indicators is addressed in turn next.

Professional manner. As was discussed earlier in this chapter, the professionals' manner in how they interact with parents during the final feedback interview "can do much to influence parents' experience of disclosure; they can ensure that parents feel supported, respected and informed, or, conversely, they can leave parents feeling confused, angry, distressed and humiliated" (Brogan & Knussen, 2003, p. 44-45). Researchers exploring elements of the assessment process that influence parents' experiences in general, regardless of diagnosis, concluded that parents who report negative experiences with the assessment process tend to complain about the unsympathetic manner of the professionals involved (Cunningham et al., 1984), as well as their lack of: sensitivity, empathy (Quine & Pahl, 1986, Stallard & Lenton, 1992), warmth, and friendliness (Jackson, Chamberlin & Kroenke, 2001). Conversely, parents who reported positive experiences with the assessment process shared that they felt respected and listened to by clinicians (Giannoulis et al., 2004; Hackett et al., 2009) and that the clinicians demonstrated compassion, sensitivity, and sympathy (Mulligan et al., 2012).

In their study exploring parents' experiences upon learning of their child's disability, Graungaard and Skov (2006) noted that a key factor that was helpful for parents when receiving a diagnosis for their child was an empathetic approach by the clinician. However, demonstrating empathy may not be enough, as the words professionals use can also affect parents. For instance, Piper and Howlin (1992) revealed that, even when professionals presented as sensitive and empathetic, parents experienced distress when clinicians made negative comments about their child. On the other hand, Mulligan and colleagues (2012) noted that parents reported positive experiences when clinicians maintained a "hopeful and strengths-based approach" (p. 317) in relation to their child.

In their investigation into parents' experiences with receiving a diagnosis for their child, such as autism or a learning disability, Hasnat and Graves (2000) revealed that parents expressed positive experiences with the assessment when professionals were direct in their interactions, particularly regarding their child's areas of difficulties and needs. Along these lines, researchers have suggested that parents report negative experiences when professionals lacked transparency, seemingly suppressing facts and/ or avoiding giving direct and honest information about their child (Cunningham et al., 1984; Quine & Pahl, 1986). Taken together, these studies have demonstrated the influence professionals' manner at the final feedback session can have on parents' experiences of their child's assessment process. However, none of these studies provided insight into the experiences of parents of children diagnosed with ADHD. Thus, future research is needed to determine whether professionals' manner also affect the experiences of these parents.

Context. Researchers revealed that contextual elements surrounding the moment parents receive a diagnosis can also affect their experience of the assessment. Several researchers suggested that parents tend to report negative experiences when they lacked privacy upon learning about their child's diagnosis (e.g., Baird, McConachie & Scrutton, 2000; Cottrell & Summers, 1990; Pearson, Simms, Ainsworth, & Hill, et al., 1999). The method by which parents are told is also important. For instance, Braiden et al. (2010) found that parents reported negative experiences of the assessment when they were given a copy of a letter addressed to their family doctor stating their child was given a diagnosis of autism, or if they had to personally call the clinician to obtain the diagnosis themselves.

Information regarding their child's diagnosis. The information parents receive about their child can also affect their assessment experience. In their study on parent perceptions of the assessment of autism, Hackett et al. (2009) concluded that parents expressed positive experiences with the process when they were given specific information about their child's difficulties and information about how to best support their child. Similarly, others demonstrated that parents expressed appreciation when clinicians provided them with: clear information regarding their child's diagnosis that is relevant to their child's specific presenting difficulties (Giannoulis et al., 2004), appropriate treatment recommendations, specific behaviour management strategies (Hilton et al., 2012), and information about their child's strengths (Mulligan et al., 2012). Taanila and colleagues (2002) revealed that families who were provided adequate and specific information regarding their child's diagnosis and who were offered follow-up supports were better able to cope with the diagnosis and establish realistic expectations for their child.

In contrast, researchers noted that parents reported negative experiences with the assessment when they were provided with inadequate information, such as insufficient information about their child's diagnosis and about how to proceed once the diagnosis was communicated (Hackett et al., 2009; Keenan et al., 2010). Upon receiving inadequate information, parents reported feeling uncertainty about what their child's needs were (Boström, Broberg & Hwang, 2009). Elements contributing to parent feelings of uncertainty included receiving written information that was too technical and difficult to understand (Hackett et al., 2009) or too general, vague, or irrelevant (Giannoulis et al., 2004; Hilton et al., 2012). Non-specific information regarding their child may leave parents feeling unsure about what part of the information provided to them applies to their child (Braiden et al., 2010) and whether their child's presenting difficulties are part of the diagnosis or not (Mansell & Morris, 2004). Parents also reported negative experiences with the assessment when they felt that their child was simply labelled, rather than described (e.g., Boström et al., 2009), or when focus was placed on the child’s disabilities and symptoms, with no acknowledgement of their strengths and abilities (Graungaard & Skov, 2006).

While some parents noted wanting detailed information regarding their child, parents of children with autism have identified negative experiences when too much information was provided at one time in the final feedback meeting (Hackett et al., 2009). Researchers have suggested that parents may feel so overwhelmed about learning their child’s diagnosis, and that they may subsequently have difficulty attending to (Braiden et al., 2010) and/or retaining the information provided to them during that final meeting (Cottrell & Summers, 1990). Mulligan et al. (2012) also found that parents reported feeling “physically exhausted, emotionally drained, and overloaded with information” (p. 318) upon receiving their child’s diagnosis, making it difficult to understand the information they were given. To address this difficulty, parents expressed the need for clinicians to have a follow-up meeting after the diagnosis was communicated so that parents could have more time to ask questions and develop a complete understanding of their child’s needs (Cottrell & Summers, 1990; Mulligan et al., 2012).

An additional consideration comes from the work of Bennett-Levy et al. (1994). They noted that the information clients receive at the end of the assessment process should be memorable and understandable. However, they concluded that, to promote positive experiences of the assessment process, clients must receive information they perceive to be useful to them; that is, specific information about their strengths and areas of difficulty, the implications the results have for their everyday functioning, and how to address skill deficits. These recommendations were commensurate with Braiden et al.’s (2010) study, revealing the need to provide parents with information specific to their child’s difficulties and about what to expect in terms of their child’s functioning in the future. Although these studies have enhanced our understanding about parents' experiences regarding the information they received at the end of an assessment process, our understanding of the specific experiences of parents of children with ADHD is limited. As such, the field would benefit from further research to illuminate what types of information would be most beneficial to share with these parents.

In sum, this section offers some insight into what we currently know about parents' experiences of the assessment process for their child. Major factors influencing parents' experiences with the assessment process were elucidated, such as understanding the assessment process, the length and comprehensiveness of the formal testing phase, the professional manner of the clinicians involved in the assessment, the context in which the diagnosis was communicated, and the information imparted.

Statement of Problem and Purpose of the Study

As discussed previously, there is a need to obtain input from parents about their experience with their child's assessment process (Hilton et al., 2012; Stallard & Lenton, 2001). However, understanding parents' experiences of the entire assessment process, from initial contact with the psychologist's office to the final feedback meeting, is limited because much of research to date has explicitly focused on parents' experiences of receiving their child's diagnosis. The work done by Braiden and colleagues (2010) is one exception, as they expanded the scope of their investigation to include parents' experiences from the time they first shared concerns about their child with a professional until after they received their child's diagnosis of autism. They offered guidance on how clinicians could adapt their assessment practices to meet parent needs, such as educating parents about community-based supports, providing information that is specific to their child, and being clear about what the assessment process entails from the outset. Although this work provided valuable information regarding parents' experiences of the assessment process for autism, a gap remains in our current knowledge about parents' experiences of the assessment process that resulted in their child's diagnosis for ADHD specifically.

Two notable studies have investigated parents' experiences of the assessment process of ADHD; however, these studies were limited in their scope. Specifically, as a small component of a broader study on parent and child perceptions of ADHD, Travell and Visser (2006) investigated how the child's diagnosis of ADHD was made, from the parents' perspective. However, they did not attempt to gain a comprehensive understanding of parents' experiences of the entire assessment process that led to the diagnosis. Likewise, Concannon and Tang (2005) limited their investigation to parents' experiences of receiving their child's diagnosis of ADHD and subsequent interventions. Together, these studies offer an understanding of parents' experiences of particular aspects of the assessment process rather than the entire assessment process from their initial contact with clinicians to the conclusion of the assessment. Nevertheless, the literature in this area remains scarce. Moreover, there is little known about the parents' experiences of the assessment process that was conducted by a psychologist. The diagnoses of ADHD in Travell and Visser's (2006) study were made by psychiatrists, while most diagnosing clinicians in Concannon and Tang's (2005) study were pediatricians, with only 8% of them being psychologists. As such, there remains a need to understand parents' experiences of the assessment process conducted by a psychologist who routinely conducts assessments for ADHD specifically.

In sum, the literature reviewed on the experiences of parents of the entire assessment process that resulted in their child's diagnosis of ADHD remains scarce, particularly those conducted specifically by psychologists. Given the dearth of information in this area, the purpose of this exploratory study was to investigate, to describe, and to seek to understand parents' lived experiences of the psychological assessment process that resulted in their child's diagnosis of ADHD.

As indicated previously, the primary question guiding this study was: *What are parents' lived experiences of the assessment process that resulted in their child's diagnosis of ADHD?* As an extension of this study, a parent input form was created to translate and exchange the knowledge obtained regarding parents' experiences into a useful and applied way for parents and psychologists alike.

Lived Experience

For the purpose of this study, the term *lived experience* is taken from the field of phenomenology, which seeks to understand people's experiences (van Manen, 2001). Lived experience is considered to be "something distinctive, a class of significant or memorable events, whose true meaning… is something we come to recognize in retrospect" (Burch, 1990, p. 132). It is a result of an experience and meaning lies in reflection "of what is lived through" (Burch, 1990, p. 133).

As it relates to this study, lived experience is not the original experience of undergoing the assessment process for one's child. However, this initial event is the prerequisite of the lived experience (Lindseth & Norberg, 2004). The assessment process becomes a meaningful, lived experience, when parents actually think about their experience of the process. Thus, lived experience is essentially the memory of the experience. In this study, the focus was not on identifying particular facts of what occurred in the assessment process; rather, meaning came from the parents' retrospective reflections regarding their experience of their child's assessment process, on how they described what the experience of their child's assessment process was like for them.

Conclusion

This study aims to fill the void in the current literature base by exploring first-hand accounts of parents' experiences of the entire assessment process that resulted in their child's diagnosis of ADHD and to extend this knowledge into practical use. Thus, parents' lived experiences of the assessment process that resulted in their child's diagnosis of ADHD was explored and analyzed. Additionally, the knowledge gained from the data analysis was translated into a raw form that can be used by psychologists in clinical practice.

Chapter Three: Methodology

The purpose of this study was to gain an understanding of parents' experiences of the assessment process that resulted in their child's diagnosis of ADHD. To translate the knowledge obtained regarding parents' experiences into an applied tool for the assessment of ADHD, a parent input form was intended to be created as an outcome of this study. This chapter describes the design and methodology used to address the research question guiding this study: *What are parents' lived experiences of the assessment process that resulted in their child's diagnosis of ADHD?* The focus of this question was broad to allow parents to share their experiences using their own words, rather than answering predefined questions. Parents were thus given the opportunity to "decide what is meaningful and important and set the criteria by which they would want their experience to be understood and evaluated" (Tattersall & Young, 2006, p. 35).

In this chapter, I describe the methodological framework and methods I used to conduct this study. This chapter culminates with a brief concluding summary. It is important to note that, given the qualitative framework by which I conducted this study, I chose to write using a first-person perspective. This decision was based on the fact that my role as researcher was active and an integral part of carrying out this study. Thus, using a first-person perspective is an important step to address my active role in the research, to demonstrate reflexivity (e.g., account for my biases and assumptions) and to increase my accountability for my work and the decisions I made.

Research Design

I chose to use a qualitative research design to conduct this study for a number of reasons. First, whereas quantitative research tends to test and confirm theories (Creswell & Plano-Clarke, 2007), qualitative research provides the opportunity to enter the lives of the participants to describe and understand their experiences to the fullest (Farber, 2006), which was the primary aim of this study. Second, qualitative approaches are well suited for researching phenomena that are poorly understood (Pope & Mays, 1995). Thus, data obtained from qualitative methods are considered to be prerequisites to understanding a phenomenon (Hoppe-Graff & Lammm-Hanel, 2006). Given that our understanding of parents' experiences of the assessment process that resulted in their child's diagnosis of ADHD is limited, conducting a qualitative study was critical to obtain "firsthand knowledge" (Jick, 1979, p. 608) about the topic. Overall, by conducting a qualitative study, I was able to develop meaningful and detailed understandings of parents' experiences.

Epistemological and Ontological Considerations

To evaluate research in a meaningful way, it is important for researchers to identify their methodology and its associated theoretical framework that guides the research (Caelli, Ray, & Mill, 2003). Thus, researchers must explicitly identify their ontological (i.e., one's understanding of the nature of reality) and epistemological (i.e., one's beliefs about what can be known) assumptions (Braun & Clarke, 2013), as these lead to the particular methodological approach and methods to be used within one's research (Madill, Jordan, & Shirley, 2000; Willig, 2008).

In considering one's ontological and epistemological position, Willig (2008) delineated three questions to address: 1) What kind of knowledge does the methodology aim to produce? 2) What kinds of assumptions does the methodology make about the world? and 3) How does the methodology conceptualize the role of the researcher in the research process? I now answer these three questions to contextualize the methodological decisions I made for this study.

What kind of knowledge does the methodology aim to produce? For the purpose of this study, I aimed to produce descriptions of parents' subjective lived experiences of their child's assessment process. I invited parents to share accounts of their experiences of their child's assessment process using their own words in a way that was meaningful to them. Additionally, as an outcome of this study, the recurring patterns of parents' experiences are to be translated into a practical form that can be used by parents and clinicians in future assessment practices.

What kinds of assumptions does the methodology make about the world? To answer this question, an overview of my ontological and epistemological assumptions is offered. First, my ontological position is most aligned with that of a critical realist, as described d by Braun and Clarke (2013). Specifically, I believe there is a knowable world that is real for the individual who has experienced it. This reality is subjective and socially influenced (e.g., by the individual's past experiences and context).

Given the experiential nature of my study, my epistemological position is most closely with a contextualist framework, as described by Braun and Clarke (2013). This framework lies between positivism, which aims to discover a universal truth; and constructionism, which claims there is no one truth, but socially created, subjective knowledges (Braun & Clarke, 2013). Sitting within the contextualist framework, I acknowledge the complexity of the world and appreciate that there is more than one way to understand parents' experiences. Thus, I recognize that there is no one absolute truth. However, I do retain some notion of truth and believe that knowledge can be true and valid in certain contexts. The contextualist framework is, therefore, well-suited for my study, as it reconciled these two viewpoints (i.e., the understanding that knowledge is contextual, but that a notion of truth can be retained). Contextualism accommodates both views by identifying their similarities while also removing the "arbitrary boundaries and assumptions that separate them" (Cupchik, 2001, p.2). For instance, constructivists claim that reality is contextually bound. Similarly, positivists acknowledge that theories are not fixed and that they are replaced with new information (Cupchik, 2001). For the purpose of this study, I acknowledged the subjective nature of parents' experiences and strived to understand and represent those experiences as thoroughly and accurately as possible, while also finding a commonality across parents' experiences.

How does the methodology conceptualize the role of researchers in the research process? Overall, as the researcher, I was inherently implicated in the research as a primary research instrument. I considered parents' experiences to be locally situated, as they were influenced by my interaction with them. Given my active role in this study, it was imperative to delineate my personal framework and assumptions that may influence this study. Doing so is important to help demonstrate quality research and to provide the reader with an understanding of the assumptions I bring to this research. Moreover, acknowledging my assumptions was important so that I could attempt to bracket, or put aside, those assumptions as much as possible to minimize their effect on this study. Thus, I now offer an overview of my experiences and key assumptions relevant to this study.

Assumptions and personal framework. In terms of my relevant personal experiences, I am a psychologist and have worked in different settings over the past several years, including working independently in private practice. I have conducted assessments that resulted in a child's diagnosis of ADHD; additionally, I have experience offering parent support and training to parents of children diagnosed with ADHD. Thus, I came to this research with a desire to improve my understandings and practices associated with the assessment process.

I first became interested in undertaking this study because most parents I worked with expressed dissatisfaction with their child's assessment process that resulted in their child's diagnosis of ADHD. Approximately a third of these parents dismissed their child's diagnosis.

After listening to parents' experiences, I wanted to learn more about what contributed to their negative experiences and what could be done to promote positive experiences.

In terms of my key assumptions about parents' experiences, I believe that the assessment process can be anxiety-provoking for parents. Much of the anxiety may be a result of not understanding what the process entails. Often, parents indicate that a teacher or doctor recommended that they have their child assessed for ADHD, but I am not confident they understood what that means. I believe parents likely experience anticipation and perhaps fear about the assessment and the final outcome. Will their son or daughter be diagnosed with ADHD? What will that mean for them? Will their child need medications?

Identifying my personal framework and assumptions is important to limit my influence on this study as much as possible. Otherwise, for instance, I may have found myself asking only about areas of personal interest, rather than following the parents' lead and focusing on what they identified as being important for them. Furthermore, I actively listened (e.g., fully concentrated) to parents' accounts and reflected what I heard in an attempt to get as close to understanding their lived experiences as possible. While I recognized I do not have direct access to their lived experiences, I took steps to ensure that I described parents' experiences in a way that honoured how they reported and understood those experiences. Further details about the steps I took to establish the credibility of my findings are delineated later in this thesis.

Role of participants. It is also important to discuss the role of parents in this research given the interpersonal nature of this research. I considered the parents in this study as experts whom offered important perspectives on the assessment process. As such, they were given the opportunity to offer information they identified as important and to provide feedback whether the final themes reflected their experiences. Together, parents helped to co-create an understanding of their experiences of the assessment process that resulted in their child's diagnosis of ADHD.

Pragmatic Qualitative Inquiry

The qualitative methodology I chose for this study most closely aligns with a pragmatic qualitative inquiry (Butler-Kisber, 2010; Creswell, 2009). Pragmatic qualitative inquiry has many of the fundamental characteristics of qualitative research (e.g., understanding the meaning of people's experiences, using the researcher as the primary data collection and analysis instrument, using an inductive orientation to analysis; Merriam, 2002). However, pragmatic inquiry is independent from other established methodologies and is "not guided by an explicit or established set of philosophic assumptions in the form of one of the known qualitative methodologies" (Caelli et al., 2003, p. 4). The focus of pragmatic qualitative inquiry is to first and foremost "discover and understand … the perspectives and world views of the people involved" (Merriam, 1998, p. 11). Thus, this approach was effective in addressing my first research question by allowing me to provide a comprehensive understanding of parents' experiences. Given the parameters of this study and the strategies of inquiry that I employed, pragmatic qualitative inquiry proved to be well suited to fulfill the aims of this research.

In general, using pragmatic qualitative inquiry provided the flexibility to directly answer my research questions without limiting my focus primarily on the theoretical perspective of an established methodology (Sandelowski, 2000). In doing so, I was able to make decisions on how to conduct the study (e.g., the methods to gather and analyze data) based on how to best address the research questions and goals of the study, as opposed to trying to fit the research question to a specific theoretical orientation (Patton, 2002). Using a pragmatic approach allowed me to garner a rich understanding of parents' experiences of their child's assessment process, in which

I could focus on their perspectives without forcing their narratives into a theoretical framework, which was not the goal of my study. Although pragmatic inquiry is independent from other established methodologies, researchers using this framework have the flexibility to combine one or more methodologies to suit their research questions (Caelli et al., 2003; Lichtman, 2013). Thus, by using pragmatic inquiry, I could borrow the concept of lived experience from phenomenology to suit the needs of this research.

Finally, pragmatic qualitative research was beneficial for this study because this approach allows researchers to better understand parents' experiences of professional services they access (Smith, Bekker & Cheater, 2011), such as psychological assessments. Smith et al. (2011) suggested that pragmatic qualitative research may be most appropriate when it relates to clinical practice, such as is the focus of this study. In contrast, theoretically driven research may be more appropriate when the researcher is interested in generating and testing theories (Smith et al., 2011). Overall, pragmatic qualitative inquiry proved to be a good fit for this study, as it allowed me to gather rich, detailed information regarding parents' experiences.

Although pragmatic qualitative inquiry is well-suited for this study, there is debate about the credibility of pragmatic qualitative inquiry; specifically, how can studies that are not grounded within a theoretical context be evaluated (Caelli et al., 2003)? Credibility tends to diminish when researchers fail to outline their methodology and theoretical underpinnings and employ "incommensurable methods of data collection and analysis" (Caelli et al., 2003, p. 3). Thus, insufficient methodological clarity makes it difficult for the reader to evaluate the research.

Given the diverse range of qualitative approaches and differing epistemological perspectives, there are no standard set of guidelines that can adequately evaluate all qualitative research. Therefore, each qualitative study must be evaluated individually "in a manner that is congruent with its epistemological and methodological origins” (Caelli et al., 2003, p. 4). Therefore, to effectively evaluate a study employing a pragmatic approach, the researcher must clearly outline detailed explanations about the theoretical underpinnings of the research, the fit between the methodology and methods used to conduct the study, how rigour is achieved, and how data are analyzed (Caelli et al., 2003). In addressing the credibility of my pragmatic qualitative inquiry, I address each of these guidelines throughout this paper. Specifically, I have taken the steps to detail my epistemological and ontological position, to delineate my personal framework and relevant assumptions, to clearly outline how all decisions were made and how data was analyzed, to discuss the congruence between the methods and methodology I used in this study, to highlight how the chosen methods directly addressed the research questions, and to demonstrate how rigour and credibility was maintained throughout this study.

Thematic Analysis

I chose thematic analysis (TA; Braun & Clarke, 2006) as the qualitative method of analysis for this study. TA is beneficial in exploring areas in-depth where there is little known about the topic (Braun & Clarke, 2006). Similar to pragmatic inquiry, TA does not stem from a particular theoretical orientation, such as grounded theory (e.g., Strauss & Corbin, 1998) or interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009) and can be “applied *across* a range of theoretical and epistemological approaches” (Braun & Clarke, 2006, p. 78).

Although TA is considered a flexible method to analyze data, guidelines are provided to ensure that it is conducted “in a way that is theoretically and methodologically sound” (Braun & Clarke, 2013, 79). Specifically, Braun and Clarke (2006) addressed a few important issues, such as the need for clearly describing what TA is, what questions can be addressed using TA (e.g., exploring people’s experiences), highlighting the need for researchers to be explicit with their epistemological positions and assumptions, and identifying how to conduct TA. I addressed each of these points throughout this paper. Taken together, I was able to conduct this research in a way that directly related to the goals of the study, while also taking the steps to ensure that I conducted theoretically and methodologically sound research to promote its quality.

TA is a widely-used approach in research for a wide range of research interests (Braun & Clarke, 2014; Bornman & Rathborne, 2016; Buetow, 2010; Farvid & Braun, 2016; Joffe, 2012; Karuncharernpanit, Hendricks, & Toye, 2016; Mboyne et al., 2016; Terry & Braun, 2016). This approach is described as a "foundational method for qualitative analysis" (Braun & Clarke, 2006, p. 78) and is appropriate to investigate people's experiences (Clarke & Braun, 2013; Tracey, McElearney, Adamson, & Shevlin, 2009). Case in point, several researchers demonstrated how TA can be used to garner a rich, comprehensive understanding of their participants' experiences and to clearly identify themes that reflected those experiences in a meaningful way (e.g., Gilburt, Rose, & Slafe, 2008; Kovshoff et al., 2013; Richardson, Cobham, McDermott, & Murray, 2013).

Historical overview of TA. Holton (1975), a physicist and historian of science, proposed that thematic analysis is a necessary component in the analysis of scientific work, noting that most concepts and hypotheses have elements of themes. Building on this work, Merton (1975) explicated that themata are identified inductively, conducting "case-by-case analyses to obtain a working list of themata" (p. 335), which are subsequently categorized. He highlighted the value of thematic analysis, indicating that, "if we do not perceive the basic themata in a scientific work, we cannot understand well enough what makes it important" (Merton, 1975, p. 337).

TA draws primarily from content analysis (CA), which was traditionally quantitative in nature and used to determine the frequency of established categories (Joffe, 2012). While TA is similarly systematic and determines the frequency of themes, TA offers "the advantages of the subtlety and complexity of phenomenological pursuits" (Joffe, 2012, p. 211). That is, the researcher can go beyond frequency counts and analyze the data to derive rich meaning. For this study, TA allowed access to a richer and more intimate understanding of parents' experiences than what CA would have offered.

Researchers have also suggested that TA rose from the need for a sophisticated tool to facilitate qualitative analysis. Indeed, Attride-Stirling (2001) noted that "researchers have traditionally tended to omit the 'how' question from accounts of their analyses" (p. 386). Likewise, Tuckett (2005) argued that researchers often fail to explicate how they systematically analyzed their data. Building from these criticisms, Braun and Clarke (2006) concluded that, "qualitative psychologists need to be clear about what they are doing and why, and to include the often-omitted 'how' they did their analysis in their reports" (p. 79). To help researchers demonstrate how they conduct their analysis, Braun and Clarke (2006) delineated a clear set of procedures for analyzing data using TA in the field of psychology specifically, which is discussed in detail in the data analysis section of this paper.

Theoretical considerations. TA can be either deductive (e.g., themes drawn from previously established theories) or inductive (e.g., themes drawn directly from the participant's words) in nature (Joffe, 2012). For the purposes of this exploratory study, I conducted the data analysis inductively. Specifically, I based the identified themes on parents' accounts of their experiences of their child's assessment, as opposed to confirming or refuting pre-established hypotheses or confining parents' experiences to imposed categories.

Commensurate with pragmatic inquiry, TA is theoretically flexible and "does not prescribe methods of data collection, theoretical positions, epistemological or ontological frameworks" (Braun & Clarke, 2013, p. 178). This flexibility is considered a strength of TA and allowed me to draw from appropriate theoretical underpinnings that best addressed the aims of the research. In particular, I could draw from phenomenology; specifically, the concept of *lived experience* and inquiry that focuses on the individual's lived experiences from their perspective, in their own terms (Ashworth, 2008).

Procedures

The procedural steps of this study involved a) recruiting parents of children diagnosed with ADHD; b) conducting a series of in-depth, semi-structured interviews with participating parents; c) analyzing interview data to identify themes and supporting evidence regarding parents' experiences of their child's assessment process; and d) developing a parent input form to facilitate knowledge translation. Each of these steps is outlined in the remainder of this section.

Participants

For the purpose of this study, I employed criterion-based purposeful sampling, in which participants met predetermined criterion characteristics. Specifically, the participating parents included the primary caregivers of children diagnosed with ADHD. Primary caregivers were chosen because, in my experience, they are most heavily involved in the assessment process. Additionally, much of literature that explored parents' experiences of the assessment process included mainly primary caregivers in their sample (e.g., Braiden, et al, 2010; Goin-Kochel, Mackintosh, & Myers, 2006). Second, all participating parents had a son between 8 and 11 years of age when he received a diagnosis of Attention-Deficit/Hyperactivity Disorder-Combined presentation (ADHD-C). The children may also have associated comorbid diagnoses such as Oppositional Defiant Disorder, Anxiety, Depression, Conduct Disorder, and Learning Disorders. These criteria were chosen because 1) of the high incidence of boys with ADHD (Carpentier, 2012), 2) most children with ADHD would have been diagnosed between these ages (APA, 2013), 3) children with combined presentation make up the most clinical referrals (Aguiar et al., 2010), and 4) 50% to 80% of children with ADHD also meet diagnostic criteria for another disorder (Tannock, 1998). Finally, because this study was interested in parents' experiences of the assessment process that was conducted by psychologists in private practice, the child's diagnosis of ADHD-C must have been made by a psychologist in private practice.

Purposeful sampling was appropriate for this study for a number of reasons. Specifically, the focus of this study was on quality and gaining as much of a complete understanding of parents' experiences as possible. Purposeful sampling mandates that the researcher purposefully recruit research participants from a specific group of people who have experience with the phenomenon under investigation (Creswell, 2007); in this case, with the assessment process that resulted in their child's diagnosis of ADHD. Using criteria to recruit participants, purposeful sampling is considered the most appropriate method to choose a representative sample of people who could provide rich information about the specific phenomenon (Patton, 2002). In turn, the researcher can generate a deep and comprehensive understanding of that phenomenon (Patton, 2002). Thus, purposeful sampling was the method best suited to recruit participants for this study, as it was congruent with the aims of this research. That is, it allowed me to ensure that all participants met the inclusion criteria so that they could provide relevant and meaningful information as it pertained to the research question.

Recruitment. Upon successful ethics approval from the University of Calgary, I dispersed pamphlets with information regarding this study to private agencies and ADHD-based organizations (e.g., Children and Adults with Attention Deficit Disorder [CHADD] – Calgary chapter) and psychologists working in private practice serving families of children with ADHD throughout Calgary and surrounding areas. I invited interested parents to contact me directly via phone or email to obtain additional information about the study. If interested in participating, parents answered a brief telephone screening questionnaire (see *Appendix A)* to determine whether they met the inclusionary criteria to participate in this study, as discussed above. If criteria were met, I booked an interview time over the telephone with parents. I then mailed parents additional information regarding the study and their role within the study (e.g., participating in a one-time interview, reviewing the qualitative parent input form for feedback), consent forms, limits to confidentiality, a written explanation regarding the voluntary nature of participation, and a brief demographic questionnaire (see *Appendix B)*. These documents were also provided on the day of the interview. Parents provided written informed consent (see *Appendix C)* at the beginning of their scheduled interview. At the same time, parents provided consent to review the qualitative parent input form if interested in doing so.

Participant description. Altogether, fifteen parents participated in this study. Of these, two were male and thirteen were female. All participants were Caucasian, and tended to be middle class and educated. The parents' average age was 44 years old. Four parents were single; the rest were married. Additional demographic details are provided in *Appendix D*.

Data Collection

For the purpose of this study, I personally conducted in-depth, semi-structured interviews with each of the participating parents to obtain a rich understanding of their experiences of their children's assessment process. Semi-structured interviews are beneficial for innovative studies such as this. Indeed, because there is little known about parents' experiences of the assessment process that resulted in their child's diagnosis of ADHD, I could not predetermine a list of questions about those experiences, which is what is done for structured interviews. While there were a few predetermined questions related to the purpose of the research, the questions were open-ended to allow for an in-depth exploration of parents' lived experiences. I invited parents to describe their lived experience in detail to honour their lived experiences and invite them to share what was most important and meaningful for them, rather than dictating questions from a structured interview. Taken together, I considered qualitative semi-structured interviews to be well-suited to collect data for this study. This method allowed for the flexibility to learn about issues that were meaningful for parents and were therefore conducive to elicit rich, detailed information regarding their experiences. However, it also provided the structure needed to obtain information related directly to the purpose of this study.

Semi-structure interview outline. The purpose of the interview was to explore parents' experiences of their child's assessment process to obtain rich accounts of those experiences. To help facilitate data collection, I developed a semi-structured interview outline (see *Appendix E)* based on the purpose of this study, a critical review of the literature, and the guidelines set forth by Braun and Clarke (2013). Although this interview outline was constructed to address the overarching research question, it was used primarily as a guide, rather than a script. In this way, parents had the opportunity to address issues that were meaningful for them. Furthermore, by maintaining such flexibility, I could uphold the integrity of the methodological approach used in this study, which is inductive in nature.

I divided the questions into four principal areas of inquiry. The first area of inquiry was geared towards obtaining parents' descriptions of their experiences of each of the phase of the assessment process. This section constituted the majority of the questions in the outline. Second, I explored parents' overall experiences of the assessment process and what aspects of the assessment they identified as being most important for them. Third, I aimed to understand parents' experiences working with their psychologist. Fourth, I conducted an exploration into what parents believed was important for other parents and psychologists to know about the assessment process to promote positive experiences. The questions progressed slowly in such a way as to establish rapport with parents so that they felt more comfortable disclosing personal information as the interview progressed. I began each interview by giving parents the opportunity to ask any questions or discuss any concerns they had. Once addressed, I opened the interview with an introductory question. Throughout the interview, I used broad, open-ended and non-directive questions to continually invite parents to share their personal experiences of the assessment process in a way that was meaningful for them, to address issues they identified as being important to discuss, and to allow for unexpected accounts that may otherwise be missed. I used more detailed, follow-up questions as prompts to encourage parents to elaborate or to clarify their responses, as needed. These subsequent questions were reflective of the answers parents provided from the initial questioning. Although parents had the flexibility to discuss what mattered most to them, I focused the conversation specifically on their child's assessment process and I redirected the conversation back to the topic at hand as needed.

I developed the specific questions included in the interview outline using the following steps. First, I wrote down a list of questions related to this study, which were informed by the literature. I then organized the questions in such a way that topic-based questions were clustered together and that the questions flowed logically. I structured the questions to initially elicit general comments regarding parents' experiences, moving towards more specific details of the assessment process. I then refined the questions to ensure that they were not too direct or leading to allow parents the opportunity to provide detailed responses on issues they identify as being important. If parents had difficulty coming up with thoughts regarding a particular area, probes were included (in italics) to assist parents to elaborate on their responses. I also rewrote questions to ensure they were short, singular, and precise to minimize confusion. Questions were also concrete, to keep as close to the experience of the assessment process as possible. The interview concluded with a closing question, giving parents the opportunity to address any topics that they considered to be important but that had not yet been discussed. The final questions were reviewed and approved by my research committee.

Interview procedures. Parents who were interested in participating in this study participated in one semi-structured interview that was between 45 to 90 minutes in length. To facilitate verbatim transcription of the interviews, I recorded each interview using an audio recording device. Before beginning the interviews, I reviewed the following topics: informed consent, the voluntary nature of participation, and the limits of confidentiality. I also provided all parents who completed the interview a $25 gift card for a family-appropriate vendor of their choice (e.g., movie theatre, bookstore, restaurant) as a small recognition of their participation.

Interview transcription. Once the interviews were complete, they were transcribed professionally using orthographic notation in which all spoken words and sounds (e.g., hesitations, false starts, cut-offs in speech, laughter, long pauses, and strong emphasis) were identified. I anonymized all transcripts, where I used the pseudonyms parents gave themselves and the names of other people mentioned in the data. I changed any other identifying information, such as the name of specific schools. I also created a separate password-protected document that contained non-anonymized data and a record of all changes to the transcript. To ensure the accuracy of the transcripts, I reread each transcript while listening to the interview and amended the transcription as I went along.

Data analysis

Once all interviews were transcribed and reread for accuracy, I began my data analysis using thematic analysis (TA; Braun & Clarke, 2006). TA is a useful method in allowing researchers to identify and categorize recurrent and common themes in the data (Braun & Clarke, 2006). I conducted the data analysis in six phases, as delineated by Braun and Clarke (2006). A visual representation of the phases is provided in Figure 2. Although these steps are presented in a somewhat sequential fashion, I used two-way arrows to demonstrate that the data analysis was a recursive process in which I moved back and forth throughout the phases.

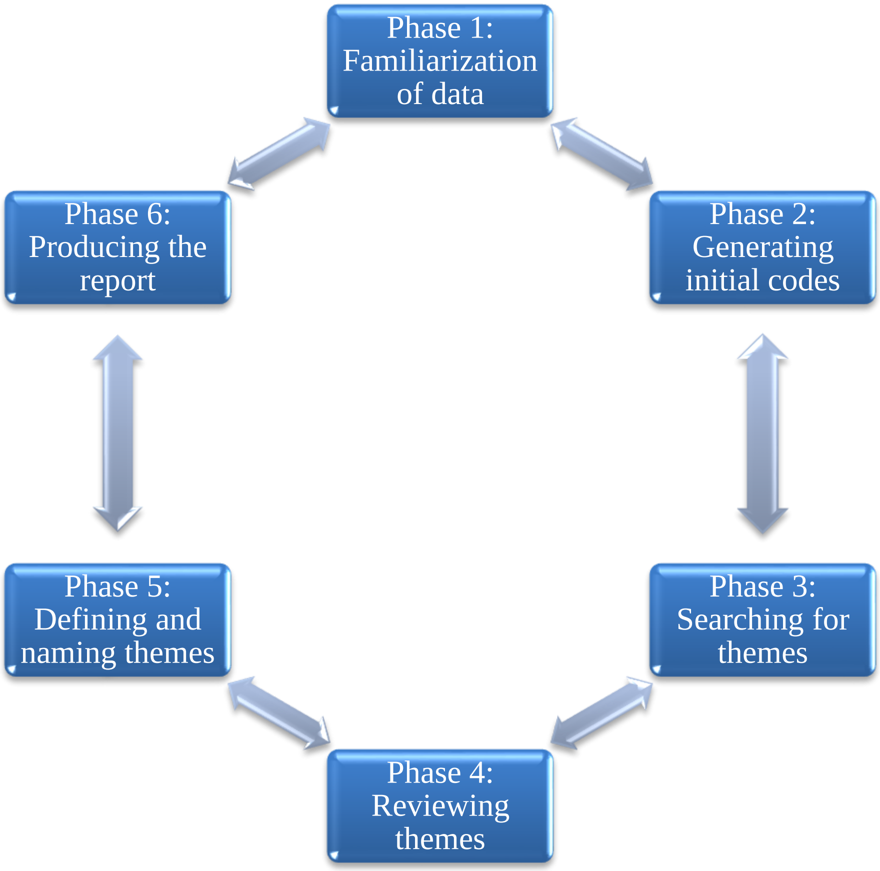

Figure 2. Steps in Thematic Analysis. Adapted from “Thematic analysis” by Braun, V., and Clarke, V., 2006, In Cooper, H. (Ed.) *APA handbook of research methods in psychology*. Copyright 2006 by the American Psychological Association.

It is important to note that I focused the data analysis on organizing the data into recurrent themes. Given the nature of this study and the loose structure of the interviews, it was not appropriate to quantify the data for this analysis. Thus, frequency counts on codes were not calculated. Instead, I was interested in the parents' qualitative experiences of the assessment journey and the stories that they identified as being important.

I used various validation strategies (elaborated later) while I conducted the data analysis to uphold the credibility and rigorousness of my work, including thick descriptions (i.e., supporting themes from parents' accounts), researcher reflexivity (i.e., accounting for my experiences, biases, and assumptions), peer evaluation (i.e., comparing my analyses with those for the same data by experienced qualitative researchers who have used TA), and member checking (i.e., parents offer feedback on whether the analysis reflects their experience).

Phase one: Familiarization with the data. Phase one of data analysis involved familiarizing myself with the breadth and depth of the data. First, all interviews were transcribed verbatim, as discussed above. To ensure the accuracy of the transcripts and entrench my familiarity of the data, I reread each transcript while listening to the interview. I often stopped and replayed the recordings to ensure the nuances were represented accurately. I noted all utterances, laughs, hesitations, sobs, and other notable behaviours, such as a discrepant tone (e.g., sarcasm) within the transcripts. I cross-referenced the transcripts with my notes to identify any additional points noted in the interview that may not be evident in the audio recording, such as physical reactions to certain topics. Although a lengthy process, this step was important to include as much detail from the interviews as I could in creating a narrative account of parents' experiences and later supporting my data analysis. I then closely read and re-read each transcript. Each reading was active as I searched for patterns. I noted any ideas, topics, observations, reflections, or phrases that seemed significant in the left margins of the transcript. Table 1 offers an excerpt of some of my initial thoughts and the initial meaning I attached to the data.

Table 1

Transcript Exploration

Exploratory comments	Verbatim extract from transcript	Initial ideas
This seems very meaningful for her. There is a sense of helplessness here. Giving up. Disempowering. It seems like there is too much effort to keep going, to keep fighting to get her son support – so it's easier to walk away. There seems to be hints at the relationship here too that needs to be explored. She talked earlier about not trusting the psychologist – does this fit?	Obviously, I could have made an appointment, let's go back and then I thought, 'you know, this whole process, I'm done. I just, I don't need to go back and hammer out the: I just, I can't do this anymore.' So, we just walked away and kind of, yeah I mean what do you do? (Jennifer)	- Helplessness - Back to status quo - Empowerment (or lack of) - Relationship with the psychologist

After completing the initial steps above, I imported each transcript into NVivo11©, a qualitative data management software program. It is important to note that this program does not analyze the data, but aids in the organization and management of the tremendous amounts of data I collected in an efficient and effective manner. NVivo11© was the best program to fit the intent of my study and my technological skills. This program was the most user friendly for me, came with 24-hour training and support, and it offered immediate training modules I could use to familiarize myself with the program. I reviewed all my notes of interest and used annotations to attach these notes to the data extracts in NVivo11©.

Phase two: Generating initial codes. Next, I read through each interview again and noted initial codes related to parents' experiences. A code refers to "the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998, p. 63). A "good code" depicts the qualitative richness of the phenomenon under investigation (Boyatzis, 1998, p. 1). Within this phase, I coded data systematically across the entire data set, giving equal attention to each data item and collating supporting data for each code.

To limit my involvement in directing meaning from the transcribed data, I maintained transparency by coding based on the data, using parent words as much as possible. The codes I created within NVivo11© represented parent responses to the open-ended questions I asked based on my overall research question. I coded diversely, coding anything that parents themselves identified as being important to them and anything that seemed related to my research question. Coding in this way was important in case anything could be interesting later as I began to identify patterns. I also coded inclusively, in which I kept the surrounding data to maintain context, though NVivo11© made it easy to find the context of a code immediately. Finally, many data items were coded into as many different codes they fit into initially. Table 2 presents an example of how I coded data.

Table 2

An Example of Generating Initial Codes

Verbatim data extract	Initial Codes
Parent: And so they did this, they gave us this – we had a meeting to discuss the results and then you just get dumped afterwards and nothing happens after that. You get dumped back to your paediatrician. Interviewer: Like after the assessment you're dumped? Parent: After the assessment, you're just dumped with no direction as to what to do next or where to go next. And this is our answer, there's no other answer but that.	- Being dumped - No direction - No other answer (lack of collaboration)

Each parent had several verbatim quotes in the form of a phrase, a sentence, or paragraph. Each quote was attached to one or more initial codes. Given the tremendous quantity of codes (I generated over 350 codes initially), I spent a lot of time refining the codes at the end of this stage, and moving into the next stage, in which I read through the data again to code, recode, collapse codes, and in a few instances, uncode. Data were uncoded when they did not relate directly to the research question (e.g., comments regarding parents' experiences with pediatricians). Through this process, I reduced the code count to 183. However, as I progressed through my data analysis, the final code count was reduced to 64.

Phase three: Searching for themes. This next phase involved beginning to organize the codes and relevant excerpts into meaningful groups to identify potential overarching themes. A theme is defined as "something important about the data in relation to the research question, and represent[s] some level of patterned response or meaning within the data set" (Braun & Clarke, 2006, p. 82). Themes primarily included manifest/explicit (i.e., directly observable) content because, from my ontological framework, I considered what parents said as evidence for what they experienced. As such, I did not attempt to look for latent content such as multiple meanings or sociocultural contexts behind the data.

In this phase, I began to group similar quotes together using a phrase used by parents to denote the identified theme. Here, I grouped codes under initial headings that mapped onto the structure of the interview/phases of assessment. I chose to follow this sequence to keep the data organization manageable at first. I used NVivo11©, but also used a word document and paper-and-pencil visual representations to jot additional ideas and help with the organization of codes into themes and to guide the analysis.

Table 3 is an excerpt example of a theme development tool I created when I first tried to map key findings on to each interview question. As I organized the data in this way, I used the comment feature to talk about things to consider and ideas about where things may potentially fit better as I worked through the data set.

Table 3

Theme Development Chart

Question	Key Finding Statements	Explanation/Outcome	Theme
What was your experience of the 1st phase?	Finding 2: Most parents had a journey that led them to the assessment.	Parents' previous journey laid the groundwork that led to, and seemed to inform, the assessment that resulted in their child's diagnosis of ADHD. Most discussed the difficulties they went through that brought them to the assessment.	Previous journey
	Finding 3: Parents reported feelings of hope mixed with stress, guilt and blame initially.	Moved to Shadows and allies: emotional journey	
	Finding 4: Parents identified their relationship with the psychologist as being important.	Moved to Shadows and allies: social journey	

Although I attempted to represent the data in this way, as shown in the chart above, the data was still quite messy and did not fit into the sequential order of the assessment process. This structure was very limiting and it became clear that the data did not fit nicely into categories. Although the tasks conducted within the assessment fell nicely into each phase of the assessment (e.g., the intake interview was part of the initial phase and the final feedback session was part of the final phase), the more pervasive, personal, and emotional experiences overlapped all the phases, making for convoluted data. Given the inductive nature of my study, I abandoned the idea of trying to identify patterns based on the inherent structure of the assessment process and instead focused on developing themes based on parents' narratives of their experiences.

As I continued to work through this iterative process, I cut and pasted data into word theme piles. This stage of my analysis was largely descriptive, organizing data based on patterns within the explicit data. I cross-referenced data and compared codes, moving back and forth between codes, data set, and excerpts to look for patterns and characteristics of similarity and consistency. Grouping codes together according to a consistent pattern helped to support the development of a theme. When I identified a pattern, I then determined whether it answered my research question. If it did not, or I was unsure, I put the theme into a miscellaneous category for later review. Table 4 illustrates how I identified codes that combined to create an initial theme.

Table 4

Searching for Themes

Verbatim extract	Initial Codes	Initial Theme
And, and I try to read little things that I, come in my emails that I subscribe to…(Jean)	Email (for info)	Dr. Google
I felt like I was going home and googling on the internet… (Jessica)	Google internet	Dr. Google
[The assessment is] over and then you're left with Dr. Google to help you. (MTNI)	Dr. Google	
It's like studying for a final, I guess (Bob)	Final exam	It's like studying for a final
50 million pieces of information shoved down my throat (Jane)	50 million pieces of information	
Who is going to take the time to read that? …I didn't even want to read the whole thing. So, that, no, I would say that was ridiculous. (Jessica)	Ridiculous (amount of info)	
Everybody is just glassy eyed and… It is a lot of information. (MTNI)	A lot of info	

Often, some of my initial themes grouped together as a sub-theme of a broader theme. Indeed, I initially had a large number of themes and realized I needed to reorganize the information and narrow the themes down. In the example above, the code *Dr. Google* related to parental reports about not knowing what they were supposed to do to support their son once the assessment was over. Some explicitly stated that they turned to the internet, but all parents noted that they experienced thinking they had no idea what to do once the assessment was done. As such, the codes from Dr. Google were collapsed under a sub-theme, *My son has ADHD. Now what?* to exemplify the broader experience parents went through once the assessment was over.

In developing the themes, I extracted direct quotes from the data to demonstrate the kind of data classified by each theme (Breakwell, 2000). In conducting the analysis, I explored prevalent themes, sub-themes, and any idiosyncrasies, in depth. It is important to note that prevalence was measured by whether an experience signified something important in relation to the purpose of my study. Certainly, common issues discussed by many parents were identified; however, focusing merely on frequency limits the breadth of parents' experiences because they all had different journeys. Thus, my focus went beyond quantity to include experiences in which parents attached a level of emotion, such as anger or sadness.

Phase four: Reviewing themes. At this point in my data analysis, I became even more explicit and specific with my theme refinement. I reviewed the identified themes using Patton's (2002) dual criteria; specifically, exploring for internal homogeneity (i.e., the data within themes cohere) and external heterogeneity (i.e., each theme clearly differentiates from one another). Specifically, I re-examined the identified patterns found in the theme and then investigated the themes in-depth to see if there were any overlap between them. Defining themes in this manner became critical because there was still overlap of data between themes and the overall structure still did not seem to fit.

This phase incorporated two levels of analysis. Level 1 involved reviewing and refining the themes to ensure that they fit the coded excerpts from parents, in which I read the extracts for each theme organized in NVivo11© and whether they formed a coherent pattern. If they did, I moved on to the next code. If not, I found I ended up re-coding because the data fit better somewhere else. Sometimes the data did not seem to fit anywhere, so I put it in my miscellaneous section to review later.

Level 2 involved reviewing the data in its entirety to see how each theme fit in relation to the whole data set. In doing so, I engaged in frequent cycles of reflecting on the initial thematic patterns and continued the process of coding and re-coding with NVivo11© until saturation was achieved (i.e., no new information is identified). I used sticky notes with the names of each theme to move them around and see the possible connections between the themes. Those that fit together were combined or created as sub-themes of a broader theme.

Within this phase, I defined the identified themes by describing what each theme contained and what types of data could be included. It is important to note that, whenever I found myself getting caught up in the data, overwhelmed, or unsure of what to do with a piece of data, I kept focusing back on parents' experiences of the assessment process. Focusing on the experience helped to maintain clarity and made decisions easier. Whenever I was still unsure, I added annotations to come back to review once all extracts were joined together.

As I went through the data, I came to think about parents' experiences as a journey. Although I had moved away from the sequential nature of the data as outlined above, I still found that there was a progression parents seemed to go through. I created a visual map to represent this journey, as illustrated in Figure 3.

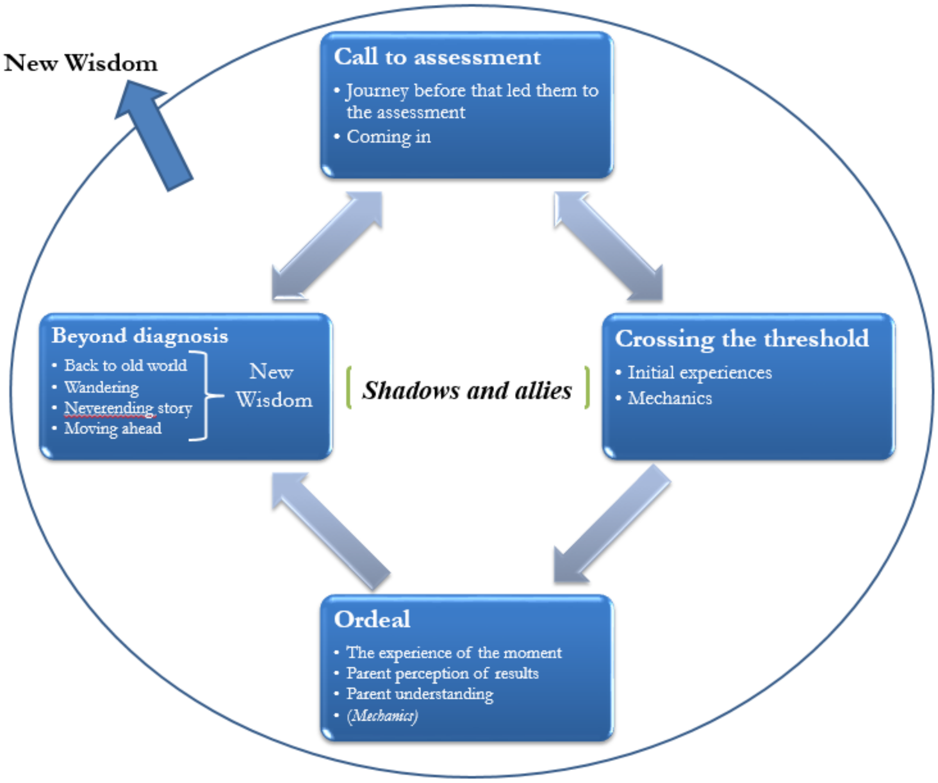

Figure 3. Visual Representation Based on the Parents' Journey

Phase five: Defining and naming themes. Phase five involved defining and refining themes and analyzing the data within them. Here, I identified the meaning of each theme and how it represented parents' experiences. I began to make clear distinctions between the actual doings of the assessment process and the parents' experiences of those doings and, as a result, I abandoned the mechanical side of things in getting the assessment done, such as setting up appointments, as that was not what parents focused their attention on. The core of their journey lay in their emotional and relational experiences.

As I worked through this phase, I realized that the representation illustrated above did not directly reflect parents' experiences. First, I did not use their words in the preliminary labels. As such, I went back to use their words to reflect each step in their journey. In doing so, I questioned whether their experience could still be represented in this sequential nature. I began to consider the connections between themes and subthemes from a different perspective and focused on the experiences parents seemed to identify as being most compelling, such as those experiences in which they exhibited the most emotional intensity. With greater investigation, reflection and discussion with my supervisors, I re-named the themes using parents' words and chose not to represent parents' experiences as a sequential journey because their experiences were so complex and could not be represented in a linear way.

Next, I organized parents' accounts in such a way as to demonstrate how they supported each of the identified themes. I also identified additional sub-themes as needed to give structure to the larger themes. Additionally, I identified how each theme related to the other themes and to the research question. Through this process of further refinement, I identified five main themes, two of which had two components. At this point, I created a thematic chart, in which I identified and defined the themes and accompanying subthemes and included sample extracts from the parents to support the defined theme (see *Appendix F*).

Once completed, I presented my analysis to six other qualitative researchers to review my analytic decisions and to establish the appropriateness of the themes. This process provided multiple perspectives from a variety of people with differing expertise. I reviewed my decisional audit trail with the group and we discussed questions I had to clarify, to confirm, or to refine the themes. Through this process, everyone agreed on the five established themes, though I renamed two themes and two subthemes to reflect the data better. I intentionally chose to use the words parents used to ensure that the theme was reflective of their voices. I added one subtheme to identify the paths parents seemed to end up on when given little support after the assessment. I also split data under theme 5 to create two subthemes, but, after further discussion and revision with my committee members, later incorporated the information from one of the subthemes (recommendations for psychologists) into the relevant places in which the information overlapped across the other four themes. I engaged in one last revision in collaboration with my supervisors and committee, which resulted in five themes and fifteen subthemes, as shown in Table 5. A more detailed thematic chart is offered in *Appendix F*.

Table 5

Revised Themes

Themes	**Subthemes**
1. Hoops and barriers	*We need to find out what is going on with this kid!*
	Be careful who you see.
2. What does this tell me about my son?	*It's like studying for a final*
	Big $50 words
	What he's all about!?
	That's not my son!
3. We're not coming for label. We're not coming for drugs. We're coming for roadmaps.	*My son has ADHD. Now what?*
	Moving ahead or being dumped.
4. It's such a big journey. a) You've got to find a person you feel comfortable with b) A fragile family	*Talk to me like I am your friend*
	He's a relationship-based kind of kiddo
	Left in the dark
	The weakest link
	Between hope and despair
5. Rich Insight: I want parents to know…	*It's the manual for your kid*
	It's not your fault

At this point in my analysis, it was important to me to engage the parents who had participated in my study to get their perspective on my analysis of their experience. In doing so, I created a document containing each theme and subtheme accompanied with data extracts that exemplified each. I emailed each parent a copy of the document and invited them to offer their insight about my analysis. They were invited to meet with me in person, to discuss via telephone, or to respond via email to go over their thoughts. Nine parents responded via email, all indicating that my summaries reflected their experiences. No one had additional information to offer. As such, I finalized the themes as outlined above. These final themes and subthemes are presented in the next chapter.

Phase six: Producing the report. The sixth phase included the final analysis of the data and writing the report of the analysis. To accomplish this, I created a narrative about the content and meaning of each theme. The write-up provided evidence, based on parent accounts, to support the identified themes. Because of the inductive approach of my study, it was not until this phase that I engaged with the research. This is where I considered the significance of the themes and their implications in relation to the research question and the existing body of literature.

Parent Input Form Development

This extension of the study was practical in nature; namely, to develop an input form to translate the knowledge generated from the parent interviews in a way that could be used in clinical practice. It is anticipated that the parent input form might be used in clinical practice to prepare parents for the assessment process, to give parents the opportunity to identify information they believe is important for the psychologist to know as they proceed with the assessment, to identify what information parents believe would be most helpful for them to learn from the assessment, and to open dialogue with parents and promote a collaborative working relationship.

Early in developing this practical form, I translated themes analyzed from the parents' interview data into an initial pool of potential items that could be used on the input form. As discussed below, these items were later reviewed by parents and psychologists in the final development stages of the form. The initial pool of items included any data that was relevant to parents' experiences and to the goals of the form as listed above. Once I generated a pool of items, I reviewed each item, considering its clarity, brevity and relevance. As many parents in this study did not seem to know what to expect when they came to their child's assessment, I created a menu of items parents could choose from but also left space for parents to write additional comments they may have.

Once the first draft was finalized, I provided the parents who participated in the interviews the opportunity to provide feedback regarding the form. If interested, they received a draft copy of the form via email. They then had the opportunity to provide written or verbal feedback regarding the form. Verbal feedback was either via telephone or in another face-to-face meeting, depending on their preference. I asked parents questions such as, "What is your overall impression of the helpfulness of the parent input form?" "What questions on the form may be helpful for other parents undergoing the assessment process? Unhelpful?" "What is your impression of how the form was written (e.g., probe: language)?" "To what extent is this form helpful in preparing parents for the assessment?" "To what extent does the parent input form address topics that are important for psychologists to know, from the parents' point of view?" "Was there any information that was missing from the form that you think should be included? Why?"

Six parents provided feedback; five via email, one via telephone conversation. All parents shared that the parent input form reflected the input and recommendations they provided. They all agreed that the form would be useful and feasible in practice. One parent shared that she would like to have seen one section regarding the child's experiences of the assessment process to ensure he/she was included collaboratively as part of the assessment. In finalizing the draft of the parent input form, I listed specific feedback parents provided under each item and considered how the feedback could be incorporated to appropriately revise the item.

Once the draft was completed, I gave the participating psychologists a copy of the form via email. Psychologists were recruited in the same way as parents (i.e., information regarding the study was dispersed to private agencies and ADHD-based organizations). To be included, psychologists must work in private practice and have a minimum of five years' experience conducting diagnostic assessments for ADHD with boys between the ages of 8 and 11 years old.

I invited twenty psychologists to provide written or verbal feedback regarding practical considerations of the form, including its utility, relevance, comprehensiveness, clarity, and feasibility. Eleven agreed to review it; five provided written feedback via email. Four agreed that the form was useful and feasible in practice. Some offered suggestions to simplify some of the language and to be more specific with some of the areas to help parents think about concrete examples in their own life. Two commented they were impressed with the document and were ready to use it right away. One shared that although the form was thorough, well-constructed, and useful for research, it was too long to use in a clinical setting. She noted that the form was "one more form for parents to fill out" and was not sure it would be feasible to use.

I used the feedback obtained from the psychologists, along with additional conversations with my committee, to revise the parent input form into its final version, which is included in *Appendix G*. The objective of obtaining input from parents and psychologists was to develop a form that could be used in clinical practice as a valuable guide and resource for the assessment to individualize the assessment process to meet parents' needs. Future research will be valuable to determine the clinical utility and feasibility of this form.

Evaluating Qualitative Research

Qualitative researchers tend to differ in their fundamental assumptions on how to conduct research as compared to quantitative researchers; therefore, "…the criteria traditionally used to evaluate quantitative research …are not applicable to qualitative research" (Willig, 2012, p. 17). It is nonetheless important to ensure qualitative research is methodologically rigorous, thus increasing the readers' confidence in the final write-up of the study (Yardley, 2000). There are no standard criteria for evaluating qualitative research; however, authors have noted that qualitative research can only be meaningfully evaluated when the evaluation is informed by the researcher's epistemological position (Madill et al., 2000; Willig, 2012). From a realist epistemology, researchers tend to believe there is a single truth to be discovered. Therefore, concepts such as objectivity (e.g., no research bias) and reliability (e.g., consistency of meaning and the extent to which findings triangulate) are useful evaluative criteria for research conducted within a realist framework (Willig, 2012). Conversely, research conducted from a contextualist approach, such as this study, aims to, and is justified by, generating meaningful accounts from participants (Henwood & Pidgeon, 1994). Rather than seeking an absolute objective truth, the emphasis is on explaining, with the understanding that there are inter-subjective meanings (Henwood & Pidgeon, 1994). From this standpoint, realist terms such as reliability and validity cannot be measured in the same way as a traditional psychometric approach because different people construct different meanings (Madill et al., 2000). However, researchers must have strong justifications for the knowledge generated within their work, ensuring that they are plausible to the research community.

In terms of reliability, researchers have cautioned against its relevance in qualitative inquiry because it "undermines the very assumptions on which qualitative inquiry is based" (Butler-Kisber, 2010, p. 15). As discussed previously, I believe there is no one single truth. Knowledge is provisional and dependant on particular situations. Thus, there is no one correct way to find truth. Furthermore, I do not believe differing experiences are invalid; rather, they can be valuable in obtaining a complete understanding of parents' experiences. Taken together, reliability cannot be measured the same way it is in quantitative research. Instead, the focus is on obtaining a rich understanding of parents' experiences. With this emphasis, there is room for the development of new ideas that may otherwise be missed (Madill et al., 2000). Additionally, concepts such as transparency (e.g., outlining the steps the researcher takes to answer the research questions so that others can clearly follow the decisions made in the study) and researcher reflexivity have been posited as more appropriate means by which to evaluate qualitative research (Butler-Kisber, 2010). Additionally, qualitative research cannot be judged by its generalizability in the same way as quantitative research because of the small sample sizes and contextualized processes (Butler-Kisber, 2010). Instead, transferability may be more appropriate, which points to how the study resonates with the readers and the degree to which the results are applicable to their own situation (Butler-Kisber, 2010).

Although the concept of reliability and validity is not measured in qualitative research the same way as it is in traditional psychometric approaches, they are nonetheless important for this study. Indeed, reliability and validity are inherently connected with the inferences that were made from the data and are necessary to ensure my findings are representative of parents' experiences (Hubley & Zumbo, 2011). In addressing the quality, reliability and validity of this study, I used the relevant guidelines set forth by Yardley (2000) and Elliot, Fischer and Rennie (1999). I address credibility, rigour, transparency, and transferability in turn.

As discussed elsewhere in this paper, from the contexualist perspective, I played an active role in this research. Therefore, one validation strategy I employed to demonstrate credibility (i.e., accurately presenting parents' lived experiences) in my work was to identify and manage the influence my personal beliefs, interests, assumptions, and personal frameworks may have in this study to fully represent parents' experiences and honour their voices (Yardley, 2000; Willig, 2012). In doing so, I engaged in reflexive activities. I created and maintained a reflective journal throughout the process of this study to record my thoughts and impression of the process, as well as my reactions, assumptions, expectations, and biases about the process and about the data. I took note of interesting ideas that came up while reading the literature. In addition to this reflective journal, I engaged in other reflexive activities, including creating summary notes immediately after each interview and seeking support as needed. These reflexive practices were important to help reduce my influence over the study as much as possible, to separate the research findings from my own preconceptions, and to promote this study's credibility (Caelli et al., 2003). I recognize that my involvement in the research has some influence on the study; as such, I have explicitly identified and acknowledged any potential influences I have where appropriate for the readers' considerations.

I also maintained a collaborative relationship with each parent and engaged in member checking to promote the credibility, and thus, validity, of this study. Specifically, I invited parents to critically review the pool of items I generated. They therefore had the opportunity to provide feedback on the accuracy of the content and whether the items represented the important aspects of their experiences. Additionally, I had ongoing discussions with my supervisors and colleagues in which my themes were critiqued to establish their appropriateness, as a check and balance to confirm that my analysis was defensible. In doing so, this process of critiquing provided a broadened and varied lens from which to review and understand the data. Finally, throughout this paper, I have demonstrated credibility by linking the decisions I have made on how to conduct the study (e.g., obtaining an appropriate sample, data collection and analysis strategies) to the goals of this study.

I demonstrated rigour throughout this study, which was initially achieved by listening to the recorded interviews while rereading the transcripts to ensure that the data are transcribed accurately. I also continuously double checked my analysis with parent accounts and supported all themes with parent excerpts to ensure that the themes are richly described and supported by parent accounts. Detailing how I generated each theme from the raw data also strengthened the credibility of the results, as readers are then able to judge the degree to which my analysis was grounded within the data (Madill et al., 2000; Patton, 2002). I also maintained rigour by obtaining additional sources of information from parents through their review of the parent input form, thereby offering an additional layer of understanding (Yardley, 2000). Furthermore, I kept an audit trail (Patton, 2002), in which I maintained clear records and described the research process and my analytic decisions in detail. I also delineated how interpretations of the data were made and directly linked the findings with parents' words.

In terms of transparency, I detailed what assumptions informed the decisions made in conducting this research, including participant recruitment, the creation of the interview schedule, data collection, and data analysis. I provided an explicit outline of the step-by-step process of how themes were chosen, organized, and analyzed. Part of this transparency included my personal reflections and the maintenance of an audit trail, as outlined above. I demonstrated coherence by highlighting the connections between the research question, TA, and the final analysis. I also wrote an integrated summary in a way that is meaningful for readers so that they can evaluate the research themselves.

Additionally, I offer a discussion about the limitations of the study, the limits of the sample, and who the final product may be relevant to. With this information (along with a clear description of the sample and recruitment method), readers have the opportunity to make judgments regarding the fit of the research and about to whom the research may be relevant, thus addressing the transferability of this study (Butler-Kisber, 2010). Finally, I established the representativeness of the analysis by representing all participating parents in the final analysis.

Ethical Considerations

Prior to commencing this study, I obtained ethical approval from the University of Calgary's Conjoint Faculties Research Ethics Board (CFREB). In obtaining informed consent, I reviewed the following with all participants: the purpose of the research; what is expected of parents, including the amount of time likely required for participation; expected risks and benefits of participating; the voluntary nature of participation and their right to withdraw from the study up until the end of data collection with no negative repercussions; how confidentiality would be maintained; and contact information for both myself and my supervisors in the event they have any questions or concerns. Consent also included their permission to present on and publish the study, my ownership of the data, and the use of the data for future analysis. I obtained ongoing informed consent throughout the study. I organized all hard copies of materials, including consent forms, demographic information, and audiotapes, in individual folders labelled with pseudonyms and stored and locked in a cabinet in my home office. I saved all soft copies of materials, such as original transcripts (i.e., with identifying information), on a password-protected computer used solely by myself in my home office. I will store data for five years, at which time all soft copies will be permanently erased and hard copies of information will be shredded.

Conclusion

The purpose of this chapter was to provide a detailed account of my methodological approach and of how I analyzed the data. By using an inductive thematic approach, I strived to distill the meaning of parents' lived experiences with a contextual richness for translating that knowledge into a useable parent input form that might be used in clinical practice. In this way, the translated results from this study could be made accessible and useful for clinical practice. I anticipate that the parent input form may help parents to prepare for the assessment process investigating their child's ADHD and to identify information they believe is important for the psychologist to know as part of this assessment. Additionally, the form may be useful in helping psychologists to individualize their assessment practices to address what parents identify as important and to promote a collaborative working relationship with parents.

Chapter Four: Results

The purpose of this study was to explore parents' lived experiences of the assessment process that resulted in their child's diagnosis of ADHD. This chapter presents the key findings obtained from fifteen in-depth interviews from parents. I first provide a brief overview of the parents that participated in the study. They are all identified by pseudonyms to protect their privacy. Following this, I provide an overview of the parents' overall experience of the assessment. I then delineate the five themes developed from my analysis of the interview data to reflect their experiences. The themes include: 1) Hoops and barriers; 2) What does this tell me about my son?; 3) We're not coming for a label. We're not coming for drugs. We're coming for roadmaps; 4) It's such a big journey; and 5) Rich insight for other parents.

The Parents

Each parent that participated in this study was the primary caregiver in the family, except for one, who had shared caregiving responsibility with his wife. Each shared their personal stories and experiences of the assessment process. All parents appeared comfortable and willingly participated in the interviews, openly responding to all questions asked. Each parent talked about their thoughts, feelings, and ideas about their experiences. Listening to their personal stories was a source of rich information that helped me generate a deeper understanding of their experiences. Every parent shared a unique story, though they all discuss the shared phenomenon of participating in the assessment process that resulted in their son's diagnosis of ADHD.

All parents have been identified by pseudonyms of their choosing to protect their privacy. Fifteen parents participated in this study altogether. There were two men, Bob and Mr. Incredible; in addition to thirteen women, Crystal, Helen, Jane, Jean, Jennifer, Jessica, Melly, Mom-that-needs-info (MTNI), Nicole, Ray, Sally, Sarah, and Song. Each of these parents had a son that was diagnosed by a psychologist working in private practice. Each of these parents met the core inclusion criteria, they had personal experiences with their son's assessment process, and they voluntarily agreed to be interviewed for this study. Six parents who were interested in the study did not meet the inclusion criteria (e.g., their son was diagnosed by a physician).

Parents' Experiences

The following section provides a description about each of the five themes I developed that reflect parents' experiences of their son's assessment process. I have presented a broad range of parents' experiences to promote the reader's understanding of those experiences. Furthermore, I identified verbatim examples from the parents' stories to provide textual expressions of the identified theme.

Theme 1: Hoops and Barriers

The first theme addresses the parents' initial journey and their call to assessment; that is, what brought them to the point of assessment. This theme includes the experiences parents had leading up to the assessment and how they came to the current assessment.

My first question to every parent was what the overall experience of the assessment process was like for them. Many parents responded with a short, one-word response, such as "fine" or "arduous," pointing to mixed experiences. However, rather than elaborating further, almost all parents wanted to share their story of what led up to the actual assessment in question in the first place.

We need to find out what is going on with this kid! Most of the parents in the current study indicated that they knew their son was having problems; however, almost half of them reported that their concerns were not validated by others, which left them in a state of not knowing what to do. For instance, Ray shared that she “asked every teacher every school year, ‘Should I go see a paediatrician? What do you think?’ And every time [the teachers would] be like, ‘Oh, no I don’t think so… I think he’s okay and let’s sort of see what happens.’” It was not until parents later experienced a catalyst moment that confirmed their suspicions that something was wrong, which ultimately led them straight to the assessment “a little frantic” (Ray). Ray explained that her son’s

> …behaviour kind of exploded…it smacked me head on and it needed to be dealt with right away. So, that was sort of like the urgency came out in that beginning phase, I think that really pushed me to make the phone call to contact the psychologist and, you know, start reaching out.

When that catalyst event occurred, parents reported being taken by surprise. As Ray put it, she was “gobsmacked at first,” especially when they asked the questions previously that no one seemed to acknowledge. Jennifer’s catalyst moment was when she was confronted with the remark that her son “…can't do anything, how did you not know?” and was left thinking, “What do you mean he can't do anything and how did I not know? Everyone said he did well.” From that conversation, Jennifer declared, “I went home, I phoned my husband and said ‘I don't care what we have to do; we need to phone, like we are starting today. We are finding out what is going on with this kid.’”

Be careful where you go. Be careful who you see. Unfortunately, once the decision to get an assessment is made, parents shared stories of enduring long arduous battles to get the assessment. Jane illustrated this point, noting, “I was hitting all these hoops after hoops after barriers after barriers.” Sarah animatedly shared her long and frustrating journey with professionals. She stated that she tried seeking help by the time her son was in Kindergarten but was told, “We’re not going to diagnose him at five.” Sarah lamented,

> …He was just diagnosed last year at the age of eight; and so, we’re looking at three years to finally get this poor kid some help. And it’s frustrating for the family, frustrating for him. Like, when you can’t control yourself it’s frustrating because everybody expects a certain level from you, and that’s not a possibility, so then you could totally see his self-esteem drooping…. And his anxiety in those three years skyrocketed.

Helen shared a similar story and indicated that she had to go a long time without proper support and held “a lot of resentment” because “things were caught later on” and that they could have received help earlier if they were taken seriously right away. She deduced, “people just didn’t want to diagnose [a younger child]. They wanted to delay it.”

Others told stories of receiving a diagnosis, but the wrong one. For instance, Song’s son was first sent to a psychiatrist for his difficulties. She reported, “After seeing him for a few minutes, [the psychiatrist] told me that [my son] had anxiety, just anxiety, no diagnosis and that I should read a book and put him into counselling and he’ll be fine.” Years later, he was not fine and Song continued to battle to find out what was going on with her son and how to help him.

Other parents shared that they felt like just thinking about where to go and how to get the assessment started in the first place was a daunting task. For instance, Jane shared,

> In my mind, the way it sounded… [the assessment] was such a big thing and so important and this big list and we couldn’t get on it; I really felt like I was going into this ‘oh my God’ process that was stressing me out.

She went on to state, “I’ve heard a lot of horror stories and even the school warned me, like, ‘Be careful where you go. Be careful who you see.'"

Further to this, parents had no idea how to get the assessment started. Crystal declared that it was hard to finally get the assessment started "because there wasn't much information as to where to go…[and]…what you need to do to get your child a diagnosis." A few parents were fortunate to have teachers or friends who could recommend specific psychologists, which made the process easier from the start. Ray illustrated this point, noting that getting into the assessment "was definitely easy, and I think it's because I, you know, reached out to a colleague who had had an experience with [the psychologist] already, and so… So, that kind of was easy." Ray acknowledged that she was lucky because, "with other families, maybe it wouldn't be so seamless because they wouldn't have, you know, colleagues that would…know where to get that, you know, quick, good feedback."

Theme 2: What does this tell me about my son?

The second theme addresses the ultimate ordeal of the parents' journey: The communication of the diagnosis. What parents talked about most was their understanding of the assessment results; not only what the words mean, but also what it means for their son and whether the results reflect who they know their son to be.

It's like studying for a final. Parents shared common sentiments of feeling overwhelmed with the quantity of information they were given in the feedback meeting. As Bob noted, "It's like studying for a final." Jean said that she had initially thought, "Yeah, yeah, well, I'm sure it'll be fine" when the psychologist had warned her there would be a lot of information in the meeting. However, she admitted that the amount of information "was a little overwhelming" and "a lot to take in." Similarly, Jennifer explained,

> What kind of blew my mind was at the end of the process when we got our report you get fed two hours of pah pah pah pah pah *(fast – indicating loads of information)* ...So basically we got tons of feedback and you're kind of overwhelmed.”

The amount of information in the report was also overwhelming for parents. As Jessica noted,

> It was ridiculous. Like, ridiculous and I had to give a copy of that report to the school and I don’t even know if anybody’s read it totally…. Like, you could probably pick out and highlight like a few points, which are the important ones for the school to know. Who is going to take the time to read that?...I didn’t even want to read the whole thing. So, that, no, I would say that was ridiculous.

Big fifty-dollar words. In addition to the amount of information, all the parents interviewed shared that they did not fully understand the information they were given. As one parent noted, the report “was more of a clinical report than it was a parents’ report” (Sarah); a common theme for parents. For instance, Melly commented, “We don’t identify with all the big fifty-dollar words.” Jessica too explained that understanding the information is “a challenge for most parents unless they were psychologists themselves.” She noted that she and her husband were both frustrated with the information they received because

> …we were looking for layman’s terms. Instead, we got a lot of technical words and there was never, nothing was very clear… It wasn’t clearly described to us exactly what that was in layman’s terms. And that’s really what we needed to hear. You know, we’re not educated psychologists, doctors

> that know these technical terms. So, you need to break it down. So, that was kind of frustrating to us. I felt like I was going home and googling on the internet, like what does this mean? Right? So, that was kind of frustrating.

MTNI acknowledged the fact that the psychologist "walked us through step by step, what she found." However, she declared,

> I think we kind of get glassy eyed, right? And get stuck on what is executive functioning and does that mean…? I remember leaving and my mum and my dad and [husband] were there, and I remember my dad saying, 'Does that mean he's a retard?'… So, we all kind of, we all left thinking…what is it?

MTNI later admitted,

> I think I was trying to hold it together so I didn't look *(laughs)* like I felt on the inside. So, I think I was putting on quite a façade of – I don't – I remember at one point thinking I don't know what [the psychologist] is talking about, I don't understand any of this... But I was trying to be brave and put on this façade of, 'It's okay, I can manage, I'm a nurse, I can figure all this out.' Instead of just falling apart and saying, 'I don't know what – what does this mean?'

What's he all about!? Parents talked about the fact that the results of the assessment should provide them a better understanding of their son. However, they expressed mixed views about whether the assessment actually helped them better understand their son.

On the one hand, some parents indicated that they felt that they did not leave the assessment understanding their son any better than before starting the process. Sarah shared that although she was given a lot of information from the assessment, she had to "really look to find out where [my son fell]," asking, "What does that tell me about him?" She confirmed that she "really didn't find out anything new about him" and that the results were vague. Melly noted, psychologists "don't sit and talk to you enough at the end to let you know exactly what your child is going through." She commented, "We enjoy the one-on-one to tell me exactly what, what's going on with him and what I can do to help, that type of thing."

On the other hand, other parents noted that the results of the assessment gave them a better understanding of their son, an "inside view," as Jane put it. Melly admitted, "It was like opening a window." Crystal shared that the assessment results were helpful "just to have a deeper understanding of where he's, what he might be experiencing on his end, on what he might be thinking or how he might be thinking or not able to think or that sort of thing."

With a greater understanding about their son, parents seemed to shift their perspectives of who their son is, as reflected by Jean's comment, "I know that's not really his fault, it's just the way his brain works." Jane's story revealed a process of re-storying the narrative she had about her son, highlighting a major shift that occurred for her:

> Caroline, I swear to God, I used to hate the hockey, I hate the money for the hockey, I hate all the time the hockey takes, but guess what? Now, I love the hockey because I realized that that's played such an important role for him…It's funny how things impact your whole life, the ripple effect of it. Because my new outlook on the hockey and the sports actually really helps the rest of my life, right?

Overall, Jane explained that the information from the assessment "really transformed the way I think…Sometimes, my boy is *not* just a brat. Sometimes, there are reasons for things." She went on to share examples of how this transformation in thinking helped her change her reactions to his behaviours, noting, “I feel like I’m looking at him in a new light” and that

> …it’s changed everything for me, just my perception of him and things that have happened…back to the way that I deal with him...I’ve got much more patience than I did before…So, it really makes you look at yourself and your parenting… but yeah, I seem to be much more patient and he seems to be responding better to that.

Others shared similar experiences to Jane. For instance, Jessica commented the assessment “gave me a better understanding so I don’t get frustrated with [my son]. One thing at a time. You know, and that’s just the way his brain processes things.”

That’s not my son! Although parents had additional questions about what the assessment results meant for their son, a few pointed to stark inaccuracies in the results. For instance, Jennifer noted that there were pieces in the report “that didn’t make much sense.” Although she agreed that her son had ADHD, “Everything, the assessment kind of was so wrong” and that there was so much “mismatch” between her son’s needs and what was written in the report. She conceded that she got “a booklet of ‘who he is’, but it isn’t who he is” and concluded, “It's too late now, because now we have a report that isn't going to help anything right?” As a result, she explained that she did not “trust their information anymore” and did not pass the report to the school “because it was just too, it wasn’t appropriate to follow him.”

Others shared similar stories, with numerous instances of inaccuracies, such as having someone else’s name in the report instead of their son’s, and even inaccuracies about important family information written in the report. For instance, Sarah noted that, “when I got the final reports back, there were all kinds of errors in it.” Misinformation about the child, but also in her background history. She shared, “You know, I’ve never had a learning disability in my life and yet the report states that ‘mother has a learning disability;’ and just really makes me go, ‘Who are you listening to that this report is so rife with errors?’”

Some of the inaccuracies were attributed to “a lot of cut and paste” (Jennifer). However, parents noted that the psychologist seemed to have a narrow scope of focus and did not have a full understanding of their son because the psychologist did not conduct a comprehensive assessment. For instance, Jennifer noted that too much focus was on the school’s input, stating,

> I think people know who their kid is…And I think that school's take *waaaaay* too much of the, they take away a lot of parent knowledge. And you know, what happens in the classroom is not who that person is.

She went on to state,

> Very few parents come in [for an assessment] instigated by home life. It's almost always a school referral. Something's not working at school and I think it's *really* important that there's a really distinct understanding of who that child is outside of school and who that child is inside of school because I think too much emphasis is put on – and I know it's because there's a problem in the school – we need to figure out how to make school work. But, you’re never going to solve it just by looking at what's going on in the school. That's not who they are. Who they are is over here…. if you want to know who they are… find out who they are outside of school.

Other parents expressed similar concerns that their psychologist failed to understand the entire context of their child. For instance, Melly noted that her psychologist asked a couple of questions, but did not have a full

> …background information on our family or our dynamics or anything that went on in my home or his birth or anything. [The psychologist] looked at the medical point of view and not the psychology point of view of him, or how we operate.

Jennifer also shared that although her psychologist collected background information, the questions were limited and missed important details, failing to capture the full picture of her son. She noted that, as a result, there are “assumptions about your kids’ background.” Sarah stated, “They didn’t capture any more of a picture than a stranger looking at him could, you know, an uneducated stranger looking at him could.” Song conceded that psychologists only “see the kids for a short snapshot” and that “it’s not enough to really, to really know the child.” She questioned the ecological validity of the assessment because

> …they’re always in a very small confined structured place, and that’s not how the world works. It’s not how the world works, it’s not how kids function, it’s not how classrooms are, that’s not how home is…. So, I don’t think [the results] are very accurate or applicable.

Song disclosed that she tried collaborating with the psychologist to help fill out the picture of who her son was outside the clinical testing walls. Despite her attempts, she noted that her information “really didn’t go anywhere because [the psychologists] have to go by their data. And their data is what speaks, what comes up in their scoresheet is what is what.” Unfortunately, as Jennifer noted, those scores “don’t really represent what’s going on. You can’t kind of tease the human out of the scores.” She stated the forms she had to complete “…say nothing about [my son],” explaining,

> Even the forms that I've filled out, you know, they came back in the report and I went ‘I don’t feel that way at all.’ So, one, two, three, four, didn't say at all what I was thinking. They don’t really articulate what the nuance is actually happening in your life. So, there were a number of things where I went, ‘What? I said that?’ That's not; I don’t *think* that... Like, in my mind I'm interpreting it one way and it comes out as something else and you go well no, I never thought that. I've never really felt *that* way.

Song indicated that the psychologists “get this ADHD blinder thing going on,” failing to consider the rest of the child and other areas of difficulty the child is experiencing. In sum, Song declared that the psychologists

> …need to be open minded and they need to realize that the snapshot they’re going to look at is incomplete and shouldn’t form their total idea of how things work. And that they should look at the whole family instead of just the child, that’s another big part too I forgot to mention, it’s the whole family.

Theme 3: We’re not coming for label. We’re not coming for drugs. We’re coming for roadmaps.

Every parent in this study shared that they required support on how to manage their child’s difficulties, which was what brought them to the assessment in the first place. They asserted that that support should be part of the assessment. Instead, parents found themselves on a whole other journey after the assessment to try to find the appropriate support they needed. MTNI explained, “After the [assessment] process is complete, that should not be a period. It should be a comma…because I don’t think the psych assessment is; that’s not the end. That’s really the beginning.” Sarah exclaimed that parents are “not coming for labels. They’re not coming for drugs. They're coming for a roadmap." This comment reflected a common theme identified by parents. Specifically, although they thought the assessment would be the point in which they would finally get help, they came to realize the assessment was only the beginning and that there was a whole other journey to get the support they needed for their child.

My son has ADHD. Now what? Upon completing the assessment, whether parents felt the information was helpful or not, they all reported not knowing what to do next, lacking that roadmap they had come for. Jennifer commented, "He has ADHD... What do you do with that?" Melly's experience reiterated this perspective, "Yes, we have the assessment, and I know what's wrong with him. But what can I do to help him better? … to make him more successful? And I have no idea." Crystal also explained,

> I feel like I have a whole ton of information which I experience, I see it, I feel it, I know it, I hear it, but actually doing something with it feels really – I don't know where to start… Where do I go?

Although other parents had similar questions, unfortunately, as MTNI explained, "You have none of those answers."

As noted above, without knowing the next steps, parents reported that the assessment opened a whole new journey for them. MTNI explained, "So we left [the assessment] and now it's into this gigantic world. Little did I know that [the assessment] was just the beginning of the – like it was just the pre-package." She went on to describe the end of the assessment process, stating:

> …[it] feels like – it's almost when you leave the hospital with a brand new baby, and you walk out that door the first time you think, 'Holy crap [laughs], now what?' That's what it is, you walk out with this document that now kind

> of gives you a tool that says 'This is what's up with your kid.' But then you feel like you're leaving and now what? Now what? Where's the part two to say, 'Here's what to do now'?

Parents confessed that they turned to the internet, or "Dr. Google," as MTNI termed it, for more information. Jessica explained that she turned to google because she "seem[s] to find more on the internet" (than getting information from her psychologist). From there, parents seemed to end up on one of two paths, moving ahead and seeking further support from their psychologist or being dumped and venturing out into the new world on their own.

Moving ahead or being dumped. A few parents from this study reported feeling that, even though they had initial feelings of, "what next?" they were lucky enough to move ahead feeling supported by their psychologist. Jane explained,

> I did feel like, 'Where do you go from here now? What do you do with this stuff?' But because I knew that [the psychologist] would go meet with the school, I felt like I actually kind of drew the circle of what was going on in my head, so I didn't go so crazy…. We both left here knowing that we were going to go home, read it and come up with what we wanted to try and either come back and tell the psychologist or come back with any questions that we might have.

Ray shared that her psychologist was willing to go to the school and offer suggestions to the teacher based on her observations in the classroom. She commented,

> I wasn't expecting that, so to me that was like a perk to know that after this was done the follow up was … you know that [the psychologist] was able to come to the school and do more observation and kind of create that.

She noted that she was "pleasantly surprised that that relationship still continued." Ray became emotional at this point, stating, "And I just feel so blessed and fortunate that it's worked out so wonderfully for [my son], that it's just been a tiny blip in his life. Oh, I'm going to cry. Because we're moving forward."

Unfortunately, the rest of the parents did not receive the support they needed and hoped for. As Melly put it, those parents "never heard from [the psychologist] again." These parents expressed similar thoughts as Sarah, who asserted, "And that's where doctors and psychologists have stopped. You've got ADHD, that answers all your questions and we're done;" and Song, who declared, "After the assessment, you're just dumped with no direction as to what to do next or where to go next…Once they're done, they're done. You can't call them back and get them to help you because they're done." But as Sarah shared, parents still think, "'*Are* we done?'... I don't feel like we're done."

When parents did not receive the additional support from their psychologist, they were left feeling abandoned, frustrated and disappointed. Song explicitly shared these sentiments:

> I felt really let down. I felt abandoned and angry. I think of all the things that's gone on, the thing I hold onto most is anger about this whole process that I've gone through for [my son] and to get answers and how much I've had to struggle. Because you have to, basically by yourself pick apart what to do next and what to do next and what to do next.

Although the parents admitted that they received some recommendations of what to do, they still did not know what to do next and maintained that the recommendations were not helpful. Indeed, Jennifer affirmed,

> But, then we walked out the door, got a report and didn’t know what to do from there. And so the recommendations weren't… maybe they make sense from the office perspective, but, they don’t make sense from the parent because you look at it and go okay well where do I do this?”

Song too said, “…in the end wherever you go, they don’t really teach to what is recommended.” She emphasized, “They expect you to replicate what they can do in a small controlled environment in your own home or in a classroom. So, I don’t think it’s very accurate or applicable.”

Parents admitted feeling that they were ultimately left to their own devices. As Bob put it, “I think [the psychologist] gave us some resources to do more kind of independent study but I, you know, it’s, I think it’s, maybe just left to us a bit.” Mr. Incredible agreed, stating, “The burden’s on the parents to sort of teach the child.” He further explained, “They’re going to put all the burden on the parent to not just solve the problem, but to manage.” He went on to state that there might be “relief knowing what [the diagnosis] is, but you get the absolute increased burden to somehow find the right…methodology for handling it.” He reiterated, “It’s always going to be about the parent, always. It’s always going to be about you; you’re the one responsible for your child.”

Unfortunately, these parents expressed feelings of defeat at this point in the assessment, with nothing more to give to try to access more support or to try to do anything differently. They were “done,” as explained by Sarah. Jennifer proclaimed that although she could have gone back to advocate more for her son, she thought,

> You know this whole process, I'm done. I just, I don't need to go back and hammer out the…I just, I can't do this anymore. So, we just walked away and kind of, yeah I mean what do you do?

Taken together, every participating parent agreed that follow-up support to help their child is needed once the assessment is complete. As Bob noted, parents need "that support mechanism from, you know, diagnosis and, you know, getting [our child] help out in the clinical area, how does that transcribe into his life." MTNI suggested, "A more comprehensive psych assessment would include follow-up sessions that actually are further supporting the information." Additional suggestions included reviewing the results with their child's school and contributing to the IPP development, identifying appropriate resources and sources of information, discussing relevant programs and funding bodies, connecting parents directly to relevant programs, and teaching parents how to advocate for their child. Because parents felt they were left on their own to help their son, more could also be done to "empower the parent," as Mr. Incredible noted, "because it takes the two" (the assessment and empowering parents) to best support the child.

Theme 4: It's such a big journey.

This theme points to the overarching elements that symbolizes the journey parents embarked on and that were pervasive throughout the entire assessment process. Part (a) reflects the social aspect of the journey; particularly the relationship parents had with the psychologist. Part (b) reflects the emotional journey parents experienced.

Part (a): You've got to find a person you feel comfortable with.

Talk to me like I am your friend. One topic of prevalence in both frequency and intensity within the interviews was the relationship parents had with the psychologist throughout the entire assessment process. Bob highlighted the significance of establishing a positive relationship with the psychologist from the point of first contact, stating,

> …if you don't kind of build that trust or that basis at the beginning, right, then the whole process is going to be a waste of time for both, you know, the kid, the parents and the psychologist... You've got to find a person that you feel comfortable with.

Parents shared that connecting with the psychologist directly, rather than relating information through a secretary, was important. Bob explained,

> …if you can't, you know, you don't feel comfortable with the receptionist in making an appointment, you know, how are you going to feel comfortable with the doctor when you're sitting there saying 'That's a nice chair you got there.' And it's very comfy over there but, you know.

Jean made similar a comment,

> "I actually appreciated being able to talk to the psychologist, like as opposed to a receptionist… I found [it] helpful when I knew that I was actually talking to the psychologist, like the person who's going to be doing the assessment."

Within the assessment, there were parents who shared stories of having a good working relationship with their psychologist and feeling supported throughout. Jane indicated that, overall, "I felt good with everything .... I felt like they're there for support." She later reemphasized, "Wow. These women are working for me not just because it's their job and that's what they do, but they get it, right? This is someone's child, right? It's sort of important."

Given their struggles leading up to the assessment, parents described feeling relieved when they were finally able to connect with someone who listened to them, as reflected by Nicole's comment:

> It was just relieving and exciting because I actually felt like I was being heard… Finally, somebody is listening to me. You know, I'm not just a crazy mom, and you know, and because I had gone through some of the stuff before, the fact that it was actually now being used and being paid attention to was … meant a lot.

Many highlighted the fact that feeling comfortable with the psychologist was important because it helped them be open and honest with the psychologist. Melly shared,

> She talked to me like I'm [her] friend, and that's what's key, because you can't just ask them the questions and expect somebody to open up if they don't feel comfortable, right? You're only going to give what you feel you want to hear, or you're not going to get the proper answer. You're going to get what I think you might want to hear…You're talking to me as my friend, not as my—and that's huge. But when you're more, give me the answer, I'm going to be reluctant how I'm going to answer it. So this is good, I like the kind approach, and you're just asking questions because you genuinely want to help my child and I, and that's, to feel that, and to feel that comfortable, comfort level is huge for us. So that's great.

Crystal expressed feeling "confident that I can let it all out with [the psychologist]." Jane further noted that she could be herself, because she

> …never felt like I made [the psychologist] uncomfortable and sometimes going through this too. I could've very well been a basket case or come across… but she was okay with however I was, whether I seemed upset or seemed mad and she seemed genuine, which was really good.

The parents delineated several important characteristics the psychologist demonstrated that contributed to a positive working relationship, such as being professional, open and honest, personable, easy-going, and approachable. Jessica and MTNI both indicated that they liked that their psychologist was also a parent, who could understand the difficulties of parenting and could relate to them on a more personal level. MTNI also stressed that she

> …really appreciated [the psychologist's] eye contact. That's a big thing for me is eye contact. And it's true. Often professionals they'll sit and they'll write constantly and not look at you, and I just – I felt like she listening and caring because she gave me eye contact. Which is a small thing but it's still…

Although perhaps a small gesture, MTNI noted that the eye contact helped to promote empathy. Empathy and understanding parents' grief and fears proved to be a common characteristic identified by parents as being particularly important. MTNI stated that her psychologist "acknowledged that people are sitting there *(soft screaming noise; laughs)*. You know, afraid. So I thought that was very empathetic." Nicole summed this point, stating that her psychologist

> …did well with listening and understanding and relating so it wasn't an intimidating feeling through any of it, and I think that's very important. It's

> hard enough doing this stuff as a parent and trying to convince someone to believe you, and so, you know, you don’t need the intimidation with it.

Further highlighting empathy, MTNI and Jane shared stories of how their psychologist addressed their fears before communicating their child’s diagnosis, which they both appreciated. “I liked that she asked right away, ‘What are your fears going in?’… I liked that she started with that, because she was acknowledging the fear and the anxiety in the room.” (MTNI)

Parents were relieved the times the psychologist acknowledged parent fears about medications and provided behavioural interventions to target their child’s difficulties. For instance, Jane’s psychologist first highlighted behaviour strategies to support her son, which helped Jane to later appreciate “them being able to say, ‘Yeah, you might just have to try some medicine.’” She explained, “…if you didn’t see and hear that [previous] stuff [about behavioural interventions] coming out their mouth,” she may not have been as receptive to medications. Crystal too exclaimed, “I was very happy to hear that there was other options and that [medication] wasn’t the first thing.”

Although a few parents from this study had positive experiences with their psychologists, the rest did not. MTNI saw two psychologists before she obtained the official diagnosis of ADHD and reported very different experiences between the two. She explained that she felt valued by the first psychologist she saw, which she declared was the most important part of the relationship:

> I thought, ‘Wow, that is so nice that she's caring to find out are we okay with what’s going on’… I felt like she was really taking care of us. That she wasn't so much taking care of [my son], that she was gleaning information for him to give him a diagnosis; but it was really about supporting us at that point. It

> wasn't about how can I get them as a client and service him, but really it was just about helping us. Which I think was really nice, that it was helping us.

However, her experience with her second psychologist who ultimately gave the ADHD diagnosis was very different. She noted feelings of discomfort, explaining, "Yeah, it just became kind of awkward… And it became uncomfortable. The process." When queried further, MTNI clarified, "It always seemed somehow like there was some kind of line being crossed somewhere" by her psychologist. She further explained, "So it was always this random – and it was always [the psychologist's], her Christian beliefs were coming into diagnosing, and play, and then her personal history… and her emotions, and she'd cry." MTNI further noted feeling judged by this psychologist, stating, "[The psychologist]'s a Christian also, but she had this judgment placed already because we were separated."

Other parents also shared similar feelings of being unheard, invalidated, blamed, and even attacked by their psychologist. Helen made comments like, "But it was like it all came down to us and what we were doing wrong." "Absolutely invalidating." And "I...just felt like people just weren't listening." Song noted that the assessment was a difficult and emotional process because "No one's believed us, how hard it is in our family to function."

Sarah admitted that her psychologist "…had the approachability, he had the apparent empathy and sympathies, he gave off the persona of being listening and there for you and really supportive and encouraging," but that he "turned around behind my back… like he had listened to use it against me, type of thing." She vehemently stated, "I felt attacked" and questioned the point of the assessment when professionals are "going to tell you it's all your fault anyways…What are the answers? And their answer was, 'it's your fault.'" Similarly, Song noted, "Basically, the answer that would always come up was this was a parenting issue... And that you just need – that you're a bad parent. That was the general gist of it." She further explained that she felt accused that she was "…not being consistent enough. You're not being this; you're not being that" and commented, "Everyone always does that to you. I just hate it. It's always kicked back to you and what you're doing and not doing. It is so frustrating you know…It's awful, it's awful. You're always under a microscope."

A weak relationship led families to feel that their needs were not a priority. To illustrate, Jennifer described that her and her child seemed to be "run of the mill," commenting, "I was another parent with another little kid, who was Ha! another little boy who couldn't sit still at circle time." Other comments pointed to feeling that their needs were secondary to some other agenda the psychologists had. For instance, Jean stated, "I felt, felt like I was going to be funding his new office." Similarly, MTNI noted that there was always a cost associated with getting help and that money seemed to come first. She stated that the assessment "was all this back and forth…. It was very ridiculous. It became very ridiculous. And just in email fees we paid $2,000. It was ridiculous."

MTNI explicitly identified another underlying agenda her psychologist seemed to have, noting, "Lines were blurred all over because there was a different agenda." When queried, she explained that her psychologist was doing her own research, which took away from her helping the family because the psychologist

> …had information but she didn't want to give it because she's going to write a book and so she didn't want her documents out there, in case somebody else had them and then they could use that in their book.

In sum, a common thread within parents' narratives was the relationship they had with their psychologist. This relationship was important because it seemed to affect their experience of the assessment process. This point is reflected in Mr. Incredible's comment:

> I can see how it can be so discouraging if you just suddenly don't connect with the individual on a personality level, and, yeah, it's something that can skew everything and you can give up, or you can just focus heavily on what went wrong rather than all the other positives that can be going on around it.

He's a relationship-based kind of kiddo. Although the interview probed questions around the parents' relationship with their psychologist specifically, parents brought up the point about how important the relationship between the psychologist and their child was as well. Jean said, "To me, it's important that [my son] feels comfortable." Melly shared that her son liked the psychologist because she

> …made it fun and let him be himself. I think, out of all the things—because he feels kind of annihilated a little bit, because of the way he is, and when he came here, like [the psychologist] said, 'You're so fun' and he heard her talk to me in front of him, positive things…And he needs to hear that he's a good person. 'Yeah, you may have a problem, but you're still a really good person.' And that's really huge for him too and that's why it wasn't hard for me to bring him back…So I found that was really helpful.

Jane commented that she initially thought the assessment was going to be highly clinical for her son and that "…he might get stressed out." However, she reported that her psychologist "was just so normal about it…and excited" and that "it was more personal than I thought it would be." Jane went on to state that her son "was happy and he liked [the psychologist] and she liked him, so I felt really good." Ray was also initially worried about the assessment, wondering,

> In the heat of experiencing the greatest difficulties he was and having to be forced to spend, you know, upwards to six hours answering questions, I thought, 'This isn't going to be good.' And everybody at work kept saying, 'Oh, how is he going to do with this?' Especially because he is such a relationship-based kind of kiddo; he really needs that connection.

However, Ray admitted that she was surprised at how well her son did in the assessment, acknowledging that the "questions that [the psychologist] had were obviously very, you know, child-friendly and age-appropriate and [she] built in with lots of breaks and all those kinds of things, right?" She concluded, "My son wanted to come back the next time, so that was a good sign that he wanted to come back."

Unfortunately, not all of families had such positive child-friendly experiences. Jennifer recounted that the assessment was stressful because she

> was bringing a tired, kind of stressed kid and, you know, it's quite clinical, you know, it's an office, it's strangers and he was little and…they sort of whisk him off down the hall… And there's no, there's no, he hasn't eaten, you know what I mean? There's no, you can't explain anything.

Sarah described a similar scenario, explaining that their experience was more clinical than child-friendly. She noted that her son's "anxiety went flying through the roof." She noted that her psychologist "didn't greet [my son]" and "didn't even try to engage or reassure him or anything before we got into things." Melly related that her first psychologist

> was very quick and she’s very short and [my son], he said he felt intimidated. I remember him coming home, saying that he didn’t feel like he could talk. …And I’m like, that’s huge, because then he’s just going to give you an answer he thinks you’re going to want to hear. He’s not going to give you the right answer. So, it’s comfort level is big time.

She went on to highlight the significance of developing a relationship with the child to help understand the child and validate the assessment results. She explained,

> If you would have taken the time to get to know [my son] … and asked questions about the family or whatever, you could just stamp him as ADHD and leave it at that too. Whether he did the tests or not. But you got a better understanding of him by taking the time to get to know him too, which you have to, to get a proper diagnosis of him.

MTNI further noted that it was hard having her son in the room for parent-psychologist discussions, saying,

> Your kid is right there and they’re passing around all these words and accusations and ‘Does he do this, does he do that?’, and… He’s looking at me like, ‘What are you talking about, mummy, I don’t know any of this.’ So, I think there’s not a lot of sensitivity to the children when they’re in the room.

Left in the dark. One aspect of the relationship parents identified as important is collaboration. Some parents stated that they felt the assessment was all one-sided and lacked collaboration. Jennifer flat out stated, “Yeah I didn’t feel [collaboration]. I didn't feel that at all.” Melly noted,

> [The psychologist] never gave me an opportunity to talk to her… which is unfortunate…They called you when the paper was ready and you picked them up and that was it… They don't have time to, they're allotted this amount of time to deal with him, there's zero time for [Melly] to be able to talk to you guys.

She went on to state that collaborating with the psychologist is "…the dollars and cents part right there." Others also made comments about money with regards to collaboration, pointing to the literal value they seem to place on it. For instance, Jessica highlighted her lack of involvement by stating, "You're spending, I think I spent seventeen, eighteen hundred dollars, for a few sessions, and you want to see what you're getting for that. So I felt, from that aspect, really left out." She further commented, "…If I was one of those parents that maybe couldn't afford it and I was just like making ends meet too, and then, being left completely out of that, I'd be even more concerned."

Melly suggested that psychologists need to work more closely with parents throughout the assessment. For instance, they can "…check in with parents on a more regular basis. How is this so far? How is this so far?" Melly acknowledged, "I know it makes it more expensive, that's really where it comes down to, right; is it's expensive, it's hourly." However, she justified her point by stating, "…At the end of the day, walking, spending three grand on a report you can't use is not efficient anyway."

Other parents stated they felt that they could collaborate with the psychologist. However, when queried further, these parents defined collaboration based on whether they could ask questions throughout the assessment, and not beyond that. Collaboration seemed to end there, as parents did not identify any other collaborative practices in the assessment process. These parents admitted that they did not have role in the assessment and did not know what went on in each session with their child or what was being assessed. Melly’s comment summarized a common perspective held by the parents in this study: “You drop the child off and you picked him up and you get the report…which is unfortunate.” She later re-emphasized her point, commenting, “I don’t know what’s going on there because it’s just [the psychologist] and [my son]. And then there was no feedback. You dropped him off and you picked him up and that was it.”

Two parents indicated that they were alright with not knowing more about the specifics of what was being done; for example, Ray noted, “I wasn’t involved in any of it and I was okay with that. I didn’t feel like I needed to be part of it.” However, the rest of the parents expressed wanting to know more about what was going on in the assessment. These parents had even asked their sons about the assessment to try to get more information. However, as Nicole stated, “Even when I asked him…he didn’t have a clue.” Parents were essentially unable to draw out more information about what was done in the assessment, even from their child who participated in the process, because he could not explain it himself.

Nicole shared that she wanted more information for her “own curiosity.” However, other parents believed that greater information would have helped strengthen the validity of the assessment. Jennifer explained that just showing up to the assessment without information made her feel unprepared and that she could only offer basic information, missing important details:

> You don’t really know what you're doing and you don’t know what the questions are and you don’t know, it's all kind of unclear. And then you walk out the door and you go to the desk and they book you in for a bunch

> of stuff that you don’t know what you're booking in for and then you go home and realize there's lots of important stuff [that was missed] right?

There are implications to not knowing the process. For instance, parents noted that they may have done things differently had they known more about the assessment process. Jennifer stated this explicitly, “If I had more knowledge about, if I'd been in on the process a little more, probably it would have been a different process…” When queried, she explained,

> I think that because if I'd known a little bit more, I would have had more, the conversations would have been different…And so if I'd known more of the journey, like things like why did we have all of his testing done at noon after a morning of school? [It’s] the worst possible testing circumstances for a kid who's struggling all morning. And then he hasn't eaten and then we're going and doing testing at noon? I look back and I didn't know that that's what we were doing. I would have completely structured all of that differently right?

Parents indicated that greater information about the process and all that was involved would have also helped them better understand the results of the assessment. Sally mentioned, “So we got the results of the test but I have no idea what, as a parent, what those tests were” and questioned, “How did you come up with [the result]?” Jennifer further commented, “Parents don’t even know what they're about, they don’t know the process at all. You don’t understand you just sort of get told, we're going to do this, this, this…”

Part (b): A fragile family. One of the most powerful conversations I had with parents was about the emotional journey they had through the assessment. Indeed, parent stories were imbued with stress and guilt, wanting to do good by their child and conflicted with an internal battle with feelings of guilt, despair, and hope.

The weakest link. Many parents expressed experiencing significant amounts of guilt throughout the assessment journey. A predominant source of guilt was whether parents did something wrong and/or have not done enough for their kids. Helen summarized this point clearly in her statement, “I always feel like there’s more that we should be doing…. Always wondering what more I could do for him.” Bob too stated that he began to think things like, “‘Yeah, what have I done wrong?’ or ‘What could I have done’ or ‘why didn’t we get them help earlier?’”

Jean became very emotional on this topic, pained by the guilt she faced in having possibly done something to have contributed to her son’s difficulties. She explained, “As [the psychologist was] asking questions I’m thinking, you know, ‘Is it something we’ve done?’ right, that made it this kind of, that made him have this kind of experience.” Mr. Incredible’s comment sums up parents’ sentiments in this regard, “At this point, am I the weak link in the chain?”

Parents seemed to be on high alert within the assessment process itself, second guessing themselves. Jennifer commented that parents may feel like they are in the “hot seat” in the assessment, trying to answer all the questions when they are already “in kind of a rough shape.” She shared that she “had no confidence in anything because I'd been worn down,” which made “having to review everything, you know about your kid up until this point, is complicated.” Bob too noted experiencing “…some areas of guilt and, you know, are there some things that, you know, we should have said or didn’t say and stuff like that,” such as in the background history portion of his son’s assessment. Jane also worried about what she said to the psychologist, exclaiming, “Oh my God. What did my big, fat mouth just do?” MTNI disclosed, “I felt like I had to also behave a certain way” for the psychologist. She explained,

> I have to hold it together because then we look like a normal family that’s just

> a child with – you know, like oh my goodness. Because all of a sudden you think – you're left thinking what did I do? Did I eat too much meat when I was pregnant? … You're left with what did I do? How did I affect this?

In the end, Jane explained that the assessment "brings out emotions in parents." Mr. Incredible described a "misery that ADHD parents are experiencing," a misery that is "a hidden thing, you don't discuss, because it's; it looks like the parents are doing a bad job." Other parents admitted similar feelings. Out of significant frustration, Song exclaimed that psychologists seem to forget that families "are fragile… if they look like they're coping well, they really aren't, no one's coping well."

At the end of the day, most parents interviewed agreed that psychologists should try to put themselves in the shoes of the parent. To understand the fact that "it's the whole family experiencing [ADHD] and not just the child" (Crystal). To understand "… that what [parents] are going through is really tough" and that psychologists should focus on "just being with [parents] wherever they're at." (Helen)

Between hope and despair. Mr. Incredible talked about "this in between where you're in between hope and despair." Hope and/or relief of moving forward and finding help to support their child. All parents made some comment indicating that they were hopeful coming into the assessment, relieved to "make a path" (Jane), to move "forward to the next step" (Crystal), to "get some definitive answers and, you know, get an action plan in place" (Bob), to identify the targets to "start working on" (Sally), and ultimately, to "get the support" (Helen). As reflected in Mr. Incredible's comment, parents within this study expressed feeling "very dependent upon the psychology side and the assessment to actually move forward in some way," particularly with treatment support. Indeed, all parents shared that they brought their son to the assessment knowing he had difficulties and believed the assessment would help them get the support they needed. Most, except for two, already believed their son had ADHD specifically and were just looking for the support. As Ray stated, ADHD "kind of all aligned, in kind of what my gut instinct was this whole time," which made it "a little easier pill to swallow at first."

Despite having this prior inkling that their child had ADHD, and despite the feelings of relief to be moving forward, most of the parents interviewed admitted to feeling anxious about the assessment results and found themselves caught in a web of despair. As Melly stated, despair "to think that there's anything wrong with your child." Song recognized the difficulty parents may go through, stating, "Some people, when they get the news of what's going on with their child, it's devastating. There's always a grieving process." MTNI explained experiencing "a desperation between…how do you help my family and my child, but I don't want to hear it's really bad because… because it's my baby."

Theme 5: Rich Insight for other parents.

This final theme reflects the wisdom parents have gained having gone through the assessment process. In particular, they identified specific information they believed would be helpful for other parents to know as they undertake an assessment.

It's a manual for your kid. One common piece of advice parents wanted to share with other parents who are thinking of having their child assessed is "to not be scared" (Jane), acknowledging that parents may see the assessment as a worrisome process. But, as Jane stated, the assessment "doesn't have to be probably half of what we make it in our head before it happens." Jean shared that, "whatever you're told is not necessarily bad news. It's just different." To help reassure parents, many parents from this study offered explanations such as Jessica, who stated that the assessment "…benefits the child. If you have a proper diagnosis, you know, to better help them.” Helen clarified too that labels are not to stigmatize: “You need a label to get the support” your child and family require.

MTNI explained in greater detail, stating that parents “…shouldn’t be fearful of the process,” highlighting that the assessment is

> …an incredible parenting tool. Really, I think that it should be marketed that way. That it’s an incredible parenting tool that gives you rich insight into the… Who your child is. It gives you the mirror, it gives you that medical mirror of how your child works, and why you’re butting heads, or why they’re not getting, or why – like it’s so many of the why’s... Everybody says your child should come with a manual – this is kind of like the table of contents of a manual for your kid. Right? I almost think that most parents should have it done anyway [laughs]. You know, regardless if there’s a need or not, because it’s quite insightful to really how your child works.

It’s not your fault. Parents from this study acknowledged that other parents may also experience the feelings of guilt they themselves have experienced. For instance, Helen wanted to share, “It’s not your fault.” Mr. Incredible recommended parents to “Avoid the self-judgment… move forward… allowing yourself to get help.” He also suggested, “First, you need to heal and then you need to figure out how to stand up again.”

Parents considered healing as important for their own well-being, but also to help them better support their child. Parents in the current study admitted having to be strong advocates for their child. Sarah highlighted the important role parents have as their child’s advocate because

> …the psychologist and the doctors don’t know your child as well as you know your child. And when you go in you have to be brutally honest about

> everything…Because if we're try to protect our kids and say, 'Oh no, everything's fine,' our kids aren't going to get the help they need.

Others made further comments about parents' role as advocate, such as needing to "be proactive… and educate themselves" (Song). Parents also need to be strong because, as a few parents emphasized, "the assessment is the tip of the iceberg…this is not going to just be the end" (MTNI), re-emphasizing the long journey ahead.

Summary

The purpose of this study was to investigate parents' experiences of the assessment process that resulted in their son's diagnosis of ADHD. This chapter illustrates the rich narratives parents shared in relation to this study's research questions. Throughout this chapter, I used their words to tell their story, working diligently to uphold their voices in reflecting their experiences. By including parents' firsthand accounts of their experiences, I have offered additional understandings of those experiences that was not previously addressed in the literature.

The parents' narratives highlighted mixed experiences of the assessment processes. Specifically, some parents had a strong working alliance with their psychologist, received follow-up support, and gained a better understanding of their child; all of which seemed to contribute to positive experiences. Conversely, other parents did not have a strong working alliance with their psychologist, they felt attacked, they did not receive any new insight about their child, and they did not receive any follow-up support; all of which seemed to contribute to negative experiences. From these accounts, parents identified important points that directly inform assessment practices, and are discussed in greater detail in the next chapter.

Chapter Five: Discussion

The purpose of this qualitative study was to explore parents’ experiences of the assessment process that resulted in their child’s diagnosis of ADHD. Fifteen parents participated in semi-structured interviews. Data were then analyzed and organized first by the research question and then by themes and subthemes guided by the framework established by Braun and Clarke (2006), as described in chapter three. It was anticipated that a better understanding of parents’ experiences would provide insight about how to facilitate the delivery of quality services that directly addresses what parents indicated is important for them.

The previous chapter delineated the key findings of the present study by organizing the data into their respective themes to produce a narrative of parents’ experiences. The purpose of this chapter is to provide interpretive insights into the findings from the current study and to present a synthesis of the data as it relates to the literature. The chapter begins with an overview of the purpose of the current study and the key findings that inform assessment practices. The findings from the current study fit with the literature relative to the shifting paradigm in how psychological assessments for children are conducted; specifically, with regards to parents’ perspectives on what they would have liked to have experienced in the assessment process. In this regard, the discussion chapter focuses on the relationship between the findings from the current study regarding parents’ assessment experiences relative to their child with ADHD and how their narratives help us better understand how other assessment approaches, above and beyond what is typically done in traditional assessments, are applicable to the assessment of ADHD. Therapeutic assessment is presented here as one example of how psychologists can incorporate different assessment procedures into their current assessment practices in ways that may address the key points parents identified in the current study. Practical implications are offered, followed by the limitations of this study and future research considerations.

Overview of this Study and Major Themes

The purpose of this study was to investigate parents' experiences of the assessment process that resulted in their child's diagnosis of ADHD. A major goal in collecting parent feedback is to better understand and enhance person-centred services; that is, to focus on what is important for parents. By asking parents about their experiences, detailed information was elicited from them that is applicable to future assessment practices for psychologists undertaking the assessment of children and youth for ADHD. The results from this study suggest ways that parent input can be used to promote parent satisfaction with the services provided, which is consistent with much of the empirical literature (e.g., Cunningham et al., 1984; Graungaard & Skov, 2006; Miller & Hanft, 1998; Morgan & McGucken, 1984), as well as to ultimately improve service provision, as positioned by some researchers in the field (e.g., Giannoulis et al., 2004; Mansell & Morris, 2004).

This study offers important contributions to psychological research relative to parents' lived experiences of their child's assessment process. Overall, there were five overarching themes that resulted from the data analysis of the parent interviews. From these, three key findings directly inform assessment practices, which are addressed here. First, parents highlighted that the working relationship with their psychologist was paramount. Within the relationship, parents identified psychologist qualities, such as empathy and their opportunity to collaborate with the psychologist throughout the assessment process, as being important. Second, parents indicated that understanding the assessment results and how the results related to their child and family is critical. Finally, parents noted that they did not come to the assessment for a diagnosis; rather, they came for help to support their child. These findings are situated within the literature related to collaborative assessment approaches. To set the stage in this regard, the next section provides a brief overview of how the assessment of ADHD is conducted generally, followed by a brief review of traditional and collaborative assessment approaches. Therapeutic assessment was chosen as one example of a collaborative assessment approach that has emerged over the years because it has “shown great promise in maximizing the benefits produced by clinical assessments” (Norman & Breitborde, 2014, p. 122) and has shown benefits across a diverse range of populations, including children and adolescents (Hamilton et al., 2009; Michel, 2002; Ougrin, NG, & Low, 2008; Smith & Handler, 2009; Smith, Handler & Nash, 2010; Smith et al., 2009; Smith et al., 2010; Tharinger et al., 2009; Tharinger et al., 2008; Tharinger et al., 2012). Furthermore, the tenets of therapeutic assessment address the key findings from this study, as discussed below.

Overview of the Assessment Process for ADHD

As presented in chapter two, ADHD assessment guidelines focus on the need for professionals to identify the number and duration of symptoms and age of onset, to gather information regarding the child’s developmental and medical history, to obtain information regarding the frequency and severity of symptoms, and to identify the level of impairment to determine whether a child has ADHD (Sowerby & Tripp, 2009). In general, psychological assessments include three phases, the initial intake phase in which relevant background information is collected, the second phase in which the formal assessment procedures are conducted (e.g., administration of standardized tests, observations, collateral contact), and the third phase in which the assessment results are shared with parents. Within the traditional assessment process, psychologists typically engage in three main tasks, collecting data, making deductive interpretations of the data, and offering recommendations based on the data (Finn & Tonsager, 1997). Test scores are used to compare the child's functioning with other children with and without ADHD. Parents then receive the final results at the end of the assessment.

Parents in the current study described their assessment process that seemed most consistent with the traditional model of assessment, as described in the literature review (Chapter 2). In this regard, their assessment experiences coincided with the three main phases of traditional assessment approaches. Parents described their relationship with their psychologist as being mostly one-sided (i.e., there was little collaboration throughout the assessment) and explained that their role within the assessment was passive and primarily limited to information giving, such as within the interviews. In this process, psychologists maintain the expert role by collecting data and later sharing their final formulations at the end of the assessment process, which is consistent with the traditional approach (Finn & Tonsager, 1997).

Although the traditional approach is still used in some psychological assessments, there has been a paradigm shift towards a more client-centred, collaborative approach to assessment (Dana & Leech, 1974, as cited in Korchin & Chuldberg, 1981; 2000). This paradigm shift views clients (or in the case of this study, parents) as active co-assessors within the assessment process, with a major end goal of making the assessment process a beneficial experience for them and their families (Allen, 1981; Finn & Tonsager, 1997; Fischer, 2000; Korchin & Chuldberg, 1981; Smith et al., 2010; Tharinger et al., 2009; Tharinger et al., 2007). An emphasis is also placed on understanding the child in-depth in relation to his or her context(s) within assessment over the years, from a biopsychosocial perspective (Pham, 2015).

In considering the feedback elicited from parents regarding their experiences of their child's assessment, therapeutic assessment is presented as just one example of a collaborative assessment approach that can be used in the assessment of ADHD. This approach was chosen as a part of this discussion because it addresses the key findings from the present study (e.g., parents' perspectives on what they would have liked to have experienced in the assessment process); particularly, the need for a working alliance with the psychologist, intervention strategy sessions, parent participation in the assessment process, and follow-up sessions after the assessment is completed.

Therapeutic assessment. In their seminal paper, Finn & Tonsager (1997) emphasized the benefits assessments can have for individuals. Finn (2010; as cited in Fowler, 2011) generated general guidelines psychologists can use within the therapeutic assessment process, such as eliciting parents' narratives about their child's presenting concerns and considering contextual factors surrounding the identified difficulties (e.g., when, where and with who the difficulties arise). He recommended psychologists to engage in collaborative problem solving with parents to generate possible solutions for their child's difficulties and to identify ways parents can implement those solutions outside of the assessment session. Where appropriate, parents may have the opportunity to practice these solutions within session with the psychologist. In addition, follow-up sessions may be provided to address and reassess interventions as needed. In general, this assessment intervention session gives psychologists the opportunity to explore the parents' concerns and the child's presenting problems in-depth, to discuss the results of the assessment in light of the child's contexts, to develop a rich understanding of the child, and to identify possible strategies to help manage the child's presenting difficulties (Finn, 2007; Finn & Tonsager, 1997; Tharinger et al., 2007).

Therapeutic assessment includes a few procedures common to traditional psychological assessments, such as initial intake interviews and standardized test administration, and similarly helps to identify an individual’s difficulties (e.g., diagnosis; Finn & Tonsager, 1997). However, therapeutic assessment focuses on collaborative procedures not typically used in traditional approaches, such as involving parents in the standardized testing sessions, incorporating assessment intervention sessions with the child and family within the middle of the assessment, and working collaboratively with parents to help them understand the assessment results in a way that makes sense to them (Clair & Pendergast, 1994; Finn, 1996; Fantini et al., 2013; Finn & Tonsager, 1997; Tharinger et al., 2012). The final feedback session is replaced with a collaborative summary and discussion session, which is later followed by a written report based on the collaborative efforts of parents (Tharinger et al., 2009). Additional follow-up sessions are also routinely offered (Finn & Tonsager, 1997; Tharinger et al., 2012).

Key Findings from the Study Relative to Therapeutic Assessment for ADHD

The remainder of this section integrates the key findings from the present study with therapeutic assessment as one example of a collaborative approach psychologists can integrate into their own practices that may help to enhance parents’ experiences of the assessment process, where appropriate. It is important to note that some of the procedures used in therapeutic assessment are consistent with procedures included in other approaches, including traditional approaches, and are therefore not considered exclusive to therapeutic assessment. Each of the six phases of therapeutic assessment are discussed, with reference to the assessment literature and the findings from the current study. This section concludes with a discussion on the working alliance and the assessment of ADHD.

Initial Phase: Intake

Therapeutic assessment stresses the importance of the first contact between parents and psychologists, which includes the standard intake meeting. During this time, informed consent is reviewed, parents are given information regarding the assessment process, and they have the opportunity to ask questions. Additionally, parents are invited to define the goals for the assessment and to formulate the questions they would like to have answered (e.g., “Why does my son have difficulties following through with instructions?” and “Why does he have problems concentrating in school?”) within the assessment (Fantini et al., 2013; Tharinger et al., 2007). Parents are also invited to collaborate in developing the assessment plan (Finn, 2012).

Asking parents about their goals for the assessment is central to the beginning stages of most assessment approaches for ADHD, including the traditional assessment approach. Barkley and Mash (2007) highlighted the need to obtain parent input regarding the goals of their child’s assessment to ensure that the results of the assessment are connected to parent concerns. As such, the psychologist collects background information relevant to the assessment questions and goals parents have identified. Focusing on the parents’ assessment questions and goals helps the psychologist to actively engage parents in the assessment from the very start of the assessment, while also developing the working alliance (Barkley & Mash, 2007; Fantini et al., 2013).

In addition to the physical activities within the initial phase, as outlined above, therapeutic assessment emphasizes the importance of the working alliance, emphasizing the need for psychologists to demonstrate emotional attunement (Finn, 2012) and respect for the parents’ expertise about their child and family (Fantini et al., 2013). In general, there is a need for professionals to establish a positive relationship in the early stages of their work with clients to promote collaboration and positive experiences (Martin, Garske & Davis, 2000).

Similarly, the parents from the current study identified the importance of establishing the working alliance in the initial phase of assessment to promote ongoing collaboration throughout the assessment. Parents reported that they would have better understood the assessment process had their psychologists engaged them from the start of the assessment. They also would have been better prepared in the sessions (e.g., able to provide more detailed background history) had they known what to expect, which is similar to parents' reports from other studies (e.g., Bennett-Levy et al., 1994; Braiden et al., 2010). Better parent preparation is important because it helps to elicit accurate and detailed information from parents, which is critical to a valid diagnosis of ADHD (Barkley & Mash, 2007; Bennett-Levy et al., 1994). Furthermore, better preparation helps to relieve the levels of anxiety many parents experience coming into the assessment (Bennett-Levy et al., 1994; Webster, 1992). Stories from some of the parents who participated in the current study supported this assertion, sharing that their and their child's anxiety increased due to not knowing what to expect in the assessment process.

Second Phase: Standardized testing

The second phase of therapeutic assessment, like the traditional approach, is the formal testing portion of the assessment process, in which standardized tests are used to address the presenting concerns. Each session within the therapeutic assessment approach involve consultations with parents and child before the session to prepare them for what to expect within that session. Psychologists then also debrief parents after the session to discuss what occurred in the session. In the current study, parents reported that their psychologist did not consult with them before or debrief with them after any of the testing sessions, though they all admitted to wanting to know more about what their son had done and how he did. Some parents noted that having more information was to satisfy their own curiosity, but others acknowledged that more information would have helped them better understand the final results from the assessment.

Assessment tools used in therapeutic assessment may include self-report and performance-based instruments to address the parents' assessment questions, as is done in traditional approaches. These tests are initially administered following standardized procedures. However, once formal testing is done, psychologists using a therapeutic assessment approach routinely engage in an extended inquiry, in which they invite parents and children to reflect on their responses and experiences of the tests (Finn, 2007; Smith et al., 2010; Tharinger et al., 2007; Tharinger et al., 2012). Intervention breaks may be included within the testing session as well (Fischer, 2010). For instance, if a child is nervous, he or she may be given the opportunity to try the items again (or similar items) after utilizing relaxation or cognitive reframing techniques.

These consultations and extended inquiries were missing, but crucially needed, based on the responses from the parents in the current study. In this regard, some of the parents in the current study indicated that they did not know how to respond to certain items on the rating scales and had wanted to offer clarification about why they responded to those items the way they did. However, parents were not given the opportunity to provide qualitative information about the rating scales, such as why they answered certain items the way they did or what their experience was like completing the rating scales. Some of the parents reported that their psychologist focused instead on the test scores, thereby failing to understand the child in a broader context.

Failing to engage in extended inquiry (e.g., following up with parents after they completed the rating scales) was particularly problematic in a couple of instances for parents from this study. For instance, a few parents discussed how their psychologists made seemingly faulty conclusions about their child based on the scores derived from the rating scales. The psychologists did not follow-up with parents about their responses, again failing to consider the context from which those scores came. Thus, in each of these instances, the psychologist based their final assumptions about the child on the scores they obtained from their assessment instruments. Parents stated that the psychologists then identified their child with a label that did not fit the parents' understanding of their child. One parent shared that she completed a rating scale that asked her numerous questions about her son's behaviours. Although she has never had any concerns regarding his behaviour, the scores supported a diagnosis of a behaviour disorder, which she disagreed with. She had tried to explain her position with the psychologist, though her perspective was dismissed and the label remained.

Another area psychologists could have followed up with the parents from this study was to ask parents how they thought their child would perform. A few parents noted that their sons were either tired and hungry or anxious during the assessment, which likely affected their attention and subsequent performance. However, their psychologists apparently overlooked these facts and interpreted the scores without considering the possibility of error due to tiredness and hunger or anxiety. Taken together, parents from this study shared several problematic issues within the assessment and identified the need for more collaboration and in-depth conversations with their psychologists to help psychologists obtain as full understanding an of the child as possible, beyond clinical walls and assessment scores.

Another common practice in therapeutic assessment is giving parents the opportunity to observe their child within the testing sessions and then share their observations with the psychologist at the end of the session. This type of experience offers the parents the opportunity to be an active part of the assessment process, and undertake the role of co-assessor by offering observations and interpretations of their child's performance from their observations (Fantini et al., 2013; Tharinger et al., 2012). This opportunity can also facilitate the extended inquiry phase, as discussed above. Having the opportunity to observe their child is often very informative for parents; indeed, parents from other studies have reported that observing their child within the assessment was one of the most important and beneficial parts of the assessment that helped them to gain a new understanding of their child (e.g., Fantini et al., 2013; Tharinger et al., 2007; Tharinger et al., 2009). One mother from the current study had the opportunity to observe her child in the assessment process and reported similar experiences; that is, observing her son participating in the assessment helped her develop a better understanding of her child and the results of the assessment. However, this opportunity was missing in the experiences of the rest of the parents in the current study because none of them were provided the opportunity to observe their child's assessment. In one case, a mother reported that she had asked to observe the assessment, but was denied the opportunity. Notably, many psychological tests are standardized; as such, parents are often not allowed in the room to control for extraneous variables that may affect the child's performance (Weiss, Saklofske, Holdnak, & Prifitera, 2015). However, there are other ways to involve parents in the assessment, such as allowing parents to observe behind a mirror when appropriate (e.g., Tharinger et al., 2012). Regardless, for the most part, the parents in the current study reported that they had no role in the assessment process, other than delivering their child for the assessment and giving information to the psychologist.

Given the limited level of participation parents in the current study had in their son's assessment, the parents admitted to feeling left in the dark, unsure of what was happening in the assessment sessions. These stories are similar to those reported in the literature. For instance, in their exploration of parents' experiences of the assessment process that resulted in their child's diagnosis of autism, Braiden and colleagues (2010) found that the parents also felt left in the dark about what was going on in the assessment. There was inadequate communication with the assessors involved, and parents were left with increased levels of stress and anxiety in the face of a “daunting and difficult-to-understand process” (p. 385). In general, parents shared negative experiences and feelings of upset when they were unsure of what was happening within the assessment (Mulligan et al., 2012). Conversely, parents reported positive experiences when their clinician made time for the family throughout the assessment (Hilton et al., 2012), which paralleled the experiences of some parents in the current study.

Third Phase: Intervention sessions

The third phase of the therapeutic assessment approach is the assessment intervention session(s), which is not typically included in traditional assessments (Finn & Tonsager, 2007; Fischer, 2000). Here, there is an additional extension of the assessment process away from standardized procedures to test hypotheses derived from the assessment results, to gain a deeper understanding of the child and his/her family, and to promote change as part of the assessment process, rather than waiting until the end (Fantini et al., 2013). A variety of tools may be used in this phase, whether standardized tests used in novel ways, or more non-standardized tests and techniques such as role playing or drawing. Through this process, parents are actively engaged with their child and psychologist and the psychologist has the opportunity to observe the child in the family context (Tharinger, Finn, Austin et al., 2008).

This process of better understanding the child and the family context may have been valuable for many parents in the current study by addressing their concerns that their psychologist failed to understand the entire context of their child, of his environment, and of his family; all which are important aspects of who the child is and how he functions. As such, moving beyond the standard battery of testing and engaging with the child and family in a new way may help both psychologists and parents to consider the child within the family and other contexts, thus creating a deeper, richer understanding of the child. Including an intervention session as part of their assessment experience may have helped to alleviate some of the concerns parents from this study raised. For instance, some parents stated that their psychologist only saw a snapshot of their child within a very structured, clinical setting and express doubt about how the psychologist could make any conclusions without having a more comprehensive understanding about the child.

Taking the time to obtain a comprehensive understanding of the child and his or her context is supported within the literature. Some parents have reported that they believe that snap judgments were made about their child when they perceived that the assessor failed to collect enough information and/or did not have a complete understanding of their child's difficulties (Braiden et al., 2010; Concannon & Tang, 2005). On the other hand, other parents have reported positive comments about the assessment when they believed their child's assessment was comprehensive and individualized (Hackett et al., 2009). These findings relate to parent reports in the current study in that parents doubted their psychologists' final results when they believed the psychologist failed to fully understand their child. In contrast, other parents expressed confidence in the assessment results and positive experiences about the assessment process when they believed the psychologist conducted a comprehensive assessment that directly addressed their child's needs.

With the inclusion of the intervention sessions, therapeutic assessment may offer psychologists the opportunity to observe the child in different contexts. However, this step may also give psychologists the opportunity to help foster positive relationships between parents and their child, and parents the opportunity to engage with their child in new ways (Tharinger, Finn, Austin et al., 2008). Finn (2007) noted that this intervention session allows clients the opportunity to edit the narratives they have about themselves, others, and/or their world. As discussed in greater detail later, helping parents revise how they view their child was also an important outcome for parents in the current study because it helped them change how they responded to their son, thus positively affecting the family dynamics.

Finally, the intervention session also may also provide psychologists and parents the opportunity to engage in intervention planning and to test possible interventions that may be feasible for the family to support their child (Smith et al., 2009). This session may be important for parents because every parent in the present study indicated that receiving support was the primary reason they chose to have an assessment done for their son in the first place.

Fourth Phase: Summary and Discussion Sessions

The fourth phase of therapeutic assessment includes the summary and discussion session(s). The summary session is typically organized in response to the parents’ assessment questions. Because parents are actively involved throughout the therapeutic assessment process, the discussion session is essentially a way to organize and clarify what was already discussed with, and experienced by, the parents. Given their active involvement in the assessment process, parents may be invited to answer the assessment questions themselves before the psychologist shares the results (Smith et al., 2009). The results of the assessment are discussed collaboratively with parents and they are encouraged to reflect on the accuracy of the results from their perception. As such, the scores from assessment tools are not yet presented in this phase as definitive conclusions; rather, they are used to initiate an in-depth co-investigation of what is happening for the child and family, thus respecting parents’ expertise. The results are thus considered hypotheses for parents to consider in making sense of what is going on for them and their children, rather than held as “hard truths” about the child (Smith et al., 2009).

None of the parents in the current study had the opportunity to engage in this collaborative sharing of results. Rather, their feedback sessions more closely resembled those of the traditional approach, in which the psychologist takes the role of the knowledge bearer and parents take the role of knowledge receivers (Finn & Tonsager, 1997; Tharinger et al., 2008). Unfortunately, most parents in this study were not given the opportunity to reflect on the results of their son's assessment. One parent shared how she attempted to discuss the perceived mismatch between the results and what she knew about her child; however, her attempt was dismissed and the scores from the tests were upheld as "truth." Other parents in this study also noted perceived mismatches, or stark inaccuracies with their child's results, but again were not afforded the opportunity to offer clarification. As a result, these parents left the assessment feeling frustrated and even defeated.

The summary sessions used within therapeutic assessments are considered less anxiety-provoking for parents because they were involved throughout the entire assessment, they already had opportunities to discuss their child's performance, and they experienced the findings firsthand (Smith et al., 2009). Psychologists also often address any worries parents may have before engaging in the summary discussion to further minimize their anxiety. This last point, in which psychologists address parent anxiety, was one that a few parents in the current study noted as well. Two parents shared that their psychologist explicitly acknowledged their fears and anxiety coming into the feedback meeting. In doing so, their psychologists demonstrated empathy, thus promoting the working relationship, which helped to minimize the parents' anxiety. The parents indicated that they were thus better able to attend to, and more willing to accept, what the psychologist had to say. Conversely, other parents shared that their psychologists jumped right into the results, failing to consider the fact that they were dealing with emotionally fragile families. Consequently, parents indicated that the psychologist "ploughed through the results," unaware (or at least failing to acknowledge) that parents had difficulty following along with the discussion because they were caught up in emotional turmoil. One parent shared a vivid example in which she was so focused on trying to maintain a brave face that she did not stop the psychologist to get clarification about what she was saying.

Parents from the current study also had difficulty following along with the results, feeling overwhelmed given the amount of information their psychologist provided in both the final meeting and the report, a finding corroborated by other researchers (Braiden et al., 2010; Cottrell & Summers, 1990; Mulligan et al., 2012). To address this difficulty, parents from the current study expressed the need for follow-up sessions to review the results to better understand the results. Parents from other studies have similarly requested follow-up meetings so that they could have more time to ask questions and develop a more complete understanding of their child's needs (e.g., Cottrell & Summers, 1990; Mulligan et al., 2012).

The complexity of the information given to parents in this study was also problematic. Although the literature points to the need for psychologists to clearly explain assessment results using everyday language to aid in parent understanding of the results (e.g., Brenner, 2003; CPA, 2007; Sandoval & Irvin, 1990), it was evident that none of the parents from the present study clearly understood all of the results or what the results meant for their child. These parents noted that the information they were given was too clinically oriented, which made it difficult to understand. Unfortunately, parents who receive vague and/or difficult to understand information are often left unsure of how the assessment results relate to the difficulties their child was having (e.g., Braiden et al., 2010; Mansell & Morris, 2004), what their child's needs are, and how to best support their child (Boström et al., 2009; Hackett et al., 2009; Keenan et al., 2010) – all of which was true for the parents of this study. As a result, these parents were left perplexed, turning to things like the internet to try to decipher the information.

An important goal of the traditional assessment model is to facilitate communication between professionals (Finn, Fischer, & Handler, 2012; Finn & Tonsager, 1997). Within this approach, the psychologist typically focuses on the scores of the assessments to help make nomothetic comparisons to make diagnostic decisions by which other professionals can understand the individual. In general, the results are unilateral and interpreted deductively (Finn & Tonsager, 1997), then presented to parents. Although the information may be useful for other professionals, as evident within the current study, this information is overly clinical and difficult for parents to understand. One parent from the current study noted, “You can’t tease the human out of the scores.” Unsure of what the results of the assessment meant for their child, many parents from the current study were left feeling isolated, faced with the daunting task of making sense of the results and managing their son in his day-to-day life.

However, using collaborative techniques such as the ones used in the therapeutic assessment approach, psychologists may have the opportunity to use the results from the assessment to initiate a dialogue with parents about how the child performed on the standardized tests and to relate that performance to everyday situations. This process may help psychologists gain additional information about the child and his or her context and may also help to promote their empathy and understanding of the child and the family’s lived experiences (Finn & Tonsager, 1997). Psychologists often interpret the assessment results using both a nomothetic and idiographic perspective, offering a broad and rich understanding of the child. Interpreting results in this way is congruent with earlier work done by researchers such as Allport (1929), who highlighted the point that, “If psychology is to remain faithful to its natural subject matter (human nature) it must consider the individual manifestations of that subject matter (the single personality) as well as general manifestations (laws of human behavior)" (p. 25). Parents from the current study also recommended the need for psychologists to understand their child and his entire context in light of the results from the assessment. For instance, some children may have difficulty controlling their frustration when they are tired or hungry, but otherwise exhibit adequate frustration tolerance. Obtaining information about the function of behaviours and the circumstances around those behaviours may help psychologists to develop a better understanding of the nature of the difficulties the child is having.

Researchers have stressed that information communicated to parents should be clear, relevant, and specific to the child (Giannoulis et al., 2004; Hackett et al., 2009), and that it should include information useful to them, incorporating clear and specific recommendations (Bennett-Levy et al., 1994; Braiden et al., 2010; Hilton et al., 2012). Taanila and colleagues (2002) noted that parents who received specific information regarding their child's diagnosis and who were offered follow-up supports could effectively cope with the diagnosis and establish realistic expectations for their child. Conversely, when parents were provided inadequate information about their child's diagnosis and/or how to proceed once the diagnosis was given, parents expressed negative experiences of the assessment (Hackett et al., 2009; Keenan et al., 2010) and remained uncertain about what their child's needs were (Boström, et al., 2009).

Unfortunately, the parents in the current study did not understand the results and did not know how to proceed after the assessment was done. By using collaborative techniques, psychologists may help to facilitate parent understanding of the results by going beyond simply communicating the results. They can share information that is communicated in a way that is heard, understood, taken in, and applicable to parents by inviting them to actively participate in a reflective process to develop a meaningful understanding of what the assessment results mean for their child and for their family (Finn & Tonsager, 1997; Tharinger, Finn, Hersh et al., 2008).

This process should be part of any assessment; as Levant (2005) noted, “Clinical decisions should be made in collaboration with the [client], based on the best clinically relevant evidence” (p. 18). As an example, psychologists practicing from a therapeutic assessment approach may share what the test scores are believed to mean based on the normative data and research, while inviting parents to reflect on the results and identify how they may connect with real life examples (Fantini et al., 2013). In doing so, parents can play a critical role in helping the psychologist better understand how assessment results apply to the child and his/her family in their everyday routines, which can also inform treatment. Together, the psychologist and parents discuss the answers to the parents’ questions in mutually understood ways. Through this process, the assessment results can be individualized for each family. There is also an opportunity for the psychologist to balance research evidence with their empathetic understanding of the child and his/her family, which can further support the working alliance (Tharinger et al., 2007).

Furthermore, parents may also gain new experiences and/or new information about their child and family to promote positive change (Aschieri et al., 2013; Fantini et al., 2012; Finn & Tonsager, 1997). To meet this end, psychologists can work closely with parents in an attempt to help parents develop new insights and understandings of their child throughout the entire assessment process. Additionally, psychologists are encouraged to maintain sensitivity, attentiveness, and responsiveness to parent needs throughout the assessment to maintain the working alliance to facilitate those opportunities for growth.

This process of exploring the results with parents in their everyday lives was missing in the parents’ experiences within the context of this study. However, it appears that this extended step may have addressed some of the concerns parents brought up in the present study. For instance, if parents had worked collaboratively with their psychologist throughout the assessment, they may have had the opportunity to address the perceived mismatches they saw in their son’s assessment. However, parents from this study shared instances of being stripped of their parental expertise and remained passive participants in the assessment. Relatedly, researchers have suggested that parents are generally unsatisfied with their child’s assessment when their expertise about their child was disregarded and when professionals take up that expert role (Keenan et al., 2010). Some of the parents from the current study shared similar sentiments.

Many of the parents of the current study may have left the assessment with better and more meaningful understandings of their son had they participated in the type of collaborative process described above, particularly by discussing how the assessment results manifests to everyday experiences (Tharinger et al., 2007; Smith et al., 2010). With such understandings, parents are in a position to better understand their child’s needs, to create a new story about their child and his or her difficulties, while feeling empowered to take steps needed to respond effectively to their child and manage his/her presenting difficulties (Aschieri et al., 2013; Smith et al., 2010; Tharinger et al., 2007; Tharinger et al., 2009). Although many parents in the current study failed to understand the information presented in the feedback meeting, some acknowledged that, when the psychologist took the time to explain the results of the assessment, they could understand their son and the root of his difficulties. With a newfound understanding of their son’s difficulties, these parents could change how they typically understood and reacted to their son’s problematic behaviours, such as by demonstrating greater patience, which promoted more positive outcomes. For these parents, the assessment process was therapeutic in and of itself, especially when they could transform how they thought about their child and interacted with him. Their experiences are similar to parents in other studies, in which parents could shift how they responded to their child in ways that promoted their child’s adaptive behaviours and emotional well-being (e.g., Aschieri et al., 2013; Smith, 2010; Smith et al., 2010; Tharinger et al., 2009). Taken together, when parents are better able to understand their child, they could take up the results of the assessment in actionable ways, thereby promoting their child’s success and overall family well-being.

Above and beyond the “hows” and the “whats” of disclosing information, the assessor’s manner relative to how they interact with parents in the feedback meeting is important. As Brogan and Knussen (2003) concluded, the final feedback interview “can do much to influence parents’ experience of disclosure; they can ensure that parents feel supported, respected and informed, or, conversely, they can leave parents feeling confused, angry, distressed and humiliated” (p. 44-45). This position is comparable to the results from the current study, because some parents felt supported by their psychologist and others felt attacked and distressed, which is largely influenced by the sympathetic manner of assessors (Cunningham et al., 1984; Mulligan et al., 2012) and how well assessors listen to parents and the level of respect shown towards them (Giannoulis et al., 2004; Hackett et al., 2009), in addition to their level of sensitivity (Quine & Pahl, 1986, Stallard & Lenton, 1992), warmth, friendliness (Jackson et al., 2001), and compassion (Mulligan et al., 2012).

Above all, empathy is considered an important quality psychologists display when communicating a diagnosis to parents (Graungaard & Skov, 2006), which is consistent with the findings of this study. Empathy is an important part of therapeutic assessment, in which psychologists focus on trying to understand the child and parents’ perspectives and help make sense of what is going on for them. Here, psychologists can use the assessment results and parents' experiences to "get in their shoes" (Tharinger et al., 2007, p. 297); a point which proved to be very important for parents from the current study. Indeed, many shared deeply personal and emotional stories about the guilt they experienced throughout the assessment. Unfortunately, some parents often felt like they were on high alert throughout the assessment, "sitting in the hot seat." Some parents explained that their psychologist failed to understand where they were coming from and the difficulties they were experiencing, leaving them in a state of hopelessness. Most parents agreed that they would benefit from having the psychologists put themselves in the shoes of the parent and "being with them, wherever they're at," especially at this point in the assessment when they are learning about their child's difficulties.

Intervention planning. Within the summary session of the therapeutic assessment approach, psychologists work alongside parents to discuss the next steps once the assessment process is completed. Treatment utility and maximizing effective intervention is a key goal for therapeutic assessment (Aschieri et al., 2013; Finn & Tonsager, 1997), so this is an important step in the process. As such, psychologists and parents work collaboratively to develop recommendations based on what will be most effective and feasible for parents (and teachers) to implement (Fantini et al., 2013). The psychologist also explores what support parents need to learn and to carry out the recommendations (Fantini et al., 2013). In this process, parents and psychologists may work together to set up experiments to try different interventions that are most effective in addressing the child's difficulties. These experiments are directly informed by the assessment results.

The process of collaboration in identifying effective recommendations is important because the goal of conducting any assessment is to provide recommendations that parents take up and work on at home and school (Sowerby & Tripp, 2009). Unfortunately, most parents from this study found that the recommendations they were given were unhelpful and lacked ecological validity and feasibility. As such, parents were left unsure of how to support their child at home and school. Not knowing how to move forward was disappointing and a point of significant frustration and upset for parents, because they came to the assessment to explore, to create, and to implement feasible interventions with the psychologist; not to simply receive a label.

The working alliance remains essential within this phase of the assessment within therapeutic assessment. Moreover, the feedback session specifically targets key interventions that make sense for families which, when this occurs, parents are more likely to feel empowered, have decreased feelings of isolation, increased sense of hope, greater understanding, and increased motivation to move to the next steps than those who participate in a traditional model of assessment (e.g., Finn & Butcher, 1991). A few parents in the present study were fortunate enough to have had strong working alliances with their psychologist and left the assessment with hope. However, the rest of the parents did not, despite feeling hopeful coming into the process. Instead of moving ahead as they had hoped, these parents left the assessment with feelings of grief, abandonment, hopelessness, helplessness, and a lack of motivation to do more.

Fifth Phase: Written Summary

Once the discussion session is complete, parents receive a written summary of the assessment results, which includes the answers to their assessment questions that they previously discussed collaboratively with the psychologist. Written feedback often takes the form of a letter to parents, but may also include a formal psychological report they can share with other professionals (Fantini et al., 2013; Tharinger et al., 2007). Psychologists may also provide children themselves with developmentally appropriate feedback, such as a personalized story to describe the results and to share the next steps once the assessment is over (e.g., Tharinger, Finn, Wilkinson, DeHay, Parton et al., 2008).

Again, the purpose of the feedback is to help promote change and growth for families, which is why the information given needs to be understood and accepted by the parents. Similarly, the purpose of the written report is to help parents increase their understanding of their child, to offer recommendations that are easy to understand, and to ultimately improve functioning (Harvey, 2006). Unfortunately, every parent in the study who received written feedback noted that the information they were given was overwhelming in terms of quantity while it also lacked clarity with respect to what the results meant. They were not given the opportunity to further comment, correct, or provide feedback regarding the assessment results. The process of working collaboratively, up to the final report writing and beyond, may have mitigated some parent frustrations, such as having a report that was inaccurate, did not provide a valid reflection of their everyday experiences they have with their son, and/or did not offer useful recommendations.

Many parents from this study also noted that the written report was overly clinical and difficult to read. Although psychological reports should be written in clear, plain language that parents can understand, they are often written at graduate level of literacy and difficult to understand (Harvey, 2006). Wiener and Costaris (2012) offered several suggestions to produce reports that match readers’ skills, such as writing in short sentences, reducing jargon, simplifying vocabulary, providing descriptions of the skills measured, and providing concrete examples of everyday functioning. Parents with weak language or literacy skills could benefit from a simplified summary of the results, which can be presented in bullet form, highlighting the child’s strengths, difficulties, and recommendations (Wiener & Costaris, 2012). As noted elsewhere, recommendations should also be specific, clear, feasible (Wiener & Costaris, 2012), and applicable to the family's needs (Brenner, 2003).

Sixth Phase: Follow-up Sessions

Finally, in the sixth phase of therapeutic assessment, parents have the opportunity to again meet with the psychologist to discuss the assessment and recommendations provided. In addition to eliciting feedback, within this phase, psychologists invite parents to further reflect on the assessment to help consolidate what they have learned from the assessment. Progress is measured and recommendations are reassessed as needed (Finn, 2007).

Offering parents the opportunity to give feedback about the assessment process may be helpful in promoting their positive experiences of the assessment process and their acceptance of the final results (Braiden et al., 2010). This point was true from the perspective of parents in the current study; parents who expressed satisfaction with the assessment process and who accepted their son's diagnosis were those who had the opportunity to meet again with their psychologist and/or received additional support after the assessment was completed. Others, however, who were not afforded these opportunities were left with feelings of frustration and stress. Although every parent agreed that they came to the assessment with the goal to get the appropriate supports to help their son; unfortunately, only a few parents from the current study actually received that support. Some parents shared that their psychologist offered follow-up support (primarily with debriefing the results of the assessment with the school); however, most of the parents in this study indicated that they were at a loss of next steps once the assessment was done. They reported having no follow-up support and left the assessment feeling abandoned. They had a diagnosis, but had no idea how to help their son. As a result, some turned to the internet for support or to other professionals. Others left the assessment feeling exhausted and/or helpless, unable to advocate for their child further and giving up. These parents shared that having the opportunity to have additional follow-up sessions with the psychologist, whether to review the results, or to gain assistance with implementing the suggested recommendations, would have been beneficial.

Working Alliance in Assessment

In general, the working alliance is critical throughout the entire therapeutic assessment process to foster positive change for the child and family (Fantini et al., 2013; Finn & Tonsager, 1997; Tharinger et al., 2007). The importance of the working alliance was supported in the current study, in which parents reported that the relationship they had with their psychologist was crucial throughout the entire assessment process and influenced their experiences. For example, parents who reported that they had a good working alliance with their psychologist felt supported throughout the assessment. They expressed relief at being heard by someone who seemed genuinely interested in helping them and felt comfortable sharing their stories, knowing they were not going to be judged. Other parents emphasized ruptured relationships with their psychologist. In these instances, parents felt judged, unheard, invalidated, and even blamed for their child’s difficulties. Parents also discussed the relationship their son had with the psychologist, again some with positive comments regarding a good rapport versus others who noted that their son felt uncomfortable with the psychologist, which may have affected their contribution to the assessment process.

The relationship between the client and helping professional is not a new focus of research. Indeed, early psychoanalytic theories discussed the value of the therapist first establishing rapport with the client and maintaining genuine interest in, and sympathetic understanding of, the client to establish a positive alliance (Horvath & Luborsky, 1993;

Luborsky, Barber, Siqueland, McLellan, & Woody, 1997). Several professional characteristics are considered important in promoting the working alliance, including genuineness, empathy, and unconditional positive regard (Rogers, 1992), compassion, presence, acceptance, genuine commitment to the client, extending oneself, and being actively engaged (Beck & Butler, 2005; Corey, 2009).

Over the years, the working alliance has been shown to be the single factor, above all others, most strongly and consistently associated with positive outcome for clients within a therapeutic environment (Horvath, 2000; Horvath & Luborsky, 1993; Horvath, Del Re, Fluckiger, & Symonds, 2011; Horvath & Greenberg, 1989; Howard, Krasner & Saunders, 2000; Krupnick et al., 1996; Winston & Winston, 2001). Similarly, researchers have also emphasized the importance of the working alliance with parents with respect to their child’s assessment (e.g., Barkley & Mash, 2007; Brogan & Knussen, 2003; Dreyer et al., 2010). Researchers have noted that, regardless of their child’s diagnosis, parents tend to report positive experiences with the assessment process when they felt respected and listened to by clinicians (Giannoulis et al., 2004; Hackett et al., 2009) and when the clinicians demonstrated compassion, sensitivity, sympathy (Mulligan et al., 2012), and empathy (Graungaard & Skov, 2006). On the other hand, parents tend to report negative experiences with the assessment process when the professionals involved in their child’s assessment present as unsympathetic (Cunningham et al., 1984) and lack sensitivity, empathy (Quine & Pahl, 1986, Stallard & Lenton, 1992), warmth, and friendliness (Jackson et al., 2001). Importantly, developing a working alliance with parents may facilitate parents’ acceptance of their child’s diagnosis (Taylor et al., 2006) and may enhance parent engagement with recommendations and intervention strategies (Bussing & Gary, 2001; Dreyer et al., 2010; McKay et al., 1996; Taylor et al., 2006).

In general, the parents from the current study identified several professional qualities as being important within their child's assessment; empathy, approachability, genuine commitment, and openness. These qualities helped promote a positive working alliance with their psychologist as they proceeded through the assessment process. Parents who were satisfied with the assessment process often gave high praise to their psychologist's level of empathy, caring, respect, and sensitivity. However, other parents reported negative feelings towards the assessment when their psychologist failed to show empathy or sensitivity to the family and when parents felt attacked and not listened to.

It was evident that the working alliance influences parents' experiences of the assessment process, which is supported in the literature. For instance, in their investigation of parents' experiences of receiving their child's diagnosis of ADHD, Concannon and Tang (2005) found that parents reported negative assessment experiences when their assessor failed to establish a working alliance with them. These findings are also commensurate with the findings from the current study. For instance, some parents discussed that their psychologist did not seem committed to, or genuinely interested in, helping the family. In these instances, their psychologists seemed more interested in some other agenda. One parent described the impersonal nature of the relationship she had with the psychologist at the end of the assessment, explaining how she felt that her son and family were just another "run of the mill" family, ultimately insignificant to the psychologist at the end of the day. However, other parents praised their psychologist who exhibited genuine interest in wanting to help the child and family.

In addition to the psychologist's qualities, maintaining a positive and strengths-based approach is important to the working alliance. For instance, Piper and Howlin (1992) reported that parents experienced distress when clinicians made negative comments about their child, even if the clinician demonstrated empathy and sensitivity within the assessment process. Conversely, Mulligan and colleagues (2012) noted that parents expressed positive experiences when clinicians maintained a “hopeful and strengths-based approach” (p. 317) in regards to their child. Similarly, the parents from the current study stressed the importance of highlighting their child’s strengths, rather than focusing on the negatives. One mother from the current study explained how difficult it was to remember her son’s strengths when the psychologist focused so much on all of her son’s deficits. She indicated that she would have appreciated hearing more positive comments about her son from the psychologist. Together, many of the parents from the current study concluded that psychologists need to ensure that they highlight the child’s strengths within the assessment process, rather than focusing solely on the deficits.

Finally, a few parents from the current study recommended that psychologists be direct and transparent in how they share information with parents, by giving clear, straightforward information about their child’s needs. One mother indicated that her psychologist confirmed one way or another that her son had ADHD. However, she had to assume he did because her psychologist later gave a lecture on the need for medications. This failure to be direct and honest thus ruptured her working alliance and left her feeling frustrated at the end of the assessment. Researchers have made similar claims. For instance, Hasnat and Graves (2000) reported that parents expressed positive experiences with the assessment and working alliance when professionals were direct with parents regarding their child’s areas of difficulties and needs. In general, researchers have concluded that parents report negative experiences of the assessment process and working alliance when professionals lack transparency when discussing their child’s results, seemingly suppressing facts and/ or avoiding giving direct and honest information about their child (Cunningham et al., 1984; Hasnat & Graves, 2000; Quine & Pahl, 1986).

Taken together, the parents' stories underscored the importance of the working alliance in their child's assessment for ADHD, particularly in regards to the psychologist's qualities, but also to their professional manner and how they share information with adults. In addition to the professional's personal qualities and manner, the collaborative nature of the relationship is also important for the working alliance (Frieswyk et al., 1986), in which there is a sense of actively working together (Bachelor, 1995).

Collaboration is an essential part of the working alliance and a key aspect of assessment. By maintaining parents' role as "essential collaborators" (Finn & Tonsager, 1997, p. 378) and active participants in the assessment process (e.g., set the goals for the assessment, provide important background and contextual information about their child, interpret their child's performance, reflect on and explore the meaning of the test results, verify the results of the assessment by connecting them with real life examples, co-create recommendations, and review the written feedback), the assessment process is transformed "into a positive discovery experience," (Miller & Hanft, 1997, p. 55).

Although there is mention of the need to work collaboratively with parents within the assessment process in some guidelines (e.g., NICE, 2013), this recommendation is not addressed in all guidelines. Within a traditional assessment approach, collecting valid and reliable data to support assessment results is emphasized over collaboration (Finn & Tonsager, 1997). In this regard, one parent from the current study was explicit that her relationship with her psychologist was overly one-sided, as the psychologist seemed intent on getting the information he needed to support the conclusions he drew from the test data. Although the mother had attempted to collaborate with the psychologist and offer additional information to help him better understand her son, she noted that the psychologist appeared to disregard the information and made his own assumptions based on the test data. Hence, genuineness and collaboration was seemingly lacking in the relationship. Consequently, the mother shared that the psychologist's final clinical formulations were less relevant because they did not reflect her understanding of her child or his underlying difficulties. This mother's experience points to the assertion that "poor relationships and lack of communication between [clinicians] and parents can hamper diagnosis as symptoms are missed" (McLaughlin, 2005, p. 285).

Similar to the story above, collaboration was a key part of the assessment that parents from the current study valued, but that many did not experience. Rather than being essential collaborators and co-assessors, all of the parents in this study shared stories of having a passive role in the assessment, feeling that they were left in the dark about the assessment process. The parents who shared that they did collaborate with their psychologists admitted that the collaboration was limited to asking questions, rather than being actively involved in the assessment.

Finally, when collaboration is maintained, there is a mutual respect in the relationship, thus reducing the power differential between the psychologist and parent. Parents can maintain their expertise about their child (Smith et al., 2009) and are therefore an essential resource for psychologists to learn more about the child and his or her context. Parents can also be important in helping determine next steps once the assessment is completed because they have invaluable insights about what their child and family need. Unfortunately, many of the parents in the present study reported that they did not have this type of collaboration in their child's assessment, that they were not invited to share their expertise, and that the recommendations offered by the psychologists were not appropriate or feasible.

Although many of the parents in the present study did not experience a collaborative relationship throughout the assessment process, they valued collaboration. As discussed throughout this section, maintaining the working alliance and ongoing collaboration throughout the assessment process is important to foster positive experiences, to facilitate parents' acceptance of their child's diagnosis, to promote parent empowerment, and to facilitate parent enactment of recommendations.

Empirical, Clinical, and Practical Implications

This study has several empirical and practical implications. Empirically, this study makes an important contribution to the research in this area by extending our current understanding of parents' experiences to the entire assessment process specific to ADHD. This study offers detailed information regarding a broad range of parent assessment experiences and provides specific recommendations that can be used to inform future assessment practices, as discussed below.

The key findings from the current study suggest that establishing a working alliance and facilitating meaningful change for children with ADHD and their families may promote parents' positive experiences. Therapeutic assessment was presented as one collaborative assessment approach that seems to address many of the topics parents identified in the current study. For instance, psychologists using therapeutic assessment engage parents collaboratively in the assessment process, address parent goals and questions, help parents develop a better understanding of their child, develop a rich understanding of the child and his or her entire family context, and help parents promote positive change for their children and their families. Similarly, other approaches, such as the biopsychosocial model of assessment, also engage parents collaboratively to develop an in-depth understanding of the child in his or her ecological context (Pham, 2015).

In addition to addressing the issues parents discussed in this study, collaborative models of assessment such as therapeutic assessment meet empirically established guidelines for conducting assessments to diagnose ADHD (e.g., maintaining a working alliance and conducting a comprehensive assessment; CAP, 2007; NICE, 2013) and empirically supported approaches to working with families in general (e.g., establishing a collaborative relationship with families and eliciting their active engagement and input from the very first session and throughout service provision; Hoagwood, 2005). Family and contextual aspects important to facilitate change for the child and his or her family are also addressed. Indeed, the therapeutic assessment includes additional procedures to fully understand the child outside of the clinical walls, such as within the family context (Fantini et al., 2013). Researchers have demonstrated that collaborative procedures such as those used in therapeutic assessment can also help improve family cohesion, communication, conflict resolution, and overall social, emotional and behavioural functioning (DuBose, 2002; Michel, 2002; Smith et al., 2010; Tharinger et al., 2009). In their research case study, Tharinger and colleagues (2007) noted that parents reported having developed a better understanding of their child and exhibited an increase in positive feelings and decrease in negative feelings towards their child and an overall positive change in the entire family system after undergoing therapeutic assessment. Similar results were supported elsewhere (e.g., Aschieri et al., 2013; Tharinger & Pilgrim, 2012).

The findings from this study point to a number of important practical implications for the assessment of ADHD. Standardized testing and objectivity is important in maintaining the rigour of assessments (Lilienfeld et al., 2012), but should be balanced with, and can be enhanced by, collaborative procedures that focus on understanding children in their entire context, that address the child and parents' needs, and that respect their expertise in their lives. Indeed, collaborative approaches to assessment are considered complementary to traditional practices and psychologists can "enhance the therapeutic effects of an assessment without compromising in any way the valid and reliable test information that is collected" (Finn & Tonsager, 1997; p. 382) by way of developing guiding questions for assessment alongside parents, explaining the purpose of each test used and the question it will help to answer, including assessment intervention sessions and extended inquiry approaches to explore the preliminary results of the assessment, and engaging in a dialogue with parents about how the test results relate to the child's functioning at home and school.

Collaborative assessment approaches may also offer significant contributions to intervention planning. Having a broad understanding of the child and the specific factors that affect his or her success across environments may help psychologists and parents to identify the specific needs of the child and family, and therefore specific interventions to address those needs (e.g., behaviour management, social skills, social supports, emotion regulation, and parent training) that parents can implement (Pham, 2015).

In addition to the examples presented above, parents from the current study suggested several specific recommendations for psychologists to consider when conducting future ADHD assessments. These specific recommendations are outlined in Table 6 and are also presented in *Appendix H.*

Table 6

Parent-Generated Recommendations for Psychologists

Recommendations	Applications
Use the assessment process to help the child and family	• Provide more than one feedback session. • Offer follow-up sessions to review the results and questions. • Offer intervention sessions to give parents strategies to use with their child. • Implement follow up measures to ensure children and families are well supported. • Identify what types of recommendations and supports will be most useful for the family. • Offer feedback and specific strategies for the school and home. • Offer practical information and goals for the school IPP • Advocate for parents • Connect parents to community resources (e.g., support groups) • Offer packages and resources about ADHD and effective treatment
Look at the whole child	• Identify the child’s strengths. Start with the positives. • Observe and investigate the child’s functioning across contexts (e.g., at home, at school, socially), with different people and in different situations • Collect information from multiple sources of informants including parents and teachers
Look at the entire family	• Include both parents throughout the assessment process • Consider the effect the child’s difficulty has on his sibling(s) • Investigate the effects of the child’s behaviour on the entire family • Investigate parental well-being and skills and resources to cope and manage with their child’s difficulties
Empower parents	• Assess success for families and give them goals they can work towards • Teach parents specific strategies to support their child • Educate parents about the assessment process and collaborate with them throughout

Recommendations	Applications
Empower parents (cont'd)…	• Provide additional information and resources to parents to enhance their preparation for the assessment • Educate parents about medication • Help to promote hope • Coach parents how to advocate effectively for their child
Foster the working alliance	• Educate the child about the assessment process • Have regular check-in's before and after each session with parents • Explain the relevance and rationale for various tests and relate its purpose to the child's situation • Identify what will be most helpful for parents through the assessment process and beyond • Identify what structures need to be in place to increase parent participation and collaboration within the assessment process • Validate parents' experiences • Refer as needed • Respect parents' expertise on their child • Work on reflective listening skills to understand parents' perspectives • Attend to what parents have to say • Demonstrate compassion and empathy • Take the time to allow parents to share their story and journey thus far Acknowledge parents' anxiety coming into the assessment • Understand that it is hard to hear their child's diagnosis and that there is a grief process
Communicate results effectively	• Address parent fears and anxiety at the start of the feedback session • Provide honest, straightforward information • Break the information down • Confirm accuracy of the findings and report with parents • Use clear language that is easy to understand and meaningful to parents • Offer information that is useful for parents • Put recommendations up front in the written feedback • Include practical strategies that are easy and feasible to implement by teachers and parents • Identify what the test results mean for their specific

Recommendations	Applications
Communicate results effectively (cont'd)…	• Identify what the test results mean for their specific child and provide specific examples as to how that manifests at home and in the classroom • Discuss how conclusions/diagnosis was made based on the tests used • Educate parents about "normal" developmental expectations and where their child fits • Check-in with parents to explain what they understand of the information • Explain the root difficulties the child is experiencing to promote parent understanding and shift their understanding of presenting behaviours

These recommendations are presented here as specific ways psychologists can continue to promote this relationship in their current assessment practices to enhance parents' experiences of the process. Although these recommendations and examples of practice are offered, these are not meant to necessarily replace traditional assessment approaches. Rather, they are considered complementary to the established guidelines and evidence-based practices in the assessment of ADHD. Indeed, researchers have acknowledged the importance of individualizing psychological services by understanding the individual within his or her context, as well as promoting the collaborative relationship between the psychologist and client, as part of comprehensive evidence-based psychological practice (Biederman, 2005; Hoagwood, 2005; Levant, 2005; Mental Health Commission of Canada, 2012; NICE, 2013; Sowerby & Tripp, 2009). As such, these recommendations can be incorporated alongside standard psychometric tools that are also essential within the assessment of ADHD that promote the rigour of clinical decision making (Lilienfeld et al., 2012).

It is important to note here that, although there are several benefits to assessment approaches like therapeutic assessment that address parent needs, there are important financial considerations that must be made. Within private practice, taking the time to engage in the additional steps outlined here, such as the additional intervention and follow-up sessions, can be expensive for parents. However, third-party payors often reimburse for assessment approaches, such as the therapeutic assessment presented here (Fischer & Finn, 2008). When they do not, it has been suggested that "clients are willing to dip into savings, pay over time, or borrow money to purchase a service they anticipate as being individualized and therapeutic" (Fischer & Finn, 2008, p. 401). This assertion was supported by the findings from the current study, in which parents reported that they would have paid the extra money to have received a useful assessment report and follow-up sessions with the psychologist. One mother noted that had she engaged in greater collaboration with her psychologist and received additional follow-up sessions she would have ultimately saved thousands of dollars by not needing to go elsewhere for follow-up support.

Ethical Care and Standards of Practice

Ethics is foundational to the practice of psychology (CPA, 2000); thus, psychologists must be aware of their professional and ethical responsibilities and assessments must be consistent with the established principles of ethical practice. Parents from the current study reported a number of questionable behaviours of some psychologists. Therefore, in addition to the recommendations offered from parents above, it is important that psychologists review and practice ethical principles and standards of practice for assessments, such as those delineated by the Canadian Psychological Association (CPA; 2000, 2007) and the College of Alberta Psychologists (CAP, 2000). For instance, when conducting assessments, psychologists must demonstrate respect and dignity to parents and their children (CPA, 2000). Acknowledging and respecting parental expertise and input about their child is important, as is recognizing parents' ability to determine their child's needs and to make decisions for their child (CAP, 2000). Psychologists must ensure that parents fully understand the assessment process, including the purpose of the instruments used (CAP, 2000). Parents should be actively involved in each phase of the assessment, working collaboratively with the psychologist (CAP, 2000). Further, psychologists must communicate the results of the assessment in a way that is understood and meaningful for parents (CAP, 2000). Once assessments are completed, psychologists should ensure that parents are given sufficient information and follow-up support for families, such as helping parents advocate for their child (CAP, 2000).

Importantly, psychologists must practice within their area of competency (CAP, 2000). As such, psychologists must receive adequate training in administering tests, scoring tests, and interpreting test scores in the assessment of ADHD (CPA, 2007). Training should emphasize focus on ethical issues and their application to psychological assessments, standards of practice, and current professional guidelines (e.g., CADDRA, 2011; CAP, 2007; CAP, 2000; CPA, 2000; NICE, 2013). The results of this assessment suggest that it may be beneficial for training programs to also include topics on professionalism, establishing a working alliance, working collaboratively with parents, respecting parental expertise, and communicating effectively and therapeutically with parents.

Parent Input Form

As an extension to this study, the recommendations offered by parents from this study informed the development of a parent input form that psychologists can use in clinical interactions with parents throughout the assessment process (see *Appendix G*). This parent input form can be used to 1) prepare parents for the assessment process, 2) help parents identify information they believe is important for the psychologist to know as they proceed with the assessment, 3) indicate what parents find helpful to learn from the assessment, and 4) facilitate dialogues with parents that facilitate a collaborative working relationship.

Based on the current study’s findings, parents reported that psychologists did not obtain parent input regarding the assessment. However, all agreed doing so is an important part of the assessment, suggesting that a parent input form may be useful as part of the assessment process. This form offers psychologists a way to receive focused parental input before they begin the assessment process and invite parent involvement in the assessment process from the start. Furthermore, the information elicited by this form, and subsequent discussions, can help to clarify how to individualize the assessment process to address parents’ identified needs.

Psychologists can adapt this form to flexibly and feasibly match parents’ needs and the scope of their clinical practice. In its present form, the parent input form includes nine sections. The first section pertains to the purpose of the form and offers an overview of the assessment process. The second section raises questions on how to best prepare parents for the assessment. The third section elicits additional contextual information parents may want to discuss that is not necessarily directly related to their child. This section may help psychologists to ensure that they address parent concerns that may not be a focus of their standard intake questions. The fourth section invites input on the type of information parents want to learn from the assessment about their child. The fifth section focuses on the activities parents want psychologists to engage in that may not be part of a standard assessment, such as conducting a classroom observation or speaking to specific people. The sixth section seeks details on follow-up support parents want to receive once the assessment is completed. The seventh section asks parents how the psychologist can help make the child feel at ease for the assessment. The eighth and ninth sections provides parents opportunities to raise additional questions or comments they have about the assessment process.

The parent input form is meant to be given to parents upon scheduling their child's assessment. Receiving the form before the assessment begins is important because it contains information to help orient parents to the assessment process. Further, by inviting parents to fill out this information before their first visit, they can consider what is important to them and complete the forms with greater reflection and consideration than might be possible if trying to complete it at the office. With more detailed information, psychologists will likely be better prepared to address parents' needs from the very start of the assessment.

Once completed, parents would be asked to bring the form with them to their first intake meeting with the psychologist to enable a collaborative dialogue regarding the information and support sought from the assessment. In establishing a collaborative relationship with parents, psychologists can better ensure that parents' needs, as well as their child's needs, are met throughout the assessment process; such as by reviewing the form before each session to ensure they address the information parents provided. The larger check box beside each section header can be used to indicate that everything within that section has been addressed. Once all sections are completed, parents and psychologists can sign the bottom of the form to confirm that parents' needs were met at the termination of the assessment process.

Limitations of the Current Study

As with any qualitative study, a major limitation of the current study is the small sample size; thus, generalizations of findings from this study need to be tentative. This study only included boys for ADHD assessment who were diagnosed within the elementary school years; hence, the results of this study can only be considered within this context. Taken together, the results may not be indicative of all parents' experiences of the assessment process with respect to ADHD assessment and does not generalize to other parents outside of the context of this study, such as those in other geographic locations, those who have daughters diagnosed with ADHD, or those who had a medical doctor diagnose their child. Furthermore, the sample was homogeneous with regards to ethnic, linguistic, and cultural diversity; as such, these results may not apply to parents of different backgrounds. This study focused exclusively on parents' experiences of the assessment process conducted by a psychologist working in private practice; as such, parents may have different experiences if their child is diagnosed elsewhere, such as by their family doctor or in the school setting. Additionally, the focus of this study was on parents' experiences of the assessment process, rather than the child's. As such, little is known about children's perspectives and their thoughts on promoting positive assessment practices.

Notably, the self-selecting parents who volunteered wanted to share their experiences; thus, parents who were less ready to discuss their assessment journey may not be represented. It is impossible to determine if the data from this study reflects typical experiences for parents, generally; however, the parents shared a detailed and diverse range of experiences, which helped provide rich insight into a broad range of experiences parents have had.

Another limitation is potential response bias. Although I took the steps to develop rapport and ensure anonymity, and all the parents seemed relaxed and comfortable talking, it is possible that they were unwilling to divulge personal information on certain topics. The interpretative analysis of the data was necessarily subjective in nature, despite consultations with other researchers including my supervisors and supervisory committee, to justify my analysis and thematic framework. Additionally, parents also offered feedback on the presented thematic framework, suggesting that my analysis reflected their experiences.

Ultimately, there was an empirical need for an exploratory investigation into parents' experiences to develop rich insights about their experiences. Despite these limitations, this study extends the literature while highlighting practical implications for future research.

Future Directions for Research

Replication studies would possibly further validate the findings from this study. Conducting a quantitative analysis using a larger sample is implicated to offer a wider scope of understanding. Moreover, including parents who received assessments from various agencies, such as schools or community health programs would also help expand our understanding of parents' experiences depending on the types of assessments they receive.

Given that the parents in this study received their son's diagnosis when their son was in elementary school, future research could extend the findings of this study to investigate the assessment experiences of parents whose son was diagnosed before the school-aged years. Although ADHD is most frequently diagnosed in elementary aged-children, there is evidence to suggest that children as young as three-years-old demonstrate symptoms consistent with ADHD (Connor, 2002; Greenhill, Posner, Vaughan, & Kratochvill, 2008). However, the validity of ADHD diagnosis in preschool children has been questioned, with controversies pointing to developmental considerations (e.g., ADHD symptoms may represent an extreme end of normal development; Keenan & Wakschlag, 2002). Understanding parents' perceptions of the assessment process of their preschool child who receives a diagnosis for ADHD may have important implications, such as providing additional information to parents about ADHD and developmental expectations for their child.

Similarly, parents' experiences of the assessment process that resulted in their daughter's diagnosis of ADHD would also be valuable. Girls with ADHD are thought to be under-identified

(Bruchmüller, Margraf, & Schneider, 2012; Gaub & Carlson, 1997; Gershon, 2002); because they typically present differently than boys (Biederman et al., 2002; Levy, Hay, Bennett, & McStephen, 2005). Furthermore, parents of boys with ADHD often have different ideas of ADHD etiology (e.g., genetics versus life events) than parents of girls with ADHD (Bussing & Gary, 2001), extending to different expectations, by gender, of their child's behaviour (Bussing, 2001). As such, understanding parents' experiences of their daughter's assessment would be helpful to inform assessment practices that would best address their needs.

Extending the focus to other communities in Canada and engaging in cross-cultural studies would also help broaden our understanding of parents' experiences of the assessment process across cultures. Although ADHD is recognized across the globe, the conceptualizations of ADHD vary greatly across cultures for numerous reasons, such as sociocultural factors, differing perceptions of human development, and different learning environments (Bird, 1996; Bussing, Koro-Ljungberg, Gary, Mason, & Garvan, 2005; Hervey-Jumper, Douyon, Falcone, & Franco, 2008; Vance & Luk, 2000). Parents from different ethnic and cultural groups often have different explanations of their child's symptoms related to ADHD (Bussing, Zima, Gary& Garvan, 2003; Lawton, Gerdes, Haack, & Schneider, 2014); thus, understanding their experiences of the assessment process is important to promote family-centred assessment practices that address the cultural variations in understanding ADHD, preferred interventions, and desired outcomes.

The findings from this study focused on the experiences of primary caregivers; however, future research could extend these findings into an investigation of experiences of both mothers and fathers. A few mothers had noted that their husband's experience of the assessment was very different because they were not as involved in the process; thus, understanding what the other parents' experiences can be valuable to deepen our understanding of how to proceed with assessment practices. More research is also needed on the child's experience of the assessment process, as he/she is an integral component of the process.

Many of the findings of this study suggested that a collaborative approach to ADHD assessments may be beneficial for parents to promote the working alliance and address parents' needs. Furthermore, collaboration is important to promote parents' adaptive coping with their child's diagnosis (Taanila et al., 2002), parents' acceptance of their child's diagnosis (Braiden et al., 2010), and parents' engagement in their child's subsequent treatment (Dreyer et al., 2010; Fantini et al., 2013). Although researchers have demonstrated the efficacy of collaborative assessment approaches across a diverse range of populations (e.g., Fantini et al., 2013; Finn et al., 2012; Gart et al., 2016; Norman & Breitborde, 2014; Poston & Hanson, 2010; Smith et al., 2010; Stewart, 2013; Tiegreen et al., 2012; Tharinger et al., 2012; Tharinger et al., 2007), further research is needed to determine its efficacy for the assessment of ADHD specifically.

Finally, as an extension of this study, a parent input form was developed to mobilize the information gleaned from this study. Although it is flexible and meant to facilitate collaboration between parents and psychologists, future research would be valuable to determine whether this form is clinically useful and/or feasible. A standardized tool may be developed as well, based on larger scale studies investigating parents' experiences, in a way that may be generalized to a wider scope of parents.

Conclusion

"After the [assessment] process is complete, that should not be a period. It should be a comma…; that's not the end" (MTNI).

This study offered detailed accounts from the experiences of parents whose son was diagnosed with ADHD. The results from this study extend the literature by offering rich understandings of parents’ experiences with respect to the entire assessment process that was conducted by a psychologist in private practice. A major goal in collecting parent feedback is to better understand and enhance person-centred assessment practices by focusing on what is important for parents. There were five discernible themes that resulted from the data analysis of the parent interviews, with three key findings informing assessment practices that promote parent satisfaction with the services provided, and enhance positive outcomes for the child and family. Specifically, needs were identified to (a) develop a working alliance with parents (e.g., empathy and collaboration), (b) communicate information to parents regarding their child in a way that is meaningful to parents, and (c) provide appropriate support to parents to help their child.

The information gained from this study can help inform future assessment practices and illuminated the need for psychologists to reflect on how they conduct assessments for ADHD and how they may be able to enhance their current practices to promote their working alliance with parents. Additionally, all parents from this study agreed that they came to the assessment for support and intervention, which should be at the forefront of the process to promote the well-being and success of the child and the entire family. MTNI’s quote above reflected this sentiment, emphasizing that the assessment is just the first step to help support the family.

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Appendix A

Telephone Screening Questionnaire

Is your child a boy or girl?

What is your son's date of birth? Age:

Are you the primary caregiver?

Do you speak English fluently?

Does your son have a diagnosis?

If so, what is the diagnosis?

When was he diagnosed?

By whom? Pediatrician/family doctor

Psychiatrist

Psychologist:

In private practice

At the child's school

Other: __________________________

Other: ________________________________

Appendix B

Parent Demographic Questionnaire

Family Information

Child's name: ____ Date of birth: ____________

Primary caregiver's name: ______________________________ Age: ___________________

Relationship status (please circle):

Single Married/common-law Partnered

Separated Divorced Other: ________________

Occupation: ____

Highest level of education (please circle):

Graduate degree Undergraduate degree College Diploma

High School Diploma Some High School Elementary School

Ethnicity: ____

Caregiver #2 name: _________________________________ Age: ____________

Relationship status (please circle):

Single Married/common-law Partnered

Separated Divorced Other: ________________

Occupation: ____

Highest level of education (please circle):

Graduate degree Undergraduate degree College Diploma

High School Diploma Some High School Elementary School

Ethnicity: ____

Other important family members (e.g., stepparents, siblings):

Age: _____ Sex: _____ Relationship to the child: _______________ Lives at home? _____

Age: _____ Sex: _____ Relationship to the child: _______________ Lives at home? _____

Age: _____ Sex: _____ Relationship to the child: _______________ Lives at home? _____

Age: _____ Sex: _____ Relationship to the child: _______________ Lives at home? _____

Has anyone in the child's immediate family (i.e., biological parents and siblings) experienced:

ADHD Yes No If yes, who?

____

Learning Disability Yes No If yes, who?

____

Oppositional Defiant Disorder Yes No If yes, who?

____

Conduct Disorder Yes No If yes, who?

____

Depression Yes No If yes, who?

____

Anxiety Yes No If yes, who?

____

Substance or alcohol abuse Yes No If yes, who?

____

Autism Yes No If yes, who?

____

Other Yes No Please specify:

____

Please identify what best describes your child:

a) Lives with both parents in one home
b) Lives with one parent full-time
c) Lives with both parents part-time
d) Lives primarily with one parent but sees the other parent
e) Other (please describe):____

How long has this living arrangement been in place?

____

Which best describes your current yearly household income (please circle)?

0-$20,000 $21,000-$40,000 $41,000-60,000 $61,000-$80,000 $80,000+

Child Information

Has your child received an ADHD diagnosis? Yes No

If yes, when? ___________________

By whom? Pediatrician/family doctor

Psychiatrist

Psychologist:

In private practice

At the child's school

Other: _______________

Other: ______________________

Were you referred, or did you seek a diagnosis on your own? ____________________________

Has your child received any other mental health or learning diagnoses (e.g., learning disability, anxiety, autism, oppositional defiant disorder)? Yes No

If yes, please list diagnoses: ____________________________

When? ___________________

By whom?

Pediatrician/family doctor

Psychiatrist

Psychologist:

In private practice

At the child's school

Other: _______________

Other: ______________________

Has your child ever received a psychological assessment? Yes No

If yes, when? ___________________________________

For what purpose? ________________________________

Appendix C

Participant Consent Form

Name of Researcher, Faculty, Department, Telephone & Email:

Caroline Buzanko, M.C., Educational Studies in Psychology, Faculty of Education, 403-650-1616, cebuzank@ucalgary.ca

Supervisors:
Dr. Tom Strong and Dr. Jac Andrews

Title of Project:
Parents' Lived Experiences of the Assessment Process that Resulted in their Child's Diagnosis of Attention Deficit/Hyperactivity Disorder

Sponsor:
SSHRC

This consent form, a copy of which has been given to you, is only part of the process of informed consent. If you want more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The University of Calgary Conjoint Faculties Research Ethics Board has approved this research study.

Purpose of the Study

Your interest in this research is greatly appreciated. The purpose of this study is to understand parents' experiences of the assessment process that resulted in their child's diagnosis of ADHD. If you choose to participate, your contribution will be a highly valued component in providing a framework for potential improvements in how assessments are conducted.

What Will I Be Asked To Do?

If interested in participating, you have the opportunity to participate in two stages of this research. In the first stage, you will be asked to take part in one interview regarding your experiences of the assessment process that resulted in your child's diagnosis of ADHD. All interviews will be conducted by the primary researcher, Caroline Buzanko. Each interview will take approximately 60-90 minutes and will be audio taped. You are free to not answer any question during the interviews and you may choose to withdraw from the project at any time, though any data you provided up until that time will be retained for the inclusion of this study.

If interested in also participating in the second stage of this study, you will have the opportunity to partake in the development of a parent input form that may be used in clinical practice. In particular, you will receive a draft copy of potential items to include in the form via email or mail. Once you have reviewed the items, you will have the opportunity to provide written or verbal feedback regarding the form (e.g., its helpfulness, its relevance and its utility). This follow-up process is completely voluntary. You may decline responding to any and all questions and you may choose to withdraw at any time without penalty. Any data you provided up until that time will be destroyed.

What Type of Personal Information Will Be Collected?

Should you agree to participate, you will be asked to provide general demographic information (e.g., gender, age, educational level, income and family structure), in addition to information regarding your son's diagnosis (e.g., whether the diagnosis was given by a registered psychologist and when). As part of the project, you will also be asked to provide a description of your experiences of your child's assessment process. All information will be kept anonymous. Confidentiality will also be maintained, except in specific circumstances, as described below. Your name will not appear in any transcript or report of the results. A pseudonym will be used in all records.

There are several options for you to consider if you decide to take part in this research. You can choose all, some, or none of them. Please review each of these options and choose Yes or No:

I wish to remain anonymous: Yes: ___ No: ___
I wish to remain anonymous, but you may refer to me by a pseudonym: Yes: ___ No: ___
The pseudonym I choose for myself is: ____
I agree to participate in the second (feedback) stage of this study: Yes: ___ No: ___

Are there Risks or Benefits if I Participate?

Talking about your experiences of your child's assessment process may be upsetting for some parents. If you experience distress as a result of your participation under this study please contact Caroline Buzanko at (403) 650-1616; your primary therapist (if you have one), or the 24-hour Distress Centre at (403) 266-1605.

Benefits of taking part in this study include having the opportunity to share your experiences and have your voice heard on an important topic. It is also expected that the information collected from this study will provide us with a better understanding of parents' experiences of the assessment process investigating symptoms of ADHD, thereby contributing to a unique area of research as well as to possibly benefiting other parents and informing future assessment practices. Overall, we expect that results of this study will be helpful for researchers, professionals, and parents interested in the assessment of ADHD.

As compensation for your participation, you will receive a $25 gift card for a family-appropriate vendor of their choice (e.g., movie theatre, Chapters, restaurant) at the end of your interview. We thank you very much in advance for your help in furthering this research.

What Happens to the Information I Provide?

Your participation is completely voluntary, anonymous and confidential. You are free to discontinue your participation at any time and any information you provided up until the time of your withdrawal will be destroyed. If you choose to participate, the pseudonym you indicated above will be used in the transcripts and final draft. The only people with access to interview tapes and transcripts include the primary researcher, her supervisors, and a third party hired to transcribe the transcripts. All tapes and transcripts will be stored in a locked cabinet. A summary will be made of the information you provide and it will be compared with other participants' information in order to describe common themes and issues. Details of your interview will be left out if it is felt that these details could reveal your identity.

The anonymous data will be stored for five years on a computer disk, at which time it will be permanently erased. Tapes of the interview will be recorded over at this time and any paper information such as transcripts will be shredded. If you choose to participate there will not be an opportunity for you to review the data that you have provided. The information that you provide may be used in future publications resulting from this research.

Although all information will be held confidential, there are some exceptions. Specifically, any information that is required by law to be reported to law enforcement or other agency (e.g., child abuse) will be reported.

By choosing to participate, you are granting permission for the data to be used in the process of completing a PhD, including a dissertation and any other future publications. Permission is also granted to use quotes and stories in published articles and in presentations.

Signatures

Your signature on this form indicates that 1) you understand to your satisfaction the information provided to you about your participation in this research project, and 2) you agree to participate in the research project. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant’s Name: (please print) ____

Participant’s Signature: ____ Date: _______________

Researcher’s Name: (please print) ____

Researcher’s Signature: ____ Date: _______________

Questions/Concerns

If you have any further questions or want clarification regarding this research and/or your participation, please contact:

Caroline Buzanko
University of Calgary/Department of Education/Educational Studies in Psychology
(403) 650-1616, cebuzank@ucalgary.ca

Dr. Jac Andrews
University of Calgary/Department of Education/Educational Studies in Psychology
(403) 220-7503, jandrews@ucalgary.ca

Dr. Tom Strong
University of Calgary/Department of Education/ Educational Studies in Psychology
(403) 220-5655, strongt@ucalgary.ca

If you have any concerns about the way you’ve been treated as a participant, please contact the Research Ethics Analyst, Research Services Office, University of Calgary at (403) 210-9863; email cfreb@ucalgary.ca. A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.

Appendix D

Parent Demographics

Parent Name	Gender (m/f)	Age	Marital Status	Highest level of education	Ethnicity & Language spoken in the home	Diagnosis	# of children	Son's comorbid diagnosis	Sibling diagnosis
Bob	M	44	Married	Undergrad. degree	Caucasian English	n/a	2	n/a	n/a
Crystal	F	37	Married	College diploma	Caucasian English	Depression Anxiety	2	n/a	Learning disability & sensory processing
Helen	F	44	Married	Undergrad. degree	Caucasian English	n/a	2	n/a	n/a
Jane	F	42	Married	College diploma	Caucasian English	n/a	2	n/a	n/a
Jean	F	42	Married	Undergrad. degree	Caucasian English	n/a	2	n/a	n/a
Jennifer	F	45	Married	Undergrad. degree	Caucasian English	Depression Anxiety	2	Learning disability (writing)	n/a
Jessica	F	36	Married	College diploma	Caucasian English	n/a	1	Speech comprehension disorder	n/a
Melly	F	44	Single	Some high school	Caucasian English	n/a	2	Learning disability (reading)	n/a
Mom that needs information (MTNI)	F	42	Single	College diploma	Caucasian English	Depression	1	Developmental Coordination Disorder, anxiety	n/a
Mr. Incredible	M	45	Married	Undergrad. degree	Caucasian English	ADHD Depression	5	Learning disability, speech delay, Developmental Coordination Disorder	Autism Spectrum Disorder, speech delay & Learning disability
Nicole	F	51	Single	College diploma	Caucasian English	n/a	2	n/a	n/a
Ray	F	45	Married	College diploma	Caucasian English	n/a	2	Learning disability	n/a
Sally	F	44	Married	Undergrad. degree	Caucasian English	Depression Anxiety	2	Anxiety	n/a
Sarah	F	48	Single	Some college	Caucasian English	n/a	2	n/a	Autism Spectrum Disorder
Song	F	52	Single	High school	Caucasian English	n/a	2	n/a	Autism Spectrum Disorder

Appendix E

Interview Outline

The intent of the interview is to allow parents to describe their experience with each phase of the assessment process in a way that is meaningful to them. However, if information is not naturally given (e.g., difficulty describing the experience), or a phase is not discussed, the following semi-structured interview questions may be asked to facilitate data collection regarding their experiences. Parents will be informed that they may decline to answer any question they do not feel comfortable answering.

1. Thank you for agreeing to participate in this study. As a psychologist, I believe that this study will be very important in helping us professionals promote positive experiences for parents who are having their child assessed for ADHD. I am very interested in hearing your story about your experience of your son's assessment process. Before we get started, do you have any questions or concerns you want to address?
2. Let's start by having you tell me something about your interest in participating in this study.
3. Let's turn to your experience of your son's assessment process. Describe for me what your experience of the assessment process like for you, overall.
4. I am now interested in learning more about your experience in each of the specific phases of the assessment process. The first phase is usually an initial intake phase, which may have involved you making first contact with the psychologist's office, booking an appointment, being provided information about the first meeting, and having that initial meeting with the psychologist. What was your experience like for this part of the assessment?
    - *Think about: scheduling the appointment, what information you were provided about the assessment, how prepared you felt, what was the interview like, how you felt*

- Now let’s look at the second phase of the assessment. This phase would have been where the formal testing was done. Here your son may have had a couple of sessions to do formal testing, you may have had to fill out rating forms, there may have been classroom observations or teacher interviews. What was your experience of this phase? What was this phase like for you?
    - *Think about: formal testing, wait times, communication and collaboration with the psychologist, completing rating scales, parents’ role in the assessment*
- The third phase of the assessment process was when you may have had your final meeting with the psychologist and you found out about the results of the assessment. What was your experience of this phase? What was this phase like for you?
    - *Think about: wait time for final meeting, time given to review the results, how the feedback was given, what feedback was provided, what you learned about your child, written report, your role in the feedback session, how you felt upon hearing the diagnosis*

5. Now that we’ve discussed your experience in each of the three phases of the assessment process, what parts of the assessment would you say contributed the most to your overall experience? How so? What are your reasons for choosing that part?
6. How would you describe your experience working with the psychologist?
    - *Think about: psychologist’s communication, approachability, collaboration, professionalism, empathy, and sensitivity*
    - What was your relationship like with the psychologist?
7. What information, if any, do you think would be valuable for parents to know before embarking on an assessment for their child for ADHD?

8. What information, if any, do you think was (or would be) the most helpful for you to learn from the assessment?
9. What information, if any, do you think would be valuable for psychologists to know before starting an assessment for a child, from the parents' perspective?
10. Do you have any additional comments I missed asking about that you think are important?

Appendix F

Thematic Chart

Theme 1: Hoops and Barriers

OVERVIEW

This theme covers parents' initial journey and the call to assessment, what brought them to the point of assessment. This includes the experiences they bring with them and their previous journey to the current assessment. The hoops and barriers parents had to overcome are identified as part of this journey.

SUBTHEME: *We need to find out what is going on with this kid!*

Parents' previous journey laid the groundwork that led to, and seemed to inform, the assessment that resulted in their child's diagnosis of ADHD. Most discussed the difficulties they went through that brought them to the assessment. No one exists in a vacuum, so these experiences can be important to note to help psychologists understand where parents are coming from and best support them through the process.

SAMPLE PARTICIPANT PERSPECTIVES

"But in my mind, the way it sounded, through the school, this was such a big thing and so important and this big list and we couldn't get on it; I really felt like I was going into this "oh my God" process that was stressing me out." (Jane)

"I went back to my family doctor begging our family doctor can we please see a different paediatrician, I know you don't want to step on this paediatrician's toes but we need help and she doesn't want to address these issues, and he said no several times." (Helen)

"And sure we've got developmental paediatrician, fantastic; but to tell you the truth, he hasn't been any help at all." (Song)

"And so we went in to the paediatrician and he said: Well, we're not going to diagnose him at five. And he was just diagnosed last year at the age of eight; and so we're looking at three years to finally get this poor kid some help. And it's frustrating for the family, frustrating for him. Like, when you can't control yourself it's frustrating because everybody expects a certain level from you, and that's not a possibility, so then you could totally see his self-esteem drooping…. Like I said from five to eight and half, like I said three and a half years trying to get him diagnosed and assessed." (Jennifer)

"…it was very clear he had ADHD, we had taken him in to the paediatrician who referred us to CDC who refused to diagnose him." (Sarah)

SUBTHEME: *Be careful who you see.*

Most parents did not know where to go to get an assessment done in the first place. Some sought medical support, with little help. Some parents were given a referral to a specific psychologist, which made the process easy; however, the majority felt they had little direction and little guidance of where to go.

SAMPLE PARTICIPANT PERSPECTIVES

"It's all a big mystery." "But, I think that if there was some sort of advice along the journey we are basically already at that point you're just fumbling to kind of put one step in front of the other and you just get thrown a piece of information here and a piece of information there and you never really get that sort of big picture of support." (Jennifer)

"I went through a series of going to different places looking for answers." (Song)

"I'd say the process before the psychologist was much harder because there wasn't much information as to where to go, what tests you need, so I say the educational process is harder than the actual process of doing - Where to go and what information you need to get and how to get the diagnosis and how to get the support, afterwards. Yeah, that's all the hard part…they don't really give you much clue as to what you need to do to get your child a diagnosis." (Crystal)

"I thought you just go, you get your diagnosis or whatever, but when I have people work in the school system telling me, 'There is some bad ones and there is some good ones.' Then you really are like, 'Holy!'" (Jane)

MOVING FROM FINDINGS TO ACTION

1. What motivates parents to seek an assessment?
2. What are the key facilitators and barriers involved in getting the assessment started?
3. How can parents be educated on, and supported to, getting on with the assessment process?

Theme 2: What does this tell me about my son?

OVERVIEW

Here is essentially the ordeal of the journey: The communication of the diagnosis. What parents talked about most was their understanding of the assessment results; both the information communicated within the feedback meeting or within the written report. Understanding not only what the words mean, but also what it means for their son and whether the results provide a valid reflection of who they know their son to be. Accuracy was also described, particularly in regards to the validity of the assessment results.

SUBTHEME: *It's like studying for a final*

The most common point made here is that parents felt overwhelmed by the amount of information given. Reports were too long and often went unread.

SAMPLE PARTICIPANT PERSPECTIVES

"Yeah, there was a lot of moving parts at the end. So, just to comprehend and figure out. But, you know, I think when you put it all, all the pictures together it made sense for what Luke is. But at the end it's, you know, it's when you're sitting there it's like…It's like studying for a final, I guess." (Bob)

"It was a little overwhelming…Like there was a lot of information in there" (Jean)

"It is a lot of information" (MTNI)

"For me, I'm not a reader so it's hard to sit there and read through all of it" (Nicole)

“Yeah it’s a lot to take in at the first meeting.” (Ray)

“Well, it’s exceedingly long” (Sarah)

SUBTHEME: *Big $50 words*

This subtheme points to literally understanding the language used by psychologists. All the parents indicated they did not understand all the results, pointing to the jargon used. The mothers noted that their husbands had difficulty understanding the results, which even led to the rejection of the diagnosis in two cases.

SAMPLE PARTICIPANT PERSPECTIVES

“But yeah, it’s just the jargon. It’s kind of hard as a parent to understand, sometimes.” Crystal

“I mean, even I don’t, like I don’t get all of it, right.” Jean

“I think what we were looking for was layman’s terms. Instead we got a lot of technical words and there was never, nothing was very clear…The challenges we had [was] with understanding all her terms she was using and the way she was speaking to us. That was a challenge... To understand those terms. It’s just talking to people, like kind of the way you’d talk to a friend. You know, in laymen’s terms in regards to things.” Jessica

“I don’t understand… I just didn’t understand what, when you’re saying he has this, this, or this, I need to know what those things are.” (Melly)

“It was overly sophisticated” (Sally)

“You have to read through it and try to figure out what all the numbers meant and all the medians meant…And it wasn’t very clearly organized for a parent to read… but it wasn’t easy, I guess hard to get through and just to pick out what are they talking about.” (Sarah)

SUBTHEME: *What’s he all about!?*

The focus is on whether the parents felt the assessment results reflected what they know of their son. Some parents noted that the results gave them an inside access to what was going on with their child, which helped them shift their narrative of who their child is (e.g., he is not a brat) and how they react to their son (hence the exclamation mark). However, many did not know and what the results meant for their child and how the information could be used to support their son (hence the question mark).

SAMPLE PARTICIPANT PERSPECTIVES

[it was helpful] “Just to have a deeper understanding of where he’s, what he might be experiencing on his end, on what he might be thinking or how he might be thinking or not able to think or that sort of thing. That was more helpful.” (Crystal)

“And they put in all the averages like the general population averages, and we had to really look to find out where [my son] fell within those averages” (Sally)

“All he really needed to hear from me was, “Pick up that plate…I was getting frustrated, right? I’m like, “Just pick it up before it’s going to fall.” And then, I thought about the stuff that I had read and I thought about him and I looked at his little face wanting to help, he was just like, “Is this a mom giving too much information? Okay, just pick up that plate," I said. Then he does - a total better understanding. I feel like I'm looking at him in a new light." (Jane)

[I'm happiest with] "getting a better understanding of where my son's learning skills were at…having a better understanding that someone, him for instance, you know, I can't just ask him to do three things like, brush your teeth, put your pajamas on, and clean your room. He may just hear one of those things. Right? Whereas my other son, I could say those three things, no problem, done. So it gave me a better understanding so I don't get frustrated with him." (Jessica)

"Like I said, it was like opening a window, reading the things about him" (Melly)

"And for me, I can take that deep breath and go, I've got to get him out of here, I've got to get him some exercise, I need to get him moving somewhere; whereas if I didn't know he had ADHD people would go, oh, he's just a bad kid, right." (Sarah)

SUBTHEME: *That's not my son!*

Several parents identified numerous inaccuracies within the report, which contributed to a loss of trust in the information and/or useless reports. Many attributed the inaccuracies to the lack of comprehensiveness in the assessment, though some identified specific errors. Parents identified a variety of pieces that took away from the psychologist being able to fully understand the child, such as being unheard, ADHD blinders with a disregard for everything else, and relying on data over anecdotal information.

Others felt they had a comprehensive assessment when a full background history was taken, when the child was seen more than once, when both parents were involved, and when both strengths and weaknesses were identified.

SAMPLE PARTICIPANT PERSPECTIVES

"the whole thing ED assistant *said*, ED assistant *said*, ED assistant *said*. This was the bulk of our report was this insane Ed assistant squawking to the observer. That made no sense to me." Jennifer

[The background history] "…are obviously components of what makes him what he is, so it's an important question." (Melly)

"So that, all that complexity surrounding it, it was just so tunnel vision in the system when they diagnose it." (Mr. Incredible)

"In general, my experience was frustrating, because they tend to pigeonhole; they get an idea in their head about the family, or about the child, or about the diagnosis you're looking for, and I don't often feel they look past that." (Sarah)

"I think people get this ADHD blinder thing going on." (Song)

"I don't think she took the time to get to know you because you're many different things, you're not just an ADHD kid and leaving it at that. You're a lot of other things. But I think that she didn't take the time to get to know you properly." (Melly)

"And so I liked that we really looked at everything…. She was touching on all areas, how it affected everywhere and including all of us" (MTNI)

"And their data is what speaks, what comes up in their scoresheet is what is what…The numbers and what they felt they observed and they see the kids for sure a short snapshot. It's not enough to really, to really know the child…And all these things, they never get to see the child long enough to really get to know them." (Song)

"everything, the assessment kind of was so wrong… I think it was written up really quickly and it had someone else's name. There was a lot of cut and paste which really bothered me…." [The report said] "[my son] has no friends. [My son] has *lots* of friends. Why would you even say that?...And so she just said all this stuff and we fell off our chairs, like it didn't make, we got all the feedback at the end that a lot of it wasn't accurate." (Jennifer)

"I got the final reports back there were all kinds of errors in it… They sat down with me with this 20, 30 page report that covered a lot of inaccuracies." (Sarah)

MOVING FROM FINDINGS TO ACTION

1. How can psychologists promote parent understanding of their child?
2. How can the results be communicated in a way that parents can take up the information?
3. What are the implications of having ambiguous or inaccurate information for treatment and support?
4. Review comprehensive assessment practices

Theme 3: We're not coming for labels. We're not coming for drugs. We're coming for roadmaps.

OVERVIEW

Every parent agreed on one point: they required support of how to manage their child's difficulties, which was what brought them to the assessment in the first place. They agreed that support should be part of the assessment, rather than a whole other journey completely. This theme acknowledges that the assessment is only the beginning and now there is a whole other journey parents need to go on to get the support they need for their child.

SUBTHEME: *My son has ADHD. Now what?*

At the end of the assessment, all parents asked "now what?" and ended up on a new journey in a new gigantic world.

SAMPLE PARTICIPANT PERSPECTIVES

"You're sitting there going, how do I help him now? What do I do?... What types of things should I be doing now? Yes, we have the assessment, and I know what's wrong with him. But what can I do to help him better?" (Melly)

"I think it's a bit of both that, you know, hey now we have some information and we can do something about it. But then the next question was okay what, right, and how do you go about doing it?" (Bob)

“Not knowing what to do with it is still a little bit daunting.” (Crystal)

“I did feel like, “Where do you go from here now? What do you do with this stuff?” (Jane)

“Well, and then, and the overwhelming thing too is like where do you start like try to help him” (Jean)

“But, then we walked out the door got a report and didn’t know what to do from there.” (Jennifer)

SUBTHEME: *Moving ahead or being dumped.*

A few parents noted that they were supported by the psychologist. However, the most felt they were dumped by their psychologist, with little guidance.

SAMPLE PARTICIPANT PERSPECTIVES

“I’m going to give this to the school and the school’s going to say, well, what do you want to do now? And I’m going to have no answers. So I depend on your expertise to be able to help me help my child.” (Melly)

“After the assessment, you’re just dumped with no direction as to what to do next or where to go next... And it was extremely frustrating, it was disappointing, I felt really let down. I felt abandoned and angry… If it’s just ADHD, you’re on your own” (Song)

“The psychologist was on that right away, so I have an appointment with [the interventionist] set up. So I feel very confident in the follow-up with the psychologist, for sure.” (Crystal)

“The psychologist is going to do that for me. She’s going to go talk to them and explain to them. And that took a lot of stress of me because now I don’t have to worry about whether I explained right, whether I portray what they said adequately and whether some of the fact that I don’t really like go out to those ladies, particularly right now that that came across, right?” (Jane)

[The psychologist] contacted me just before the Christmas break and said, you know I’m going to come out and do another observation and kind of come up with a few ideas of what we can do to work on, you know school related things. And I wasn’t expecting that, so to me that was like a perk to know that after this was done the follow up was … you know that [she] was able to come to the school and do more observation and kind of create that. And I didn’t realize that was part of it so I was pleasantly surprised that that relationship still continue, because that would have been probably really hard.” (Ray)

MOVING FROM FINDINGS TO ACTION

1. How and in what ways can follow-up measures be set in place to ensure that children and their families are well supported and guided to/through treatment?
2. What types of recommendations/roadmaps do parents and schools find most useful?

Theme 4: It’s such a big Journey

a: You’ve got to find a person that you feel comfortable with

OVERVIEW

This theme points to important overarching elements that parents discussed that were pervasive throughout the entire assessment process, rather than any one point in time, which contributed to parents' experiences of the assessment process. This theme highlights the assessment as a journey for parents. Theme 4a reflects the social journey, one that focused specifically on the relationship parents had with the psychologist and the parents' role in the assessment.
SUBTHEME: *Talk to me like I am your friend* All parents talked about their relationship with the psychologist, though their views were mixed. Some parents felt judged and attacked by their psychologist; others felt supported and validated, which helped them be open and honest. Parents identified characteristics they agreed were important for the working relationship. Key characteristics that contributed to positive relationships with the psychologists included professionalism, as well as being open, honest and approachable. Empathy was key, particularly with addressing parent fears about the diagnosis and treatment options.
SAMPLE PARTICIPANT PERSPECTIVES "But it was like it all came down to us and what we were doing wrong, and, you know, like that's…absolutely invalidating…I just felt like people weren't listening." (Helen) "Yeah, it just became kind of awkward. There was this awkwardness." (MTNI) "It was just relieving and exciting because I actually felt like I was being heard…Finally, somebody is listening to me" (Nicole) "I felt attacked… I think they took an hour, an hour and a half to sit down with me and go over the results, which would have been great if they weren't attacking me while they did it." (Sarah) "I think I've been treated like I'm over anxious, overly concerned parent." (Song) "I found it very easy to talk to the psychologist…I like working with her. I felt confident that I can let it all out with her." (Crystal) "She was okay with however I was, whether I seemed upset or seemed mad and she seemed genuine which was really good. And she seemed opened and honest." (Jane) "I think for me it was actually like that I felt like the psychologist was very, she … I felt very comfortable like just, I felt very comfortable talking to her." (Jean) "She was very empathetic. And I really like that about her." (Jessica) "I found them very approachable, very likeable." (Song)
SUBTHEME: *He's a relationship-based kind of kiddo*

Although not asked directly, a few parents discussed the relationship the psychologist had with their son, which was important to facilitate a smooth process and to garner valid results.

SAMPLE PARTICIPANT PERSPECTIVES

“I mean he just went into meltdown mode and shut down on me; he couldn’t do anything and she took that and [made her decisions]” (Sarah)

“I do remember him coming home with, you know, saying it was fun or whatever cause he’d had some activities that he enjoyed doing.” (Bob)

“Well, for me, it was good to have the psychologist go to the school and to be with him because he would act out more around me or around his dad or anybody else, so it was good that she went to him. I liked that part of the process because he’d be more willing for her.” (Crystal)

“he was happy and he liked her and she liked him, so I felt really good because he said positive things, too. And she was complementary with him.” (Jane)

“And he, he was comfortable too…And to me it’s important that he feels comfortable. Cause otherwise, he wouldn’t want to do it, right?...I felt comfortable…I felt like he was going to get somewhere.” (Jean)

“she always rewarded him with like a little toy. Like a little mini toy.” (Jessica)

SUBTHEME: *Left in the dark*

Here, parents shared mixed feelings about whether they worked collaboratively with the psychologist. Parents who indicated they had a collaborative relationship defined that as being able to ask questions. Some did not have that opportunity. All parents indicated they did not understand the process and had no role in it other than giving information when asked and dropping off/picking up their son from the assessment appointments.

SAMPLE PARTICIPANT PERSPECTIVES

“I kind of felt like, I mean, we were asked what we were, like what was needed of us kind of thing.” (Jean)

“And I think that when you're left in the dark about a lot of stuff and that wasn't their fault…but, it just felt like it was always surprises at the end too late. So, for example when we first started I didn't, I had no experience with this process so I don’t really know and I think that's a big assumption that parents don’t even know what they're about, they don’t know the process at all.” (Jennifer)

“You know, that’s the one thing, she didn’t give me a lot. She said she did not want me in the room. She wanted his focus on her. And she was going to be doing these exercises with him, different, like writing, getting, reading and I’m not really sure. Because I wasn’t there…I wasn’t part of it. At all.” (Jessica)

“What I felt when I took him to the psychologist’s, is I dropped him off, I don’t know what’s going on there because it’s just her and him. And then there was no feedback. You dropped him off and you picked him up and that was it…. and I asked him, so what did you ask you? What did you do? What did—oh, just a lot of stuff. He probably doesn’t even remember half of it. So it’s unfortunate I can’t even ask him.” (Melly)

“I knew that something somewhere in there was going on, but I just didn’t know.” (Nicole)

“I mean my role other than that was basically to bring [my son] there because they had their own time together.” (Ray).

“To this day I don’t really know what the tests involved. He was, we brought him in, um, he started his testing and we left him. So we got the results of the test but I have no idea what, as a parent, what those tests were.” (Sally)

Theme 4: It’s such a big Journey
b: A fragile family

OVERVIEW

Theme 4b reflects the emotional journey parents experienced within the assessment process. The emotional journey points to the ebbs and flows of emotions and stress parents identified as having experienced throughout the assessment process.

SUBTHEME: *Between hope and despair*

All parents made some comment about feeling relief and/or hope about the assessment, as the first step to finally getting help. However, they also identified the grief they experience, knowing anything is wrong with their son. There was also fear around treatment options – particularly medications.

SAMPLE PARTICIPANT PERSPECTIVES

“[My wife] was stressed. Before and sort of after.” (Bob)

“Just relieved a little bit that, you know, I was probably going to get some kind of way to go forward.” (Jean)

“It’s heartbreaking as a parent to—the first time I got the letter in the mail, I knew he had a problem...yes, your child does have a disability. It hit home and I started to cry and it’s hard to think that your kid has this…So that was huge, and it’s a hard pill to swallow, that there’s something wrong with your child.” (Melly)

“It’s this in between where you’re in between hope and despair…. and so you’re in the state and then when you go into the process of being diagnosed you get more, it’s a relief.” (Mr. Incredible)

SUBTHEME: *The weakest link*

Parents noted experiencing guilt about not doing enough and experiencing misery that they try to hide because it may reveal the truth that they are doing a bad job as parents. A few parents shared they then had to feel like they were putting on a show to seem like a normal family and second guessed what they should or should not say to the psychologist. Although parents identified themselves as being a potential weak link, they all admitted that they would do whatever it took to make help their son.

SAMPLE PARTICIPANT PERSPECTIVES

“Because like time and time and time again it’s like did we not do something, did I... you know.” (Helen)

“Well, I wonder if I did something wrong.” (Jean)

“I can’t even help my child. You feel helpful, you can’t help him...So it’s a snowball effect and it’s really terrible on my side.” (Melly)

“At this point, am I the weak link in the chain?” (Mr. Incredible)

MOVING FROM FINDINGS TO ACTION

1. Supporting parents – goes in with relationship – empowering parents, being with them
2. How can the working relationship between parents and the psychologist be nurtured?
3. How can the working relationship between the child and psychologist be nurtured?
4. What can be done to help support parents as they struggle with despair and grief?
5. What structures need to be in the place to increase parents’ participation and collaboration within the assessment process?
6. How can parents be educated about the assessment process? How can additional information and/or resources be introduced to enhance their preparation for it?

Theme 5: Rich insight: I want parents to know…

Theme 5 reflects the wisdom parents have gained having gone through the assessment process, which delineates specific information for other parents to know as they undertake an assessment.

SUBTHEME: *It’s the manual for your kid*

Most parents agreed that at the end of the day, the assessment was a valuable tool to better understand their son. They encourage parents to seek assessment and not fear the process or let financial restraints get in the way because of its benefits in helping you understand your child.

SAMPLE PARTICIPANT PERSPECTIVES

…have faith in it, to honest to Godly, to know that [psychologists] didn’t pull [their] degrees out of a cracker jack box, that these people have actually gone to school and worked hard to learn stuff to help you and not be afraid. (Jane)

I think for those parents that are worried about what it costs, of course, right? I would reassure them that, even though they’re going to get tested for one specific thing, they may end up learning a lot more, you know, in regards to other learning disorders their child might have. And at the end of the day it just benefits the child. If you have a proper diagnosis, you know, to better help them.” (Jessica)

They should know that, don’t let the direct billing hold you back, keep looking. Because really, if that’s the only factor, you have to keep going. Your child will not benefit by not helping him or her. (Melly)

They shouldn’t be fearful of the process, but that… that it’s an incredible parenting tool. Really, I think that it should be marketed that way. That it’s an incredible parenting tool that gives you rich insight into the… Who your child is. (MTNI)

SUBTHEME: *It’s not your fault*

Parents also noted that parents need to heal and overcome feelings of guilt and blame. They are in it for the long haul and need to be strong to best advocate for their child’s needs.
SAMPLE PARTICIPANT PERSPECTIVES …first you need to heal and then you need to figure out how to stand up again. (Mr. Incredible) It’s not your fault. (Helen)

Appendix G

Parent Input Form

Child Name:
Parent Name:
Date:

This form is to help orient you to your child's assessment process and to ensure that your/your child's needs and expectations are addressed in this upcoming assessment. First, an overview of what you can expect of the assessment is provided. On the next page, you have the opportunity to identify aspects of the assessment that are important to you and to ask any questions you have. Please complete all the sections that are important to you and your child.

Items within this form will be reviewed and discussed with you at the beginning, and throughout, the assessment to ensure that you understand the process and to maintain your involvement and collaboration with your psychologist. At the end of the assessment, the form will be reviewed again to ensure all the things you identified as being important were addressed. Each section has a check box to indicate that the items in that section were covered. Signatures at the end of this form indicate that all the items you identified as important were addressed.

In addition to this form, please offer any additional input, insights, or questions you have to your psychologist at any time throughout the assessment.

Assessment Overview

This assessment is broken into three main phases. In the initial interview meeting, the psychologist will ask questions regarding your child and family's background. Questions will include topics about your child's prenatal experience and delivery, early development (e.g., when he/she walked and talked), medical history, social development, behaviours, emotional well-being, and academic performance. As part of this meeting, you will also have the opportunity to identify your goals from having this assessment done and what information would be most useful for you to learn as part of this assessment.

The second phase includes the formal assessment. This may include direct work with your child, discussions with other people (e.g., teachers), and rating scales for your child and/or important adults in your child's life (e.g., teachers, caregivers) to complete. It is important for you to let the psychologist know of how your child slept the night before and whether there are any incidents that may affect your child's performance (e.g., feeling worried, hungry, and so on).

The final phase of the assessment process is when you discuss the results of the assessment and receive the final report and recommendations to support your child. You will have the opportunity to address any additional questions you may have in this meeting.

Parent Input Form

Please complete each section of this form that is important to you. Feel free to write additional comments anywhere on the page.

☐ I would like to receive the following information to prepare me for the assessment (check all that apply):

- ☐ An overview of the assessment process
- ☐ What types of assessment tools are used
- ☐ How each assessment tool addresses the goal of this assessment
- ☐ What each session entails and its purpose
- ☐ What each assessment tool measures
- ☐ What types of tasks my child will do
- ☐ What I can tell my child about the assessment
- ☐ Other: ____

☐ Besides information pertaining directly to my child, I have other topics I would like to discuss with the psychologist to help give him/her a full understanding of myself and my child (check all that apply):

- ☐ Parent functioning
- ☐ Marital concerns
- ☐ Other: ____
- ☐ Sibling difficulties
- ☐ Family/household concerns

☐ I would like to learn the following information from this assessment (check all that apply):

- ☐ My child’s strengths
- ☐ My child’s cognitive capacity
- ☐ My child’s learning profile
- ☐ My child’s ability to pay attention
- ☐ How to support my child at home
- ☐ How to support my child at school
- ☐ Other: ____
- ☐ How to support my child socially
- ☐ How to support my child emotionally
- ☐ How to manage my child’s behaviours effectively
- ☐ What the test results mean for my child at home
- ☐ What the test results mean for my child at school

☐ As part of this assessment, I would like the psychologist to (check all that apply):

- ☐ Tell me what my child did at the end of each session
- ☐ Tell me how my child did at the end of each session

☐ Share their initial hypotheses on my child's difficulties

☐ Do a classroom observation

☐ Speak with my child's teacher(s) and/or other adults who know my child

☐ Other: ____

☐ I am hoping for the following support as a result of this assessment (check all that apply):

☐ Follow-up in-home support to manage behaviours

☐ School consultation to share the results of this assessment with teachers

☐ School consultation to discuss strategies with teachers

☐ School consultation to contribute to my child's IPP

☐ Follow-up sessions to learn strategies to support my child's emotional needs

☐ Follow-up sessions to learn strategies to support my child's social needs

☐ Follow-up sessions to learn strategies to support my child's academic needs

☐ Follow-up to learn strategies to promote my child's behaviours/attentional capacity

☐ Follow-up sessions to learn strategies on how to advocate for my child

☐ Resource package with community services available

☐ Resource package with information regarding ADHD

☐ Follow-up session with the psychologist to review the results and go over any additional questions I may have

☐ Other: ____

☐ The following things will help my child feel calm and comfortable for this assessment (e.g., talk about topics of interest, play games to help him/her warm-up): _______________________________

____

____

____

____

☐ I have the following questions about the assessment: ____

____

____

☐ Additional Comments: ______________________________

Signatures:

Parent: ______________________ Psychologist: ______________________

Print Name: ______________________ ______________________

Date: ______________________ ______________________

Appendix H

Parent-Generated Recommendations for Psychologists

Recommendations	Applications
Use the assessment process to help the child and family	• Provide more than one feedback session. • Offer follow-up sessions to review the results and questions. • Offer intervention sessions to give parents strategies to use with their child. • Implement follow up measures to ensure children and families are well supported. • Identify what types of recommendations and supports will be most useful for the family. • Offer feedback and specific strategies for the school. • Offer practical information and goals for the school IPP • Advocate for parents • Connect parents to community resources (e.g., support groups) • Offer packages and resources about ADHD and effective treatment
Look at the whole child	• Identify the child’s strengths. Start with the positives. • Observe and investigate the child’s functioning across contexts (e.g., at home, at school, socially), with different people and in different situations • Collect information from multiple sources of informants including parents and teachers
Look at the entire family	• Include both parents throughout the assessment process • Consider the effect the child’s difficulty has on his sibling(s) • Investigate the effects of the child’s behaviour on the entire family • Investigate parental well-being and skills and resources to cope and manage with their child’s difficulties
Empower parents	• Assess success for families and give them goals they can work towards • Teach parents specific strategies to support their child • Educate parents about the assessment process and collaborate with them throughout • Provide additional information and resources to parents to enhance their preparation for the assessment • Educate parents about medication • Help to promote hope • Coach parents how to advocate effectively
Foster the working alliance	• Educate the child about the assessment process • Have regular check-in’s before and after each session with parents • Explain the relevance and rationale for various tests and relate its purpose to the child’s situation • Refer as needed

Recommendations	Applications
Foster the working alliance (cont’d…)	• Identify what will be most helpful for parents through the assessment process and beyond • Identify what structures need to be in place to increase parent participation and collaboration within the assessment process • Validate parents’ experiences • Respect parents’ expertise on their child • Work on reflective listening skills to understand parents’ perspectives • Attend to what parents have to say • Demonstrate compassion and empathy • Take the time to allow parents to share their story and journey thus far • Acknowledge parents’ anxiety coming into the assessment • Understand that it is hard to hear their child’s diagnosis and that there is a grief process
Communicate results effectively	• Address parent fears and anxiety at the start of the feedback session • Provide honest, straightforward information • Break the information down • Confirm accuracy of the findings and report with parents • Use clear language that is easy to understand and meaningful to parents • Offer information that is useful for parents • Put recommendations up front in the written feedback • Include practical strategies that are easy and feasible to implement by teachers and parents • Identify what the test results mean for their specific child and provide specific examples as to how that manifests at home and in the classroom • Discuss how conclusions/diagnosis was made based on the tests used • Educate parents about “normal” developmental expectations and where their child fits • Check-in with parents to explain what they understand of the information • Explain the root difficulties the child is experiencing to promote parent understanding and shift their understanding of presenting behaviours